

Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit



World Health
Organization

Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit

Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit

ISBN 978-92-4-009635-6 (electronic version)

ISBN 978-92-4-009636-3 (print version)

© World Health Organization 2024

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: “This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition”.

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization (<http://www.wipo.int/amc/en/mediation/rules/>).

Suggested citation. Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit. Geneva: World Health Organization; 2024. Licence: [CC BY-NC-SA 3.0 IGO](https://creativecommons.org/licenses/by-nc-sa/3.0/igo).

Cataloguing-in-Publication (CIP) data. CIP data are available at <https://iris.who.int/>.

Sales, rights and licensing. To purchase WHO publications, see <https://www.who.int/publications/book-orders>. To submit requests for commercial use and queries on rights and licensing, see <https://www.who.int/copyright>.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO be liable for damages arising from its use.

Cover photo: (top to bottom): © WHO / Maria Gutu, Mother and daughter in refugee center in Moldova, 2022; © WHO / Saiyna Bashir, Father and son at a basic health unit in Pakistan, 2023; © WHO / Mwesuwa Ramsey, Young child communicating with sign language at primary school in the United Republic of Tanzania, 2023.
Design and Layout by burosvenja.com

Contents

Acknowledgements	iv
Abbreviations	vii
Executive summary	viii
1. Introduction	1
2. Integrated approach to neurological disorders	9
3. Stakeholder engagement	14
4. Situational analysis	20
5. Implementing the IGAP strategic objectives	29
5.1 Prioritization and governance	30
Advocacy and awareness-raising	31
Policy, plans and legislation	37
Health systems financing	46
5.2 Diagnosis, treatment and care	53
Care pathways	54
Capacity-building of the health workforce	62
Access to medicines and technologies	69
Carer support	79
5.3 Promotion of brain health and prevention of neurological disorders	85
5.4 Research and information systems	92
5.5 Approach to specific neurological disorders	102
Brain infections	104
Dementia	110
Epilepsy	117
Migraine and other headache disorders	123
Neurodevelopmental disabilities	127
Stroke	133
6. Monitoring and evaluation	139
References	145

Acknowledgements

Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit was developed by the Brain Health unit, Mental Health, Brain Health and Substance Use department of the World Health Organization (WHO), under the overall supervision and guidance of Dévora Kestel and Tarun Dua.

The overall development of the toolkit was led by Neerja Chowdhary and written by Gergana Manolova with substantial inputs from the following colleagues from the Brain Health unit at WHO headquarters (in alphabetical order): Elaine Brohan, Rodrigo Cataldi, Vanessa Cavallera, Laura Garcia Diaz, Stéphanie Fréel, Noline Schiess, Katrin Seeher, Chiara Servili and Sebastian Winter.

The following experts and people with lived experience participated in the consultations, and/or reviewed the draft of the toolkit:

Foad Abdallah (Cairo University, Egypt); Suvarna Alladi (National Institute of Mental Health and Neurosciences, India); Ricardo Allegri (Instituto de Investigaciones Neurológicas Fleni, Argentina); Action Amos (International Bureau for Epilepsy, Malawi); Melody Asukile (University Teaching Hospitals in Lusaka, Zambia); Claudio Bassetti (University Hospital Bern, Switzerland); William Carroll (Multiple Sclerosis Research Australia, Australia); Augustina Charway-Felli (African Academy of Neurology, Ghana); Audrey Craven (Global Patient Advocacy Coalition, Ireland); Helen Cross (University College London, United Kingdom of Great Britain and Northern Ireland); Carol D'Souza (India); Elaine Devine (Meningitis Research Foundation, United

Kingdom); Ding Ding (Huashan Hospital, China); Meritxell Donadeu (University of Melbourne, Australia); Cleusa Ferri (Universidade Federal de São Paulo, Brazil); Agnès Fleury (National Autonomous University of Mexico, Mexico); Orla Galvin (European Federation of Neurology Associations, Belgium); Wolfgang Grisold (Ludwig Boltzmann Institute for Experimental and Clinical Traumatology, Austria); Alla Guekht (Moscow Research and Clinical Center for Neuropsychiatry, Russian Federation); Tadeusz Hawrot (European Federation of Neurological Associations, Belgium); Volker Hömberg (World Federation of Neurorehabilitation, Germany); Hoo Fan Kee (University Putra, Malaysia); Evan Kervella (Chipiron, France); Edward Kija (Muhimbili University of Health and Allied Sciences, Tanzania); Vibha Krishnamurthy (Ummeed, India); Sidney Krystal (University of Paris Est Créteil, France); Joanna Laurson-Doube (NCD Alliance, United Kingdom); Matilde Leonardi (Institute Carlo Besta, Italy); Chris Lynch (Alzheimer's Disease International, United Kingdom); Nina Mago (Purple Bench Initiative, Uganda); Barbara Maistrello (Institute Carlo Besta, Italy); Charles Newton (University of Oxford, United Kingdom); Bo Norrving (Lund University, Sweden); Njideka Okubadejo (University of Lagos, Nigeria); Sebastian Porta (Argentina); Kameshwar Prasad (All India Institute of (Medical Sciences, India); Jean-Pierre Pruvo (University of Lille, France); Martin Rossor (University College London, United Kingdom); Kevin Rostasy (European Pediatric Neurology Society, Germany); Anja Sander (European Academy of Neurology, Austria); Palmira Santos (Ministry of Health, Mozambique); Deanna Saylor (University Teaching Hospitals in Lusaka, Zambia); Bhagteshwar Singh

(University of Liverpool, United Kingdom); Pratibha Singhi (Medanta Hospital, India); Jennie Socha (International Parkinson and Movement Disorder Society, United States of America); Tom Solomon (University of Liverpool, United Kingdom); Kiran Thakur (Columbia University Irving Medical Center, United States of America); Chahnez Charfi Triki (University of Sfax, Tunisia); Susanne Walitza (University of Zurich, Switzerland); Donna Walsh (International Bureau for Epilepsy, Canada); Andrea Winkler (Center for Global Health at the Technical University of Munich, Germany); François Zhu (University of Nancy, France).

Valuable technical inputs were received from the following WHO colleagues at headquarters, regional and country offices:

Bernadette Abela-Ridder (Vet. Public Health, Vector Control and Environment unit, WHO headquarters), Ben Adams (Mental Health, Brain Health and Substance Use department, WHO headquarters), Onyema Ajuebor (HRH Policies and Standards unit, WHO headquarters), Hadeel Alfar (WHO Country Office for Jordan), Florence Baingana (WHO Regional Office for Africa), Mercedes Bonet Semenas (Maternal and Perinatal Health unit, WHO headquarters), Marie Noël Bruné Drisse (Chemical Safety and Health unit, WHO headquarters), Andrea Bruni (WHO Regional Office for South-East Asia), Fiona Bull (More Physical Activity unit, WHO headquarters), Emilie Calvello Hynes (Clinical Services and Systems unit, WHO headquarters), Bernadette Cappello (Access to Medicines and Health Products unit, WHO headquarters), Claudina Cayetano (WHO Regional Office for the Americas), Matteo Cesari (Ageing and Health unit, WHO headquarters), Sudipto Chatterjee (Mental Health unit, WHO headquarters), Daniel Chisholm (Mental Health, Brain Health and Substance Use department, WHO headquarters), Bernadette M.E.G. Daelmans

(Life Course unit, WHO headquarters), Gampo Dorji (WHO Country Office for Nepal), Antoine Durupt (Agenda, Policy & Strategy unit, WHO headquarters), Antony Duttine (Sensory Functions, Disability and Rehabilitation unit, WHO headquarters), John Fogarty (Clinical Services and Systems unit, WHO headquarters), Leveana Gyimah (WHO Country Office for Ghana), Ignacio Ibarra (WHO Regional Office for the Americas), Matias Irrarrazaval (WHO Regional Office for the Americas), Ishakul Kabir (WHO Country Office for Bangladesh), Taskeen Khan (NCD Management-Screening, Diagnosis and Treatment unit, WHO headquarters), Alisa Ladyk-Bryzghalova (WHO Country Office for Ukraine), Ledia Lazeri (WHO Regional Office for Europe), Lidiia Lukasevych (Mental Health, Brain Health and Substance Use department, WHO headquarters), Debra Machando (WHO Country Office for Zimbabwe), Aiysha Malik (Mental Health unit, WHO headquarters), Kedar Marahatta (WHO Country Office for Nepal), Carmen Martinez (WHO Regional Office for the Americas), Hasina Momotaz (WHO Country Office for Bangladesh), Alana Margaret Officer (Demographic Change and Healthy Ageing unit, WHO headquarters), Renato Oliveira e Souza (WHO Regional Office for the Americas), Marie-Pierre Preziosi (Agenda, Policy & Strategy unit, WHO headquarters), Shanthi Narayan Pal (Pharmacovigilance unit, WHO headquarters), Teri Reynolds (Clinical Services and Systems unit, WHO headquarters), Khalid Saeed (WHO Regional Office for the Eastern Mediterranean), Giovanni Sala (Mental Health, Brain Health and Substance Use department, WHO headquarters), Alison Schafer (Mental Health, Brain Health and Substance Use department, WHO headquarters), Slim Slama (NCD Management-Screening, Diagnosis and Treatment unit, WHO headquarters), Yuka Sumi (Ageing and Health unit, WHO headquarters), Shamsuzzoha Babar Syed (Special Programme on Primary Health Care,

Policy and Partnerships, WHO headquarters), Tova Tampe (Special Programme on Primary Health Care, WHO headquarters), Emma Tebbutt (Access to Assistive Technology and Medical Devices unit, WHO headquarters), Martin Vandendyck (WHO Regional Office for the Western Pacific), Jasmine Vergara (WHO Country Office for the Philippines), Marco Antonio De Avila Vitoria (Treatment, Care and

Service Delivery unit, WHO headquarters), Juana Willumsen (More Physical Activity unit, WHO headquarters), Matteo Zignol (TB Prevention, Diagnosis, Treatment, Care and Innovation unit, WHO headquarters).

WHO gratefully acknowledges the financial support of the World Federation of Neurology.



Abbreviations

CT	Computed tomography
DALYs	Disability-adjusted life years
GBD	Global Burden of Disease
GDO	Global Dementia Observatory
GSED	Global Scale for Early Development
IGAP	Intersectoral global action plan on epilepsy and other neurological disorders
IHME	Institute for Health Metrics and Evaluation
LMICs	Low- and middle-income countries
MNS	Mental, neurological and substance use disorders
MRI	Magnetic resonance imaging
NCDs	Noncommunicable diseases
NTDs	Neglected tropical diseases
PAHO	Pan American Health Organization
PET	Positron emission tomography
PHC	Primary health care
SDGs	Sustainable development goals
UHC	Universal health coverage
UN	United Nations
UNICEF	United Nations Children’s Fund
WHO	World Health Organization
YLL	Years of life lost

Executive summary

Neurological disorders carry the leading burden of morbidity and mortality globally and cause over 11 million deaths every year. People with neurological disorders face a significant treatment gap everywhere – and particularly in low- and middle-income countries – due to a complex host of reasons such as lack of political prioritization, inadequate health workforce, limited access to medicines and lack of awareness. Their lives and those of their families and carers are also affected by stigma and discrimination which reduce their opportunities, entrench poverty and inequality, leave them vulnerable to human rights violations and have a negative impact on their relationships. Addressing these challenges and improving the quality of life for people with neurological disorders requires a whole-of-society approach which takes account of the critical importance of brain health as an integral part of the well-being of individuals, communities, societies and economies.

The adoption of the Intersectoral global action plan (IGAP) on epilepsy and other neurological disorders (2022–2031) by the Seventy-fifth World Health Assembly in May 2022 presented a breakthrough for neurological disorders in the global health agenda. The action plan recognizes that efforts to prevent and reduce the global burden of neurological disorders and associated disability should go beyond the health system and encompass all aspects of services and governance. To this end, IGAP outlines a systematic course of action that involves strengthening policies, systems and services, raising awareness, reducing discrimination and fostering research and innovation.

The implementation of IGAP by countries requires a practical approach, which will look different in every country according to the needs of the population and the context. This toolkit accompanies and operationalizes the action plan. The toolkit complements the development of national plans and strategies for neurological disorders by listing actions and suggesting tools and resources that can be utilized to realize fully the vision of IGAP, regardless of the level of progress already made towards achieving the 10 targets of the action plan. The toolkit is primarily intended for use by policy-makers, programme managers and service planners, helping countries plan a step-by-step implementation of IGAP at the national and subnational levels in a manner that reflects their setting, burden and priorities. It is also relevant to other implementation partners such as civil society organizations, professional societies, advocacy groups, academic institutions, donors and funders of programmatic work. People with neurological disorders, their carers and families and associations that represent them are an essential part of the implementation process and are placed at the heart of all actions.

Each section of the toolkit is populated with curated tools and resources from WHO and other global sources, available online, to be used for practical purposes in the implementation of IGAP. Case scenarios are used to illustrate the inner working of actions in particular contexts.

An integrated approach to neurological disorders involves a holistic, comprehensive and cohesive strategy that incorporates various

aspects of health and social care to address the needs of people with neurological conditions, their families and carers. The approach involves fostering collaboration between sectors, service providers and disciplines to ensure seamless care, and reflects the clinical complexity of neurological disorders by themselves and when interacting with other health conditions. The integrated approach emphasizes policy integration, person-centred care, interdisciplinary collaboration, a life-course approach and community and primary care involvement. The approach offers benefits such as stronger health systems, improved access to care and health outcomes, prevention and early detection, optimized resource allocation and reduced stigma and discrimination. All actions listed in the toolkit are geared towards these principles.

The foundation of IGAP implementation rests on comprehensive stakeholder engagement which identifies stakeholders from the key sectors and their roles, clarifies the engagement strategy and ensures diverse and balanced representation. People with neurological disorders are essential partners at all stages of IGAP implementation and are one of the key groups in an effective engagement.

A thorough situational analysis underpins further planning by gathering information from all relevant sources on the status quo, existing gaps and opportunities for improving services for neurological disorders. The analysis of information helps in prioritizing the most urgent issues and informs about the resources available. The toolkit provides detailed steps and actions which follow the strategic objectives of IGAP in the key domains that address the burden of neurological disorders.

Prioritization and governance refers to: 1) the important work of raising awareness and advocating for neurological disorders in order

to bring more recognition; 2) reviewing and developing policy, plans and legislation that specifically include and protect people with neurological disorders; and 3) organizing resources for appropriate health system financing.

Diagnosis, treatment and care covers: 1) the establishment of thorough care pathways; 2) strengthening the capacity of the specialist neurological and non-specialist health workforce; 3) improving access to medicines and technologies for managing neurological disorders; and 4) bolstering carer support.

The promotion of brain health and prevention of neurological disorders lay out the importance of the larger framework of health and society by listing actions in the areas of policy, clinical care, research and raising awareness of brain health and its social determinants.

Research and information systems consider the knowledge gap and how it can be addressed through more robust and equitable research efforts and efficient data collection integrated with routine health information systems.

Actions for some priority neurological disorders have been suggested. These conditions have been selected based on the high burden of disease and their public health importance. The toolkit, however, is relevant to all neurological disorders. Suggested actions in relation to priority conditions can help in planning for national contexts and customized measures.

Monitoring and evaluation describe how to prepare the ground for implementing IGAP by establishing indicators for measurement, integrating a monitoring framework, gathering relevant information, and setting up iterative feedback cycles while monitoring the roll-out of implementation.



© WHO / Mwesua Ramsey. Person with disability shopping at the market in Tanzania, 2023.

1. Introduction

In May 2022, the Seventy-fifth World Health Assembly adopted the Intersectoral global action plan on epilepsy and other neurological disorders (2022–2031) (referred to as IGAP) with the unanimous agreement of its Member States (Decision WHA75(11))¹. This represented a breakthrough in terms of putting neurological disorders on the global health agenda. The strategic document that is referred to in this toolkit as IGAP² highlights the high burden of neurological disorders around the world for individuals, communities, health systems and economies, as well as the importance of considering brain health as a crucial part of global health. The global action plan charts a concise path towards preventing and reducing the global burden of neurological disorders and associated disability, as well as improving the functioning and quality of life of those who live with neurological disorders by strengthening policies, systems and services, raising awareness, reducing discrimination and fostering research and innovation. The 10 global targets of IGAP (Box 1) are a way to measure the progress along this path to implementation. The main goal of this IGAP toolkit is to help WHO Member States to plan a step-by-step implementation of IGAP at the national/subnational levels while incorporating the provision of services and care for neurological disorders into their health and social services.

1 Decision WHA75(11). Follow-up to the political declaration of the third high-level meeting of the General Assembly on the prevention and control of non-communicable diseases. In: Seventy-fifth World Health Assembly. Geneva: World Health Organization, 2022.

2 Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031. Geneva: World Health Organization, 2023.

BOX 1.

The 10 global targets of the Intersectoral global action plan on epilepsy and other neurological disorders

1.1.

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

1.2.

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

2.1.

75% of countries will have included neurological disorders in the Universal health coverage (UHC) benefits package by 2031.

2.2.

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

3.1.

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

3.2.

The global targets

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

- *Global Action Plan for the Prevention and Control of NCDs (NCD-GAP);*
- *Defeating meningitis by 2030: a global road map; and*
- *Every newborn: an action plan to end preventable deaths.*

4.1.

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

4.2.

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

5.1.

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

5.2.

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

Case for action in neurological disorders

The significant morbidity and mortality associated with neurological disorders are challenges that need a coordinated response at global, regional and national levels. Neurological disorders are the leading global cause of disability-adjusted life years (DALYs), affecting 3.4 billion individuals, and the leading cause of years of life lost, accounting for over 11 million deaths per year (Box 2) (1). The significant burden of morbidity and mortality of neurological disorders is compounded by the treatment gap and multi-level stigma and discrimination (the “inclusion gap”), which can hamper life opportunities, increase the risk of ill-health and poverty, and lead to difficulties in accessing and receiving care. Health systems have not yet responded adequately to the burden of neurological disorders. The majority of people with neurological disorders live in low- and middle-income countries (LMICs) but their needs are poorly recognized. Neurological disorders are not well reflected in country policies, the number of health workers specialized in neurological health is insufficient to tackle the treatment gap globally, and access to medicines for neurological disorders such as epilepsy and Parkinson disease is woefully inadequate.

Recognizing the need for a global response, the vision of IGAP is a world where:

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

BOX 2.

Results of the Global Burden of Disease Study for 2021

The Global Burden of Disease, Injuries, and Risk Factors Study (GBD), which conducts estimates of the burden of neurological conditions, updated the grouping for neurological disorders to include 37 conditions in the 2021 estimate (1). The collective of authors estimated mortality, prevalence, years lived with disability (YLDs), years of life lost (YLLs) and DALYs by age and sex in 204 countries and territories from 1990 to 2021. The analysis included morbidity and deaths due to neurological conditions, for which health loss is directly due to damage to the central or peripheral nervous system.

According to the GBD study:

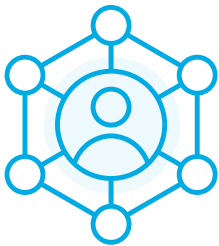
- in 2021, the 37 conditions affecting the nervous system were estimated to have caused 11.1 million deaths globally;
- these neurological disorders were collectively ranked as the leading cause of DALYs in 2021, affecting 3.4 billion people, or 43.1% of the global population;
- the top contributors to neurological health loss are: stroke, neonatal brain injuries (encephalopathy), migraine, dementia and nerve damage associated with diabetes;
- the neurological burden is greater in LMICs, where access to diagnosis, treatment and care is also more scarce;
- generally, males are at higher risk of neurological conditions than females, but some conditions disproportionately affect women (e.g. migraine and dementia);
- since 1990, the absolute neurological health loss has increased, propelled by demographic ageing.

The basic GBD grouping of neurological disorders includes Alzheimer disease and other dementias, headaches, idiopathic epilepsy, motor neuron disease, multiple sclerosis, Parkinson disease, and a residual group of other neurological disorders that includes, for instance, muscular dystrophy and Huntington disease.

The rates of DALYs were highest in western and central sub-Saharan Africa and lowest in Australasia and the high-income regions of Asia Pacific. The difference between highest and lowest is stark – e.g. approximately 18-fold for DALY rates for children under 5 years of age. This clearly shows regional inequalities in health care provision and quality of life, which disproportionately affect people in LMICs. Risk factors were also assessed for the neurological conditions with the highest burden, demonstrating the importance of tackling neurological disorders within the wider context of health to achieve a lasting reduction in morbidity and mortality.

A focus on brain health as a component of holistic health of individuals and societies is central to the vision of IGAP. Brain health is defined as the state of brain functioning across cognitive, sensory, social-emotional, behavioural and motor domains, allowing people to realize their full potential over the life course, irrespective of the presence or absence of disorders (2).

In practical terms, IGAP implementation involves focusing on key aspects of an effective, integrated and person-centred response to neurological disorders. These include prioritization and governance, diagnosis, treatment and care, the promotion of brain health, prevention of neurological disorders, research, innovation, information systems and an organized approach to specific neurological disorders.

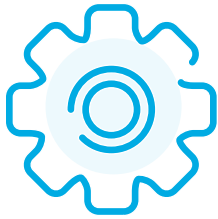


Who is this toolkit for?

The IGAP implementation toolkit is intended to be a “go-to” resource for those involved in shaping neurology policies and services. It is primarily intended for use by **policy-makers** at national and subnational levels as well as programme managers and service planners across various sectors such as health, social services, education, environment, finance, employment, justice and housing. Stakeholders in government roles are central to setting in action the implementation of IGAP – e.g. in planning health and social policies to support people with neurological disorders and their carers and revising outdated legislation or formulating strategies for enhancing the skills of the health workforce.

The actions described in the toolkit will have relevance to the work of frontline practitioners such as doctors, nurses, community health workers, teachers, educators and social workers.

The toolkit is also relevant to other implementation partners such as civil society organizations, professional societies, advocacy groups, academic institutions, donors and funders of programmatic work, where some actions such as awareness-raising campaigns, carer education initiatives, or collaboration for better neurological research can be enhanced with their involvement. Most importantly, the toolkit is designed with input from people with neurological disorders and their carers, placing them at the heart of all actions.



How was the toolkit developed?

This toolkit is the result of collaboration between a wide range of stakeholders, including government representatives, international civil society, persons with lived experience, and experts in brain health and neurological disorders. Following the adoption of IGAP, discussions with many partners from Member States and civil society established the need for the implementation toolkit and indicated its basic structure. Experts with international experience in neurology and implementation were invited to contribute their perspectives on the contents and approach of the toolkit. The compilation of recommendations was presented at two mirror workshops with global participation of stakeholders. The comments received were utilized to draft the toolkit, which was then widely circulated for review and feedback. A comprehensive mapping of tools and resources was carried out, including calls to partners to contribute. The resulting selection was reviewed for practical utility, accessibility and relevance to the implementation of the IGAP targets, as well as agreement with the IGAP principles.

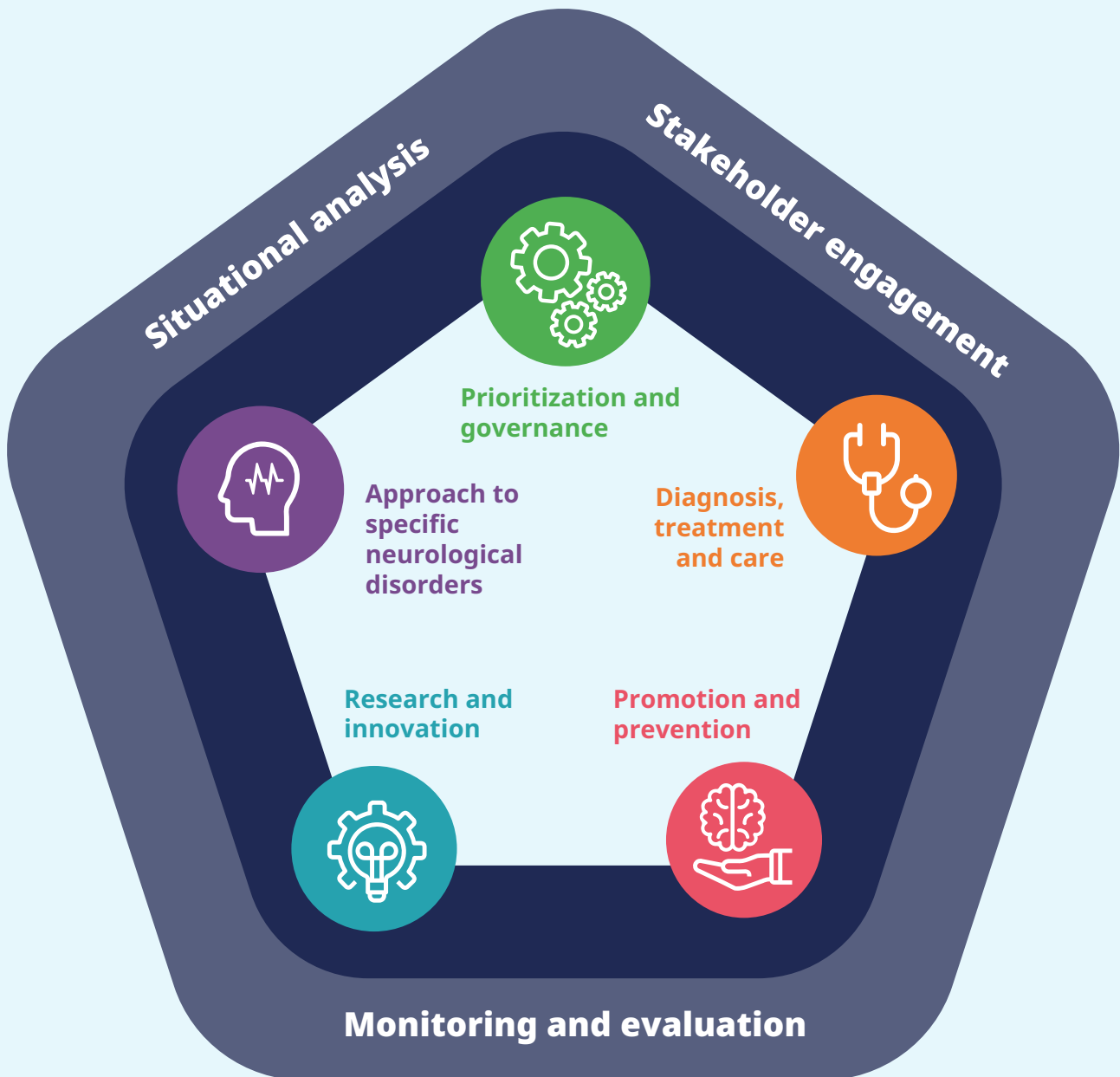


How should the toolkit be used?

The toolkit is organized around areas for action which reflect the grouping of strategic objectives and action areas of IGAP (Figure 1). It is intended to help countries to plan their approach to neurological disorders and brain health in line with IGAP in a practical way and develop their customized plans for implementation. Implementers are encouraged to consider the context of health services as a whole, since optimizing care for neurological disorders depends on integration into wider primary health care-(PHC-)oriented services.

To prepare for implementing IGAP at the national or subnational level using an integrated approach to neurological disorders, it is recommended to start with stakeholder mapping and engagement and a situational analysis, as described in the relevant sections. The sections on prioritization and governance, diagnosis, treatment and care, promotion and prevention, and research and innovation are each divided into topics which follow the structure of the IGAP and suggest specific steps to be taken in thematic areas.

Figure 1. Structure of the toolkit



While the toolkit is relevant to all neurological disorders, the section on the approach to **specific neurological disorders** lays out considerations around five neurological conditions that contribute the most DALYs, showing how addressing priority conditions in a particular setting will support the whole framework of improving services for neurological disorders.

Finally, the section on **monitoring and evaluation** describes how to plan and resource the monitoring framework so that the effectiveness of implementation efforts can be measured, and actions can be refined to maximize impact.

Within each of these sections, the relevant core concepts and importance of issue are clarified. A comprehensive list of **recommended actions** supports a systematic and practical approach to achieving IGAP targets. Implementers are provided with links to tools and resources which have global relevance and can be adapted to the specific situation in individual countries. Throughout the toolkit, **case scenarios and good practices illustrate** how incremental changes can lead to significant improvements in neurological care.

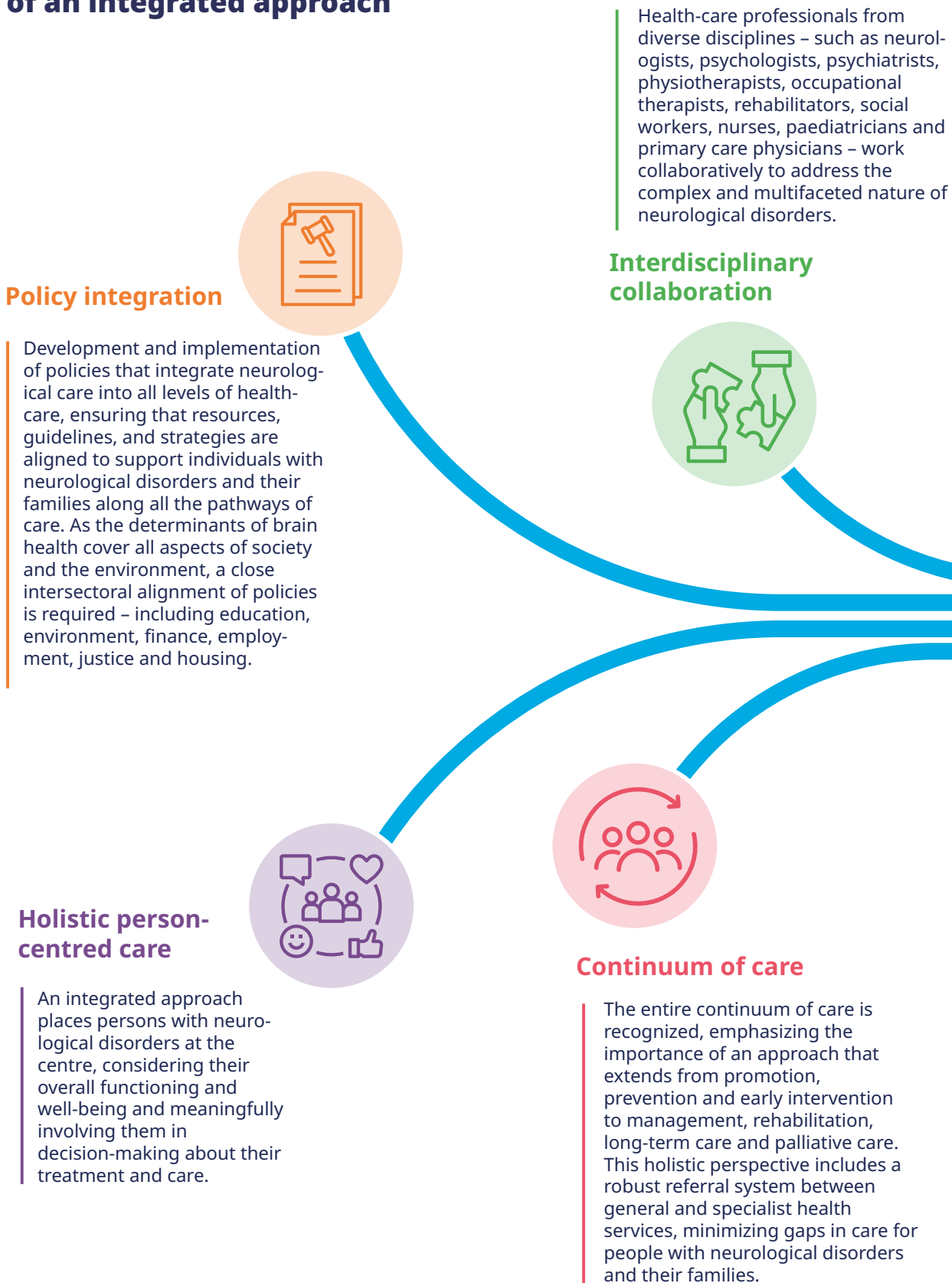
There is no single best way to carry out IGAP implementation and the process will look different in every country, reflecting the unique national context, health system characteristics, and priority needs and challenges. The toolkit is designed to allow actions to be customized according to the context of the country, allowing for recognition of advances in neurological disorder care that have already been made in that setting. While all listed actions and steps are useful for a comprehensive response, implementers may initially focus on the most essential ones in settings with limited resources and then expand these to cover all actions as more resources become available. This flexibility will empower countries to navigate the challenges, seize the opportunities and make the IGAP vision a reality.

2. Integrated approach to neurological disorders

An integrated approach to neurological disorders (Figure 2) refers to a holistic, comprehensive and cohesive strategy that incorporates various aspects of health and social care in order to address the needs of people with neurological conditions, their families and carers. This approach involves breaking down traditional health-care silos and fostering collaboration between different health-care providers, disciplines and sectors to ensure a seamless continuum of care. It also positions brain health as one of the key components of a population's health. The Intersectoral global action plan on epilepsy and other neurological disorders (2022–2031) recognizes the importance of an integrated approach and emphasizes the clinical complexity of neurological disorders not only as stand-alone conditions but also when interacting with other health conditions – which are often linked by common preventable risk factors and potentially similar diagnostic, treatment, care pathways and resource requirements. UHC provides the scaffolding to ensure that care for neurological disorders is closely aligned with other services and programmes, particularly for noncommunicable diseases (NCDs) and mental health, in the move to achieve global health equity.

In essence, an integrated approach to neurological disorders aims to provide comprehensive, efficient and person-centred care by fostering collaboration, continuity and inclusivity across the health-care system and related sectors.

Figure 2. The key components of an integrated approach



A life-course approach to neurological disorders underscores the need for care to commence before birth and persist throughout a person's entire life. Each life stage presents unique factors that influence brain health, offering distinctive opportunities for universal promotion and protection, irrespective of the presence or absence of a neurological condition. Age-specific neurological disorders should be considered, ensuring that prevention and management strategies are tailored to the distinct needs of each group.

Life-course approach

Neurological conditions share a number of commonalities, including overlapping symptoms, a chronic and sometimes progressive nature, and the impact on caregivers and similar resource requirements in terms of workforce capacity, diagnostic equipment and procedures and management techniques. These commonalities have implications for both prevention and management. First, shared pathological processes underlying many neurological conditions mean that prevention should be geared towards the circumstances from which they arise. Second, utilization of a biopsychosocial approach that considers functioning and disability provides entry points for an integrated approach to neurological disorders and involves identification of strategic opportunities within the health-care system where interventions for specific neurological conditions can be introduced effectively. These entry points serve as gateways for scaling and integrating care for different neurological conditions and maximizing the efficient use of available resources.

Integration amongst different neurological conditions

Holistic, comprehensive, and cohesive strategy that incorporates various aspects of health and social care to address the needs of people with neurological conditions, their families and carers.

Embedding with communicable and non-communicable diseases, mental health, and social determinants of health

Neurological disorders often coexist with both communicable diseases and NCDs, creating bidirectional relationships which can be addressed through the embedded integration of care for neurological disorders within health systems. On a wider scale, IGAP and this accompanying toolkit can be utilized by stakeholders in several sectors – such as health, social services, education, environment, finance, employment, justice and housing – to integrate care which meets the various needs of people with neurological disorders, as well as strategies to promote optimal brain health. These two directions of integration enhance the detection, diagnosis, treatment and care of neurological disorders, recognizing the interconnectedness of health conditions and social determinants.

Community and primary care involvement

It is essential to empower primary health-care providers and engage local communities in brain health promotion and the management of neurological disorders. This involves promoting awareness, early identification and basic care at the community level, reducing the burden on specialized services.

Integrated Approach

An integrated approach to neurological disorders offers a range of benefits that include the following:

- **Strengthened health systems:** Working to integrate neurological disorders produces stronger health systems in all aspects – from upskilling the workforce and improving monitoring and evaluation to developing specific policies and plans, resourcing initiatives and boosting the quality of care (Box 3).
- **Improved health outcomes for all:** Addressing the social determinants of brain health has a number of knock-on effects that bring about better health not only for individuals with mental, neurological and substance use conditions but also for persons with other health conditions where the same determinants play a role.
- **Improved access to care:** Integration ensures that neurological care is more widely accessible, particularly in underserved or remote areas. By decentralizing services and involving primary health-care providers, individuals can receive timely and essential care closer to where they live.
- **Prevention and early detection:** Integration allows for the incorporation of preventive measures and early detection strategies into health-care programmes. This is particularly crucial for neurological disorders (e.g. stroke) where risk factor control and early intervention can have a significant impact on outcomes and can improve the quality of life for individuals affected.
- **Optimized resource allocation and use:** By integrating neurological care into broader health-care policies and frameworks, resources can be allocated more efficiently. This prevents duplication of effort, streamlines services and ensures that the resources available meet the diverse needs of persons with neurological disorders.
- **Reduced stigma and discrimination:** Integrating neurological care into broader health-care initiatives helps to reduce the stigma of neurological disorders. By presenting these conditions as part of routine health care and conducting general educational initiatives on the importance of brain health, society is more likely to accept and support individuals with neurological disorders, reducing the stigma and discrimination associated with these conditions and enhancing the protection of equal rights.

The following sections (Chapters 3-6) define the actions that need to be implemented in order to achieve an integrated approach to neurological disorders in relation to each of IGAP's strategic objectives.

BOX 3.

The Operational framework for PHC

The WHO-UNICEF Operational framework for PHC can be utilized to strengthen health systems and support countries in scaling up national implementation efforts on PHC (3). The operational framework provides a series of 14 interdependent, interrelated and mutually reinforcing levers for action, including four core strategic and 10 operational levers. The operational framework describes the three components of PHC, including a focus on integrated health services especially at the primary care level and for essential public health functions.

Leading to the adoption of the PHC operational framework, **the WHO Framework on integrated people-centred health services (IPCHS)** was adopted by Member States at the World Health Assembly in May 2016, calling for a fundamental shift in the way health services are funded, managed and delivered (4). It supports countries' progress towards UHC by shifting away from health systems designed around diseases and health institutions towards health systems designed for people.



© WHO / Ester Ruth Mbabazi. Patients and health workers in a primary care clinic in Uganda, 2022.



3.

Stakeholder engagement

Core concepts

To ensure that IGAP implementation efforts are acceptable and desirable to all, it is vital to involve a diverse group of stakeholders and address their concerns. These include primary stakeholders, comprising those essential for success and resolution of the response to neurological disorders, notably include government entities, and secondary stakeholders encompassing those affected by neurological disorders and whose collaboration is crucial for the success of implementation. Civil society organizations, academic institutions and research entities should be involved.

People with lived experience should be at the centre of all efforts to improve care and services for neurological disorders. This includes ensuring that their participation is meaningful and that there is diverse representation with reasonable accommodations at all levels of engagement.

Why is this important?



The active participation, contributions and endorsement of a diverse array of stakeholders are indispensable for making IGAP implementation feasible and for effectively enhancing the quality of life for people with neurological disorders.



Broad engagement guarantees that persons with an interest in neurological disorders and brain health take ownership of the implementation process, contributing their unique perspectives to the planning phase. This ensures a fair, transparent and inclusive process in the improvement of services for neurological disorders that caters to the needs of everyone involved.

✔ Steps for stakeholder engagement

1.

Identify the stakeholders

The first step is to identify those who should be engaged, noting what their resources, relationships and capacities are, and how IGAP implementation affects them. Identifying and engaging stakeholders should go beyond the health system to encompass those who work in the social services, education, environment, finance, employment, justice and housing as well as civil society, academia, private sector actors and associations representing those with neurological disorders. The selection of primary and secondary stakeholders to engage should also depend on the area of work. This may mean that different groups of stakeholders are engaged for advocacy work, service delivery, education, policy planning and other areas. This is a non-exhaustive list of stakeholders by sector:

- Stakeholders from the **public sector** can include ministries and agencies (such as those related to health, social services, education, youth), local governments, international organizations (such as WHO and other UN agencies) and practitioners and service providers who work in public services (such as health-care providers, social workers, teachers and others)
- Stakeholders with **lived experience** can include organizations and individuals, such as associations of people with lived experience, their carers and families.
- Stakeholders from **nongovernmental organizations** can include, for instance, grassroots community organizations, civil society groups and networks, faith-based organizations, professional groups (such as those for neurology, research, rehabilitation, sports), academic institutions, scientific societies, disease-specific groups.
- Stakeholders from the **private sector** can include businesses, such as those which deliver services or products related to neurological disorders.

✓ Steps for stakeholder engagement (continued)

2.

Establish the roles of stakeholders

Clarifying the responsibilities of the stakeholders identified in the field of brain health and neurological disorders will help in understanding how to approach and engage with them and what contributions they may make to IGAP implementation. The 4W approach (who, what, where and when) can be helpful to establish how stakeholders' activities are related to neurological disorders (5). Mapping stakeholders in the national or local context may involve gathering more information about their work, interviewing key informants, and understanding the dynamic relationships between them, including finding out which stakeholders may have significant influence over policies and practices and how stakeholders have interacted with the government and each other in the past. This preparatory stage is important for setting the scene for the long-term engagement needed for IGAP implementation.

3.

Determine the engagement strategy

To develop an engagement strategy, the spread of stakeholders to be engaged should be reviewed and, if necessary, more stakeholders should be added. The engagement strategy will vary according to the work being done (which may include different groups for neurological disorder advocacy, service delivery, resource planning, policy planning and other roles). The format of activities and outreach will vary and may include in-person activities such as public meetings, workshops, consultations, conferences, individual meetings, or digital activities such as websites, document reviews, surveys and studies. Short-term or long-term committees or taskforces may be formed to assist with specific elements. Such groups should have a balanced and diverse representation of stakeholders, clear governance and goals, and a clear view to preventing and mitigating power imbalances. More information on the engagement process is available in WHO's Voice, agency, empowerment – handbook on social participation for universal health coverage (see Tools and resources at the end of this section).

4.

Engage the stakeholders

Following the development of the engagement strategy, the stakeholders should be invited to participate through clear and accessible communication. At this stage, it is important to set goals and a shared base of work to structure the engagement process and manage expectations. Stakeholders may also be asked to suggest others who according to them should join the process. Again, a diverse and balanced representation of views, perspectives and interests is important. To ensure a successful engagement process, plan and allocate dedicated financial, technical and human resources as necessary throughout the duration of the engagement. Establishing regular communication is also key to effective and active participation. Communication methods may appear different for different stakeholders (e.g. people with lived experience may need to participate remotely in meetings), and it is important to make sure that all receive the same information at the same time.

Placing people with lived experience at the heart of IGAP development

Throughout the development of the Intersectoral global action plan on epilepsy and other neurological disorders, WHO actively sought the involvement of a diverse group of stakeholders in shaping various iterations of the plan. This inclusive process unfolded through multiple rounds of consultations, featuring dedicated meetings with Member States, individuals with lived experience, and representatives from civil society globally.

Consultations with people with lived experience were key to the development of the plan. WHO collaborated with international organizations representing individuals with neurological disorders, families, and carers to identify potential participants, resulting in a broad representation. People with neurological disorders representing a wide range of conditions actively contributed by providing insights during the virtual meetings and submitting their contributions to the online open call. Their valuable input covered many aspects of the diagnosis, treatment, care and support for people with neurological disorders and were included in the final text of IGAP.

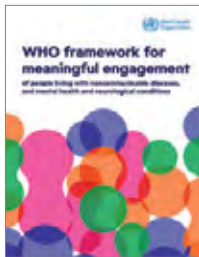
! Key considerations for stakeholder engagement

- People with lived experience of neurological disorders are at the heart of stakeholder engagement. This means – from the outset of planning – engaging people with lived experience, carers, families and organizations that represent them meaningfully. When engaging people with lived experience of neurological disorders, the principles of **meaningful engagement** must be observed: dignity and respect; power and equity; inclusivity and intersectionality; commitment and transparency; institutionalization and contextualization. Meaningful engagement should be supported by sustainable financing for all engagements with people with lived experience remunerated at a rate equivalent to that for technical experts.
- Particular efforts should be made to identify and engage with people from **hard-to-reach groups** and people who represent different perspectives – including children and older adults, those who have severe or progressive neurological disorders, those who live in poverty, migrants, minority groups, those from remote or rural areas, carers, family members and others.
- Stakeholder engagement is a process and not a phase. It should be **ongoing at all stages of implementing IGAP**. Planning for stakeholder engagement should be appropriately resourced and regularly reviewed to make sure that participation is active and inclusive, stakeholders have a platform to share their views and perspectives, and goals and communications are clear.

To ensure constructive engagement, include stakeholders from the start, regularly reach out, inform and obtain input, and be **flexible**, keeping open the possibility for other stakeholders to join.



Tools and resources



WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions (WHO, 2022)

The framework describes in detail the principles of – and gives practical guidance in conducting meaningful engagement of – people with lived experience to co-create and enhance policies, programmes and services.



WHO toolkit for developing a multisectoral action plan for noncommunicable diseases: module 2: establishing stakeholder engagement and governance mechanisms (WHO, 2022)

The toolkit explains the basics of, and process for, stakeholder engagement for an action plan on NCDs, giving guidance on stakeholder groups, engagement strategy, steering committee and other aspects.



Voice, agency, empowerment – handbook on social participation for universal health coverage (WHO, 2021)

The handbook describes how to facilitate the participation of civil society and communities in policy-making efforts by creating an enabling environment, ensuring representation and meaningful engagement, and joint decision-making.

4.

Situational analysis

🕒 Core concepts

Situational analysis is pivotal for gathering information on the current state of neurological disorders within a country or area and for showing how these disorders are being handled at the national or subnational level within the broader delivery of quality health services. It can include information about the geographical distribution of the burden and risk factors, policies and support structures available for people with neurological disorders and their carers, as well as how programmes and services are planned, organized and delivered. It also includes evaluation of strategies for the promotion of brain health at all ages and the prevention of neurological disorders.

? Why is this important?



Gathering appropriate information on care and services for neurological conditions disorders helps in prioritizing the most urgent issues to be addressed, identifying opportunities that can be utilized to strengthen services, and deciding how to allocate limited resources optimally in order to avoid redundancies.



The information is critical for supporting context-specific implementation that is tailored to the unique circumstances of each country and should be reviewed and refreshed as needed.



Partnerships between governmental and nongovernmental stakeholders (civil society, advocacy organizations, organizations of people with lived experience, professional societies, academics and researchers, the private sector and others) are key to compiling the most reliable information and to laying the foundations for stakeholder engagement and alignment.

✓ Steps in the situational analysis

1.

Identify the team or person responsible for conducting the situational analysis

Assigning responsibility and creating a focal point for the information to be gathered is an important first step in avoiding duplication of effort and miscommunication. The criteria to consider are:

- a good understanding of IGAP to ensure alignment with its objectives and priorities;
- access to diverse sources of data and information related to neurological disorders, including government reports, academic studies and community surveys;
- ability to prioritize actions on the basis of the findings of the situational analysis, ensuring that resources are allocated effectively to address the most pressing issues;
- access to necessary resources, both financial and logistical, to carry out the situational analysis effectively, including funding for additional data collection activities, if required;
- prior experience in academic research, programme implementation or service provision related to neurological disorders;
- ability to facilitate discussions with a diverse range of stakeholders – including organizations representing people with lived experience, academic institutions, professional communities and advocacy groups – to formulate pertinent questions for the situational analysis.

✓ Steps in the situational analysis (continued)

2.

Determine the scope and timeline of the situational analysis

It is important to determine the scope and analysis parameters before starting. Decisions need to be tailored to each specific setting and can include:

- what level of analysis is needed (e.g. national, regional, district or other unit of governance) and settings included (e.g. urban or rural);
- which issues of interest in neurological disorders and brain health to focus on (e.g. prioritization and governance, health-care services, health workforce and training, research, innovation and information systems, or focus on specific neurological disorders);
- which types of qualitative and quantitative data to seek (e.g. epidemiology, burden, service gaps, resources, treatment and care for neurological disorders, quality of life for people with neurological disorders, perspectives of all involved);
- where to obtain the data (e.g. government, academic, agency, private or organizational sources);
- what further information-gathering on neurological disorders should be carried out after available sources have been utilized (e.g. consultations, mappings, discussions, roundtables, focus groups);
- what outputs should result from the analysis, including how prioritization of resources and demands will be made.

The timeline of the situational analysis should be decided, as should the desired output. This will in part be determined by the scope and available resources.

3.

Gather information sources

- Key information about neurological disorders should be gathered from sources such as government policies, plans and legislation, health information systems, governmental reports and publications, civil society reports and publications, aggregated data and country profiles from global monitoring bodies.
- The information would include data on the neurological workforce, training for specialists and non-specialists, population needs, the burden of neurological disorders, barriers to accessing care, medicines and assistive products available, non-pharmacological interventions available across health and social care, policies, legislation and programmes for neurological disorders and their prevention, information systems, research data and publications (epidemiological, impact, implementation, economic, perspectives of people with lived experience and other studies).
- Complementary information to be gathered includes PHC and UHC strategies and plans, and services for NCDs and mental health. All these may be stand-alone documents dedicated to neurological disorders or documents with wider focus which include neurological disorders.
- A situational analysis may also require analysis of the wider framework for action, such as review of national and international legislation which outlines institutions' responsibilities and duty of care.
- Additionally, a situational analysis often requires interviews of key informants to ensure good coverage of the issues raised and inclusion of wide perspectives. People with lived experience and health-care workers (doctors, nurses, pharmacists and physical therapists) should be considered as essential groups for inclusion.

✓ Steps in the situational analysis (continued)

4.

Analyse available data

Desk reviews of qualitative and quantitative data are often used to summarize comprehensively the information gathered in the previous step. The goal is to construct a picture of the need for neurological disorder services in the defined setting, the available resources to meet the need, and the gaps in services available. At this step, further actions may be identified for gathering additional data, including through interviewing more key informants and commissioning surveys. The utility of gathering additional data should be balanced against the defined timeline and the expenditure of efforts and resources.

5.

Prepare the output from the situational analysis and gather feedback

The output decided in Step 2 should be prepared, usually in the form of a report or other kind of publication. At this stage, the output should be shared with key stakeholders with interest in neurological disorders in order to gather feedback and discuss the future steps which emerge from the situational analysis. This step will often include a priority-setting exercise with stakeholders to identify the most urgent actions for improving policies, systems and services for neurological disorders and to create a roadmap for stepwise implementation of IGAP.

6.

Dissemination of situational analysis findings

- After the feedback has been incorporated in the situational analysis, the final output should be disseminated to the public and be made accessible to all interested parties.
- This then forms the basis for subsequent planning for IGAP implementation with identification of setting-specific gaps and challenges as well as opportunities for a comprehensive neurological response.

! Key considerations when conducting a situational analysis for IGAP implementation

- Existing data and information on neurological disorders should be utilized first – e.g. health systems information on the burden of neurological disorders.
- The initial analysis should identify what further data need to be gathered to achieve the goals of the analysis and how to carry it out.
- The activities of the situational analysis should be positioned on a clear timeline.
- Dissemination of the analysis should be planned in order to reach all stakeholders with interest in neurological disorders and to enable timely decision-making.



© WHO / Harandane Dicko. Woman holding food on the street in Democratic Republic of Congo, 2018.

Dominant neurological conditions in the African Region: situational analysis

A regional situational analysis was carried out in 2023 by experts in the WHO African Region, encompassing 47 countries with over 1 billion people. The analysis, which used current epidemiological data, looked specifically at five groups of neurological conditions: stroke, epilepsy, dementia, headache disorders and Parkinson disease. The domains which were considered for each of these conditions included: burden of the disorder (prevalence, incidence, mortality, DALYs and determinants), stigma and discrimination, legislation, and the health system response. The last domain comprised governance and leadership, health system organization, human resources, medication and essential supplies, financing, and research and information systems.

The situational analysis identified the key challenges for neurological health services in the region in general, as well as for each of the five conditions, and made recommendations for strengthening health and intersectoral services. The general recommendations were divided into short-term and medium-term recommendations, while specific recommendations by condition focused on concrete steps to widen access to services (e.g. integrate care for neurological conditions into primary care and increase the awareness of the general public, health workers and people living with neurological disorders). The importance of addressing legislative gaps was underscored with a separate set of recommendations.



Tools and resources



WHO mhGAP operations manual

The operations manual (p. 7) provides a quick guide to planning and carrying out a situational analysis, with practical tips and example.



WHO: Toolkit for developing a multisectoral action plan for NCDs. 1. Conducting a comprehensive assessment

The toolkit explains the steps for a situational assessment and explains what information and data should be collected for better understanding of NCDs, including neurological disorders, in the relevant setting.



WHO: Global Health Estimates

WHO's Global Health Estimates (GHE) provide the latest available data on death and disability globally, by region and country, and by age, sex and cause. By providing key insights on mortality and morbidity trends, these estimates are a powerful tool to support informed decision-making on health policy and resource allocation.



PRIME: Situation analysis tool

This tool is a comprehensive template with items on health services, policies and plans, and treatment data relevant to mental, neurological and substance use disorders.



© WHO / Conor Ashleigh. Residents of a Colombo suburb doing physical exercise in the early morning, Sri Lanka, 2018.

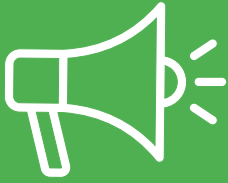
Note: Use dots to navigate between sections

5.

Implementing the IGAP strategic objectives

5.1

Prioritization and governance



Advocacy and awareness-raising

◎ Core concepts

Advocacy is an organized attempt to change policy, practice and attitudes by presenting evidence and arguments for how and why change should happen. Advocacy is frequently the precursor to policy and/or legislative changes. It can influence political commitment and help mobilize resources to support prioritization of neurological disorders, including interlinkages with broader national and international commitments (e.g. those outlined in national health plans, national plans for NCDs or mental health, health system strengthening, sustainable development).

Awareness-raising contributes to better public and political understanding of brain health, neurological disorders and sensitization to needs of people with neurological disorders – including their impact on individuals, societies and the economy. Awareness-raising is a key tool in reducing the stigma and discrimination in society regarding people with neurological disorders, their families and carers. Large-scale neurological and brain health awareness/literacy strengthens the coproduction of care across the entire trajectory of neurological care. While it can be a tool for advocacy, policy change is not the direct goal of awareness-raising – rather, the goal is to make people understand the burden of neurological disorders and generate support to address it.

Advocacy and awareness-raising are interdependent and mutually reinforcing concepts that provide an opportunity to mobilize all concerned stakeholders, including people with neurological disorders, their carers and families, to work towards achieving common goals and to catalyse change.



© WHO / Diego Rodriguez. Adolescents playing football in Tunisia, 2017.

? Why is this important?



To date, brain health and neurological disorders have not been adequately prioritized in national and global health policies and political agendas. Resources directed towards building health system capacity to deliver person-centred treatment and care for neurological disorders across the life-course are insufficient and unevenly distributed.



In many countries, people with neurological disorders continue to experience significant stigma, discrimination and human rights violations, affecting availability and access to and delivery of care. In addition, there is a lack of attention to the multifaceted needs (including social services, education, environmental, financial, employment, justice and housing) of people with neurological disorders.



Disabilities associated with neurological conditions inordinately affect the most vulnerable – children, women, older people, ethnic minorities and internally displaced or stateless persons, refugees and migrants, as well as those living in poverty, rural or remote areas. These population groups are less likely to be able to access and afford care, resulting in significant health inequities and cycles of poverty. Advocacy works to reduce these health inequities and protect the rights and access to care for people with neurological disorders.



Sustained advocacy and awareness-raising can act as a catalyst to improve access to and availability of quality, timely and affordable diagnosis, treatment and care, can reduce stigma and discrimination, and can prevent human rights violations, placing people with neurological disorders at the centre of these efforts.

✓ Actions



Effective **stakeholder engagement**³ is crucial for identifying opportunities for partnerships to support the development, implementation, financing, and evaluation of advocacy programmes, including awareness-raising campaigns. For instance, while the Ministry of Health may fund the development of an advocacy programme, a civil society partner such as a nongovernmental organization may implement it, and a research or academic institute may evaluate its reach and impact. Similarly, a network or coalition of stakeholders may be formed through which common advocacy goals are pursued, supported by pooled human and financial resources.

Advocacy programmes may be disorder-specific or integrated into broader health efforts



On the basis of the needs, priorities and goals identified by stakeholders, **an advocacy agenda or strategy** can be developed for all planned advocacy activities. This should be intersectoral and should be developed in collaboration with all consulted stakeholders – particularly people living with neurological disorders, their carers and families – to ensure ownership and buy-in. An advocacy strategy should include:

- an **operational or workplan** to identify roles, responsibilities and timelines as well as identify forums and outlets through which advocacy can be most effective (e.g. community town halls and events, local radio or television, printed or social media);
- adequate financial and human **resources** to implement the proposed activities and programmes; and
- a **mechanism to assess** impact.

Advocacy programmes may be disorder-specific, focus on the promotion of brain health or the prevention of neurological disorders, or be integrated into broader health promotion efforts such as for NCDs. Advocacy should highlight opportunities for strategic alignment with political priorities (e.g. health system strengthening, UHC, NCDs, mental health, community health).

³ See Chapter 3 on “Stakeholder engagement”.



Awareness-raising campaigns should be evidence-informed and should include information related to the burden and impact of neurological disorders, promotion of brain health and prevention of neurological disorders, protection and promotion of human rights, and/or the dissemination of evidence-based interventions.

Key strategies to consider in the design of awareness-raising campaigns for neurological disorders include:

- Identify and understand the **target audience** for the awareness campaign. This includes understanding how the population groups within the target audience perceive neurological disorders so that content can be culturally accessible and appropriate. Produce clear, concise and accessible messages that convey important information about neurological disorders using language that is easily understood by the target audience, avoiding jargon or technical terms.
- Utilize a variety of **communication channels** to maximize reach. This may include social media, traditional media (television, radio, newspapers), community events, and online platforms.
- Incorporate **personal stories and testimonials** from people living with neurological disorders. Real-life experiences can make the issues and experiences faced by people with these conditions more realistic, evoking empathy, and can make the campaign more tangible and relatable.
- **Partner** with influencers, celebrities and public figures who have a broad public reach and genuine interest in neurological health.
- Develop **informative and visually appealing materials**, such as brochures, infographics, and videos.
- Use designated **awareness months or days** related to neurological disorders to focus attention and create a sense of urgency.
- Establish mechanisms for monitoring and evaluating the **effectiveness and impact** of the campaign and the different strategies used.⁴

⁴ For more information, see Chapter 6 on “Monitoring and evaluation”.

! Special considerations for advocacy and awareness-raising

Effective advocacy for brain health and neurological conditions requires:

- the ability to identify common, overlapping interests between stakeholder groups and to unite these around a common vision that is to be carried forward by all stakeholder groups involved in order to achieve a shared goal(s);
- advocacy approaches that are tailored to each country's cultural, social and political context; and
- advocacy programmes and awareness-raising campaigns that are designed and carried out both for and by people living with neurological disorders and their families and carers, following the principle "nothing about us without us".

Advocating for change: the European Academy of Neurology's innovative training programme for neurologists

In 2024, the European Academy of Neurology (EAN) launched a dedicated online training programme in advocacy for neurology and brain health.

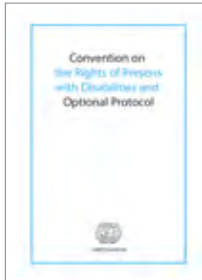
The training aimed to equip neurologists with improved communication skills for advocating neurology and brain health. It included participants from 27 countries worldwide and is part of the EAN's mission to promote brain health across all life stages. The training was designed to enhance public awareness and understanding of neurological disorders in a broad approach

to brain health. The programme consisted of three online modules focused on general advocacy, leadership insights for national-level advocacy, and strategies for engaging with patient organizations and policy-makers. Actions included workshops on creating core messages and enhancing interprofessional collaboration for advocacy.

After the completion of all modules, an assessment of the programme's impact on promoting brain health will be conducted and will be used to inform development of future training programmes.



Tools and resources



United Nations Convention on the Rights of Persons with Disabilities

The UN convention is an international human rights treaty to protect the rights and dignity of persons with disabilities, including neurological conditions. The convention describes the rights that people with disabilities should enjoy and the obligations of states towards them.



United for Global Mental Health: The toolkit to achieve mental health for all

The toolkit equips advocates to present key messaging on the importance of integrating mental health into universal health care coverage.



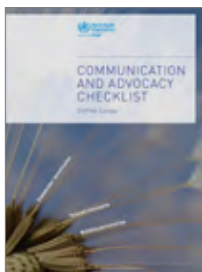
WHO: Implementing health in all policies: a pilot toolkit

The toolkit sets out in detail the mechanisms to guide intersectoral collaboration for health which draws in stakeholders from relevant policy areas.



Regional Psychosocial Support Initiatives (REPSSI): Psychosocial support advocacy toolkit

The toolkit aims to support nongovernmental and community-based organizations in low-resource settings to plan and implement effective advocacy work around psychosocial support.



WHO: Communication and Advocacy Checklist: EVIPNet Europe

The checklist gives practical advice on communication considerations in advocacy. The tips and prompts can be used to draft a communications strategy (including messaging, channels and media) for neurological disorders.



International Bureau for Epilepsy: Advocate's toolkit for reducing epilepsy stigma in Africa

The toolkit contains resources, ideas and guidance for addressing and dismantling stigma in the various communities on the African continent. The toolkit was developed to help advocates to be proactive in shaping inclusive communities.



Policy, plans and legislation

● Core concepts

Policies and plans are important tools for signalling political commitment to the prioritization of brain health and neurological disorders and need to be part of a wider health policy based on a PHC-oriented health system.

Given the interlinkages between neurological disorders and other public health areas and sectors, numerous opportunities exist to **integrate actions on neurological disorders** into policies and plans – e.g. in the areas of NCDs and communicable diseases; mental health; maternal, child and adolescent health; ageing and disability; social services; and inclusive education and employment. Brain health and neurological disorders may also be included in stand-alone national policies or plans.

Legislation concerning neurological disorders is often outdated and does not provide adequate protection of the human rights of persons with neurological disorders. It is imperative to introduce and strengthen these protections so that people with neurological disorders can be included in society and have the opportunities to lead full and productive lives.

The **integration and mainstreaming** of brain health and neurological disorders into evidence-informed national policies, plans and legislation beyond the health sector – including education, social services, employment and the environment – is crucial to meeting the needs of people with neurological disorders, their carers and families.

? Why is this important?

➔ Developing stand-alone policies and plans, or mainstreaming neurological disorders into existing ones, is important for identifying national priorities and commitments and providing a common framework for action by all stakeholders over the short-to-medium-term.

➔ National policies and plans also inform the effective allocation of financial, human and capital resources and the configuration of health service delivery to strengthen health systems for brain health and neurological disorders. This should include the earmarking of national health and social expenditures for brain health and neurological disorders through dedicated national budget lines.

➔ Updating all laws relevant to persons with neurological disorders, such as those related to education, employment, social services, health care and benefits, civil, women’s and children’s rights, as well as the rights of the older persons, is important to ensure that they are included in society on an equal basis with all citizens.



© WHO / Alasdair Bell. A family having a meal in Trinidad and Tobago, 2022.

✔ Actions

✔ Conduct a **situational analysis**⁵ that includes information about **national policies, plans and legislation** and identify priorities, including the need for updating. Priority-setting is critical to identifying which issues take precedence over others on the basis of evidence-based criteria and broad, multisectoral **stakeholder engagement** (Box 4). Priority-setting also allows possible overlaps to be identified, reducing redundancies and potentially leading to better allocation of resources.

✔ Review existing health policies, plans and programmes – including those for mental health, communicable and noncommunicable diseases, community health, child and maternal health, access to medicines, ageing and disability – for their relevance to brain health and neurological disorders in terms of IGAP’s targets.

✔ Base policy decisions on **evidence** from research studies, epidemiological data, and input from health-care professionals and neurology stakeholders. This ensures that policies are grounded in the most current and relevant information.

✔ Develop **clear and concise** policies and legislative proposals that address identified gaps and comprehensively deal with the needs of people with neurological disorders.

✔ Clearly define **roles and responsibilities** for implementing the policies, and work closely with relevant sectors to ensure a coordinated and effective roll-out.

5 See Chapter 4 on “Situational analysis”.



Review policies and legislation outside the health-care sector for their impact on people with neurological disorders. These may include policies and legislation on education, employment, environmental issues, transportation, infrastructure, human rights, civil rights, and the specific rights of women, children and older persons.



Integrate a **human rights and equity perspective** (Box 5) into policies and legislation to ensure that the rights of individuals with neurological disorders and their carers are protected, and access to health-care services is equitable.



Assess the **financial implications** of implementing new policies or updating existing legislation. Ensure that the budgetary considerations align with the overall goals and objectives.

Integrate a human rights and equity perspective into policies and legislation

BOX 4.

Stakeholder roles in the policy process

While policy-makers may lead the process of developing or updating policies, plans or legislation for brain health and neurological disorders, other stakeholders frequently play an important role.

Civil society and organizations representing **people with neurological disorders, their carers and families**, are often instrumental in raising political awareness of unaddressed needs and ongoing challenges in areas related to availability and access to health-care services, health-care worker capacity, human rights and research. In many cases, advocacy undertaken by civil society organizations may lead to government commitment to addressing brain health and neurological disorders (e.g. through the development of new, or the updating of existing, policies or legislation).

Research institutes and academia play an important role in providing evidence, data and facts at subnational and national levels to inform the policy and legislative development and updating



© WHO / Lindsay Mackenzie. A primary healthcare worker in Tajikistan, 2023.

process, including the identification of ongoing system- and service-level gaps and challenges. Research institutes and academia may be commissioned to carry out research, data collection and analysis, and/or evaluation and monitoring, and experts from these organizations may provide valuable input throughout the policy/legislative cycle.

The **private sector** may be engaged when collecting data and information during the landscape analysis, or in order to develop innovative financing mechanisms and public-private partnerships as a means of implementing policies or plans on brain health and neurological disorders (e.g. by funding private health-care facilities through pooled system-level mechanisms).

! Key considerations for policy, plans and legislation

When developing new policies, plans or legislation for brain health and neurological disorders, or integrating these into existing ones, particular consideration should be given to the guiding principles embedded in the IGAP. These include:

- ensuring person-centred PHC and UHC, placing people with neurological disorders, their carers at the centre of policies and legislation and ensuring they have equitable access to a broad range of promotive, preventive, diagnostic, treatment, rehabilitation, palliative and social care, as well as to essential, effective, safe, affordable and quality medicines and other products;
- ensuring an integrated approach to care across the life course in order to achieve better promotion, prevention and management of health and social outcomes;
- leveraging scientific evidence and/or good practices to inform the development of policies, plans, legislation, and governance and financing mechanisms for brain health and neurological disorders;
- ensuring that policies, plans and legislation are intersectoral in nature, reflect the multidimensionality of brain health and the multifaceted needs of people with neurological disorders, their carers and families and protect their human rights and dignity;
- empowering and involving people with neurological disorders, their carers, families, communities and the organizations that represent them in all aspects of policy and legislation development, updating, implementation and evaluation, ensuring that policy and legislative priorities are driven by, and reflect, the needs of people with neurological disorders.

BOX 5.**Rights-based approach to legislation for neurological disorders**

The UN Convention on the Rights of Persons with Disabilities is a hallmark of the rights-based approach to health. In developing and strengthening legislation for neurological disorders, the focus should be not just in the protection of human rights, but also expanding the responsibilities of government to promote the fulfilment of rights such as the right to health and others. This extends to the rights of caregivers to financial protection and pension.

Health-related legislation is an important component of the essential public health functions (EPHFs) and as such should be reviewed frequently through a comprehensive analysis of its impact, measuring the real outcomes of the legislation and with it, trigger a permanent evaluation and scrutiny. These responsibilities should be established under the Ministries of Health of countries. This, in particular, includes the review of impact and updating of legislation and regulatory measures to promote the protection of rights of people with neurological disorders. This work should be carried out collaboratively with other ministries and government agencies, inviting and promoting the active participation of civil society.



Tools and resources



UN Convention on the Rights of Persons with Disabilities

The UN convention is an international human rights treaty to protect the rights and dignity of persons with disabilities, including neurological conditions. The convention describes the rights that people with disabilities should enjoy and the obligations of states towards them.



WHO: Toolkit for developing a multisectoral action plan for NCDs

The toolkit is a “how to” guide for developing, implementing and evaluating a multisectoral action plan for prevention and control of NCDs, with modules that list the practical steps that need to be taken, and providing resources to follow.



WHO: Global action plan on the public health response to dementia (2017–2025)

The action plan aims to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on communities and countries. It provides a set of actions for realizing the vision of a world in which dementia is prevented and people with dementia and their carers receive the care and support they need to live a life with meaning and dignity.



Towards a dementia plan: a WHO guide

The guide provides useful information to Member States for creating and operationalizing a dementia plan. It includes associated tools such as a checklist to guide the development of a dementia plan as well as stakeholder mapping and priority-setting.



WHO MiNDbank: **A database of resources covering mental health, substance abuse, disability, general health, human rights and development**

The online platform provides quick and easy access to international resources and national and regional policies, strategies, laws and service standards for mental health, substance abuse, disability, general health, NCDs, human rights, development, children, young persons and older adults.



WHO: **Voice, agency, empowerment – handbook on social participation for universal health coverage**

The handbook describes how to facilitate the participation of civil society and communities in policy-making efforts by creating an enabling environment, ensuring representation, meaningful engagement and joint decision-making.



WHO: **Mental health, human rights and legislation: guidance and practice**

The guidance sets out a clear mandate for mental health systems to adopt a rights-based approach and provides key practical information on how to adopt a human rights-based approach when reviewing, adopting, implementing and evaluating laws relating to mental health.



Health systems financing

Core concepts

Health financing is critical to achieving UHC, ensuring that adequate resources are allocated to address the epidemiological and economic burdens of various health conditions and to protect affected persons and households from the potentially high or impoverishing costs of treatment and care. This is especially relevant when considering neurological disorders, which not only pose a significant public health challenge but also carry profound social and economic implications, often over a prolonged period of time or a person's entire life. In this context, effective health system financing becomes instrumental in providing affordable and accessible prevention, diagnosis, treatment and care for people with neurological disorders.

Evidence suggests that by investing in suitable prevention and care measures, productivity losses and other economic costs associated with neurological disorders can be mitigated.

Neurological disorders carry profound social and economic implications, often over a person's entire life.

? Why is this important?



Neurological disorders exert a substantial economic toll on individuals, families and societies. In Europe alone, the cost of neurological disorders was estimated at a staggering €PPP (purchasing power parity) 336 billion in 2010 from a societal perspective (6). This financial burden is largely attributed to productivity losses resulting from disability, informal caregiving and the lack of accessible and affordable care, particularly in LMICs.



Out-of-pocket costs associated with neurological disorders represent a significant financial strain on individuals and communities, particularly in settings where neurological disorders are not part of the UHC packages. These are costs for treatment and care, medication, assistive technology, transportation, living adjustments and other necessary expenditures, which heighten the risk of pushing people into poverty, reducing their standard of living and limiting their economic opportunities. Additionally, caregiving incurs indirect costs such as potential health and financial issues.



Persons deprived of access to treatment may find themselves unable to work, leading to a range of socioeconomic challenges. Children with neurological disorders may face barriers in education, while people of all ages may be prevented from leading fulfilling lives. This underscores the urgent need for appropriate financial planning, allocation and protection measures for neurological disorders. Furthermore, people with neurological disorders and their families have the inherent right to receive timely and adequate treatment and care. Consequently, effective health system financing is not only a crucial step to achieving UHC but also a moral imperative to ensure that individuals with neurological disorders receive the care they deserve.

✓ Actions



Assessment of the economic burden and resources requires the following actions:

- Gather comprehensive data on the prevalence, incidence, service coverage and economic costs of neurological disorders in the target population. This should include demographic information, types of disorders and the associated treatment and care costs as well as productivity losses. This information can be used to generate estimates of the economic burden of different neurological disorders as well as the resources needed to meet service coverage goals in the population (Box 6).
- Identify high-risk groups and hard-to-reach populations such as those in rural or remote areas, women, children, older persons, minority groups, migrants, homeless persons and others. Understanding their specific needs is crucial to effective resource planning and allocation.
- Financing strategies, in addition to focusing on treatment and clinical management, should take into account the social needs of persons living with the neurological disorder and their carers.



Budgetary allocation:

- Assess current health budgets to understand the existing allocation for neurological disorders and determine whether the funds align with the prevalence and impact of these conditions.
- Establish dedicated budget lines specifically for neurological disorders within the broader health budget, based on assessment of financial and human resource needs and gaps in the population.



UHC benefit packages:

- Extend or introduce, where necessary, UHC benefit packages that include comprehensive diagnosis, treatment and care for neurological disorders as well as support to carers – especially those providing long-term care.



Identify innovative financing mechanisms:

- Explore opportunities for pooling resources across sectors (health and social care), stakeholders (public, private and not-for-profit sectors) and, where applicable, international partners.
- Explore public-private partnerships. This could involve outsourcing certain services, sharing infrastructure, or jointly investing in research and development.
- Establish mechanisms for regular monitoring and evaluation of progress, outcomes and impact. Sample indicators may include new allocations or increases in existing proportions of national health expenditure for brain health and neurological disorders.

BOX 6.**Building an investment case for neurological disorders**

Making a persuasive investment case for neurological disorders is crucial for mobilizing support and directing resources towards effective prevention, treatment and care.

The components that are required to build an investment case include:

- The economic burden of neurological disorders can be estimated on the basis of an analysis of their prevalence, incidence and economic impact (especially losses in paid or unpaid production). Emphasis is needed on the social impact of neurological disorders and the barriers that people with neurological disorders and their families face in education, employment and daily life.
- Analysis of the cost and health effects of interventions can demonstrate the cost and cost-effectiveness of evidence-based interventions for many neurological disorders, which is often very low compared to their economic impacts. For instance, epilepsy can be treated at low cost, generating significant health benefits; medicines for Parkinson disease can similarly be provided at low cost to reduce the burden and support those with the condition to lead full and productive lives; and situational analyses for stroke suggest that cost-effective interventions can substantially mitigate global health and economic losses associated with the condition (7).
- A cost-benefit analysis can evaluate the potential returns on investment in neurological disorder interventions. There should be consideration not only of the immediate health-care costs but also the long-term economic benefits stemming from improved health and productivity and the reduced burden on society.
- Align the investment case with existing health policies and international frameworks. Demonstrate how investments in neurological disorders contribute to broader health and development goals, including the SDGs.
- Demonstrate that some neurological disorders such as stroke, dementia, epilepsy and headache disorders can benefit from prevention, thus reducing their burden and saving economic and personal costs.

How to build an investment case? Lessons from the mental health field

Seven case studies were undertaken by national and international experts in Africa (Kenya, Uganda, Zimbabwe) and Asia (Bangladesh, Nepal, Philippines, Uzbekistan) following the methodological guidance note developed and issued by WHO and the United Nations Development Programme (UNDP) to provide a consistent and structured approach to making national cases for investment in mental health, including epilepsy (8). The guidance note provides an overview of how to make an investment case, covering the principles and practice of analysing return on investment and its application to the mental health sector. The note further includes sections on intervention costing, estimation of population-level health impacts, monetization of benefits and return on investment metrics, as well as offering guidance for undertaking an institutional context analysis which enables institutions and/or countries to appraise the political context around implementing priority interventions from the investment case.

To complete the studies, countries formed teams of local experts to collect and review data and build consensus on the conditions and interventions to be included. The national teams also discussed the choices of analysis, assumptions and preliminary results, and received the support of an international team of health economists and mental health specialists.

Local survey data, or country-specific estimates obtained from the Global Burden of Disease study, provided age- and sex-specific incidence, prevalence, remission and mortality rates, as

well as levels of disability or functioning, for each condition of interest. Intervention effect sizes were based on estimates available from WHO's cost-effectiveness work programme. To estimate the population-level health impact of these interventions, the One Health tool, a strategic costing and planning tool developed by WHO and other UN agencies, was used.

Economic costs were established for direct mental health expenditure and for productivity losses due to absenteeism, presenteeism and premature mortality. Intervention costing was calculated on the basis of resource cost in the countries.

Both the intrinsic value of improved mental health and well-being, as well as its instrumental value (e.g. being able to form and maintain relationships, study, work or pursue leisure interests and to make decisions in everyday life) were estimated. The summary metric used in the analysis was the benefit-to-cost ratio, defined as the present value of total health and/or productivity gains, divided by the present value of total intervention costs.

The robust studies were developed for use by decision-makers at the national level, presenting context-specific information on the potential costs and benefits where efforts to increase access to quality mental health services were stepped up. The resulting economic evidence shows that the economic burden of mental health conditions is high, while investment costs are low, and the potential returns are significant.



Tools and resources



WHO: **One Health tool**

The tool provides those who carry out national strategic health planning with a single framework for scenario analysis, costing, health impact analysis, budgeting and financing of strategies for all major diseases and health system components



WHO: **A system-wide approach to analysing efficiency across health programmes**

The guidance equips countries with a framework to identify and correct inefficiencies in the delivery of priority health services, including duplications, overlaps and misalignments.



WHO: **Health for All: transforming economies to deliver what matters**

The report recommends policy approaches that reassess how health and well-being are valued, produced and distributed across the economy to create a new political economy based on Health for All.



WHO: **Mental health investment case: a guidance note**

This guidance note provides a structured approach for making national cases for investment in mental health.

5.2

**Diagnosis, treatment
and care**



Care pathways

Core concepts

The continuum of interdisciplinary care for people with neurological disorders encompasses activities from prevention, screening and diagnosis to treatment and acute, long-term, rehabilitative and palliative care.⁶ Many of these activities are handled by the health sector, but other sectors such as social care, education and employment also play significant roles. Because of the complex needs and high levels of dependency and morbidity of people with neurological disorders, integrated health and social care is essential.

Screening and diagnosis are key to accurate and timely detection of the problems that people are experiencing and to a turning point that sets people on a specific care pathway. Screening and diagnosis for many common neurological conditions can be made by non-specialist health workers using clinical interview and examination, although some cases require technology-assisted medical investigations which may be difficult to access in low-resource settings.

The treatment of neurological disorders can include medication and non-medication therapies (e.g. physical or psychological therapy) and can often be assigned and managed by non-specialist health workers.

Acute (emergency) care for neurological disorders following appropriate diagnosis is critical for the prevention and mitigation of longer-term consequences. Timely acute care can make a significant difference in health outcomes for time-sensitive conditions such as stroke, brain infections or head and spinal cord injuries.

⁶ In this toolkit and in the Intersectoral global action plan, the prevention of neurological disorders is covered in section 5.3 on “Promotion of brain health and prevention of neurological disorders”.

Care pathways

Capacity building of the health workforce
Access to medicines and technologies
Carer support

Long-term care for neurological disorders is often necessary because many disorders are long-lasting and may have complications or comorbidities. Long-term care requires continuity in health provider care, sharing of information and an interdisciplinary approach that fits the changing needs and lives of people with neurological disorders.

Rehabilitation for neurological disorders can enable people to return to and engage in work, the community and family life, and helps to reduce social isolation and to assist people to deal with the stigma associated with neurological disorders. Rehabilitation for persons with neurological conditions is important throughout the life course and across the continuum of care.

Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems associated with neurological disorders. Palliative care also improves the quality of life of adults, children and their families.

Why is this important?



Timely and appropriate diagnosis and treatment of neurological disorders leads to increased mortality and morbidity, worse health outcomes and greater suffering for people with neurological disorders, as well as economic costs, missed opportunities in life, stigma and isolation.



Care is unevenly distributed not only across regions and countries, but also within countries, where people with neurological disorders have varying levels of access and coverage depending on socioeconomic status, age, sex, urban or rural residence, minority status and other characteristics. The resulting imbalances in care perpetuate inequality, poverty, hardship, stigma and discrimination against specific groups.



Care pathways can be optimized at any level of resources through restructuring, providing and revising treatment guidelines, and strengthening the care delivery framework.

✓ Actions



Develop a model of care:

- Provide linkages between the different **levels of care** (Box 7). Primary care services should be supported by specialist neurology services in hospitals and community health services with efficient referral and back-referral mechanisms. Services should encompass the stages of care from emergency and critical care to chronic and long-term care.
- Establish protocols for timely and accurate **diagnosis**, considering the unique requirements of specific neurological disorders. In particular, implement the protocols with front-line practitioners to boost detection and appropriate referrals.
- Institute periodic revision of **treatment** guidelines for neurological disorders (e.g. every 3–5 years) to keep pace with new knowledge, technologies, medicines and approaches in tackling neurological disorders.
- Integrate **rehabilitation services** – such as physical therapy, occupational therapy, and speech therapy, based on individual needs – into neurology care pathways to address functional limitations and to improve the quality of life. Build comprehensive rehabilitation service delivery models for neurological disorders, working towards equitable access to quality services, including assistive products, for the whole population, including those in rural and remote areas.
- Develop a **palliative care plan** for progressive neurological disorders that focuses on relieving symptoms, improving quality of life and providing emotional and psychosocial support.
- Evaluate the effectiveness of the neurology care pathways and implement continuous **quality improvement** processes through regulation and feedback loops in order to enhance quality of care using effective planning, control and improvement based on feedback and data.



Implement integrated, person-centred and responsive care:

- Tailor care pathways to the **individual needs and preferences** of each person with a neurological disorder. Involve people with neurological disorders and their families in decision-making processes to enhance engagement, satisfaction and quality but also co-production of care.
- Proactively identify and provide appropriate care and support to population **groups at particular risk** of neurological disorders and those who have poor access to services, such as socioeconomically disadvantaged people, children, older persons, people affected by domestic and gender-based violence, prisoners, refugees, displaced populations and migrants, indigenous populations and other groups 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 people with pre-existing or emergency-induced neurological disorders such as traumatic injuries. Strengthen health and social care **workforce capacity** to identify and address rapidly the neurological disorders, including common comorbid and treatable conditions, paying special attention to these capacities:
 - Conduct a comprehensive assessment, considering physical, cognitive, psychological, and social aspects of the individual's health.
 - Identify and address comorbid conditions that may have an impact on the neurological disorder.
 - Work with other health and social care professionals to assess and respond to the changing needs of people with neurological disorders, their families and carers.

Care pathways

Capacity building of the health workforce
Access to medicines and technologies
Carer support



Expand care access and coverage:

- Establish smooth **transition** between age groups, such as children to adults and adults to older people, and between care settings, such as hospitals, rehabilitation centres, long-term care facilities and home care.
- Develop **community-based services** that enable people with neurological disorders to receive care closer to home. Promote collaboration with community resources, including community health workers, traditional healers, support groups, physical activity programmes and social services.
- Provide clear and accessible **educational materials**, including in digital formats, to people with neurological disorders and their families about the nature of the neurological disorder, treatment options and self-care strategies.
- Leverage **digital health solutions** to foster greater information-sharing between providers, people with neurological disorders and their carers and allow for remote consultation and care delivery through telehealth services while ensuring individual privacy and anonymity. In disseminating these solutions, consider how to provide equitable access to populations who are digitally excluded.

Care pathways

Capacity building of the health workforce
Access to medicines and technologies
Carer support

BOX 7.

Key characteristics of care models for neurological disorders

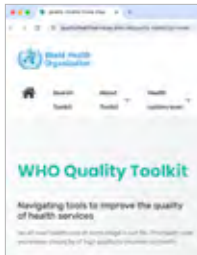
These include:

- high-quality primary care as first-contact care for neurological symptoms or conditions;
- strong linkages with timely acute care (including for out-of-hours first-contact services) and effective referral and counter-referral systems across all levels of care;
- longitudinal health care coordination for promotion of brain health and prevention of neurological disorders across the life course and for neurological conditions that require care over time;
- multidisciplinary, team-based service delivery; and
- pathways to guide people's journeys through a health system.





Tools and resources



WHO: **Quality toolkit**

The toolkit represents a wide range of WHO published materials to improve the quality of health services and supports actions for implementing a structured, systems-based approach.



WHO: **Framework for countries to achieve an integrated continuum of long-term care**

The framework identifies key elements necessary for countries to achieve an integrated continuum of long-term care service provision and to facilitate the integration of long-term services within the existing health and social care system as part of UHC programmes.



WHO: **Package of interventions for rehabilitation: module 5: neurodevelopmental disorders**

The package outlines the most essential interventions for rehabilitation for 20 health conditions, including information on the required assistive products, equipment and consumables, as well as the workforce that is usually skilled to deliver these interventions. This module comprises specific packages for autism spectrum disorders and disorders of intellectual development.



WHO: **Advocating for emergency care: a guide for nongovernmental organizations**

The guide clearly defines the role that nongovernmental organizations can have in advocating on behalf of people who need emergency care, including those injured in road traffic accidents.

Diagnosis, treatment and care >

Care pathways

Capacity building of the health workforce
Access to medicines and technologies
Carer support



WHO-ICRC Basic Emergency Care: approach to the acutely ill and injured

The OpenWHO course “Basic Emergency Care (BEC): Approach to the acutely ill and injured” is an open-access training course for first-contact health workers who manage acute illness and injury with limited resources.



WHO: **Palliative care fact sheet**

The factsheet explains the basics of palliative care and its importance, describes what actions countries can take and outlines the WHO response to the identified needs.



WHO: **Integrated care for older people (ICOPE): guidance for person-centred assessment and pathways in primary care**

The guidance assists with setting person-centred goals, screening for loss in a range of domains of intrinsic capacity (cognitive decline, limited mobility, malnutrition, visual impairment, hearing loss and depressive symptoms) and assessing health and social care needs to develop a personalized care plan.



Capacity-building of the health workforce

Core concepts

An adequate, well-trained and well-resourced neurological workforce is key to providing person-centred care, achieving better outcomes for people with neurological disorders, improving their quality of life and reducing economic and social costs for individuals, communities and governments

For the purposes of this toolkit, the health workforce is divided into two groups which require distinct approaches to capacity-building:

- **a specialist** neurological workforce which includes child and adult neurologists, neurosurgeons, neurological nurses, neuropsychologists, neurorehabilitation specialists, and speech and language therapists; and
- **a non-specialist** health workforce which includes community health workers, primary care physicians and nurses, physical therapists, pharmacists and other workers at all levels of the health system.

Capacity-building for the health workforce encompasses:

- **training and education**, including **pre-service education** (at educational institutions, in preparation for entering the health system) and **in-service training** (on-the-job training and continuing education); and
- **policies** that provide for **recruitment** (attracting new health workers), retention of existing health workers, incentivization (motivation for performance and advancement) and **task-sharing** (expanding the levels of health providers who can appropriately deliver services) of the health workforce.

? Why is this important?



At present there is a significant shortfall in the neurological workforce around the world, leading to a large treatment gap that is most pronounced in LMICs. Specialist neurological workforce cannot answer all existing needs for routine screening, diagnosis, treatment and follow-up of people with neurological disorders.



Addressing the shortage of care and neurological know-how requires a multipronged approach aimed at attracting, recruiting and training new health workers in specialist and non-specialist roles as well as training, upskilling and task-sharing with a broader range of existing health workers to diagnose, refer and manage neurological disorders.



Competences for identifying and managing neurological disorders should be built across all levels of the health system. Successful programmes and initiatives exist that demonstrate the feasibility of task-sharing in the diagnosis and management of neurological disorders by non-specialist health workers after appropriate training and resourcing



✓ Actions

The key steps in enhancing the capacity of the health workforce to provide comprehensive care to people with neurological disorders are as follows:

✓

Conduct a needs assessment by health systems planners and managers, answering the following questions to identify the specific gaps in knowledge, skills and resources related to neurological disorders within the health workforce:⁷

- How many health workers (specialist neurological and non-specialist) are there at each level of the health system?
- What are their qualifications and skills? What training programmes exist?
- What are the rates at which health workers leave (attrition) and join (recruitment) the health system?
- What are the required levels of staffing for managing the burden of neurological disorders?
- What are the functions and ratio of specialist and non-specialist health workers in the services for people with neurological disorders?

✓

Define learning objectives and develop **competency-based training** for different occupational categories of health workers (Box 8).

✓

Establish mechanisms for **continuous professional development** to ensure that health workers stay informed about advancements in the field of neurological disorders. This can include regular workshops, conferences and updates on evidence-based treatments.

✓

Integrate **technology-based** learning tools and platforms to enhance accessibility and reach a broader audience. This may include e-learning courses on neurological disorders.

⁷ For more information on how to conduct an overall situational analysis (of which a needs assessment may be a component), see Chapter 4 on "Situational analysis".

Diagnosis, treatment and care >

Develop policies to regulate the working environment of health workers that take into account:

- appropriate compensation that is commensurate with the workload, health system level and qualifications of the health workers;
- staffing standards and requirements, according to the population covered and treatment guidelines;
- requirements for content included in educational qualifications, pre-service training and in-service training; and
- retention boosters through promotions, supervision, remuneration, task-sharing and practices that create a good working environment.



Foster health-care providers' **knowledge of digital health tools** – including telehealth services, mHealth, digital devices and artificial intelligence health technologies for decision and care support in neurology – considering the potential of such tools to enhance care access and delivery (e.g. in rural/remote settings).



Implement **assessment tools** to measure the competency of health workers in managing neurological disorders through ongoing evaluations.



Update or develop curricula for **professional carers** delivering long-term home and residential care, ensuring their continued professional development in applying innovations, technologies and new approaches for neurological disorders.



Collaborate with **academia and professional societies** to identify educational pathways and strategies for brain health and neurological care.

BOX 8.

Developing competency-based training for neurological disorders

Competency-based education uses outcomes to inform curricula as well as assessments and feedback. Competency usually involves consideration of the knowledge, skills and attitudes needed to perform a task. Other characteristics of competencies include a focus on performance and application as the end-product of instruction – a behaviour that is measurable and definable and not based purely on comparison with others. Certain competencies are best assessed via knowledge tests, while others require skill-based demonstration assessments.

For neurological disorders, competencies tell us what the health-care provider should be able to do in clinical practice after the training. **Building competencies for identifying and managing neurological disorders** is a process which needs to be supported by policy-makers and health-care educators and planned by health-care managers. It will be different depending on the setting and context, and should include the following steps:

1. Identify the occupational categories, health system levels, and districts and regions where competencies should be expanded – these often include PHC workers and community health workers.
2. Analyse or commission analysis on the existing skills and practices of the selected occupational categories in managing neurological disorders, and the resources – financial, technical, human – required to build up competencies.
3. Identify a suitable method for delivering competency-based training. Some options include cascade trainings, online courses (interactive or self-paced) and qualification programmes.
4. Choose the contents to be covered by the training curriculum – available resources can be customized according to requirements – and select and define the competencies that trainers should have.
5. Organize delivery of training, paying attention to workloads, scheduling, compensation and incentives for health workers to participate. Ensure sufficient training time for learning and other organizational aspects.

6. Prepare specifically for upskilling and training in neurological disorder diagnosis and management for health workers who work with children and older people, given the specific competencies required and the burden of neurological disorders in these populations
7. Organize follow-up after training, including neurology specialists and supervisors who will oversee trainees in applying competencies and evaluation of training and learning.

Transforming epilepsy services in Kenya through training of primary health workers

WHO's *mental health GAP Action Programme Intervention Guide* (mhGAP-IG) is widely used around the world for training non-specialists in detection and management of mental, neurological and substance use conditions. Epilepsy and dementia are among the 10 priority conditions addressed by mhGAP.

The project Epilepsy Pathway Innovation in Africa (EPIInA) aimed to improve epilepsy services in three African countries, including Kenya. Between August 2021 and November 2022, 172 PHC workers in Kilifi County received in-person mhGAP training delivered over 10 consecutive days by master trainers trained in a cascade model. The mhGAP package of materials is extensive and, together with providing all necessary materials, describes in detail the methods of delivering the curricula which comprise didactic lectures, role-plays

and group work. Support supervision was provided by specialists through in-person workshops and via teleconsultation. An adaptation manual allows for customization according to the context and culture of the setting, and the guidelines are also available as a mobile application. Study results of the Kilifi training showed that the levels of stigma held by the health-care workers (measured as knowledge, attitude and behaviour) significantly improved after the training, while the number of clinical consultations which the health-care workers delivered rose significantly. Patients' severity of illness, quality of life and levels of disability also improved over the follow-up period. The EPIInA project showed the value of tailored training, ongoing support and technology use for improving epilepsy using mhGAP in resource-limited settings.



Tools and resources



WHO: **mhGAP Intervention Guide (mhGAP-IG) for mental, neurological and substance use (MNS) disorders in non-specialist health settings**

The intervention guide package has step-by-step algorithms for health providers to diagnose and manage epilepsy and dementia in their practice, as well as detailed curricula for training them in the use of these algorithms.



WHO: **Global Competency and Outcomes Framework for Universal Health Coverage**

The framework identifies the health worker competencies leading towards the achievement of UHC and sets out competency-based health worker education outcomes, together with guidance to educators for pre-service education pathways.



WHO, UNICEF: **EQUIP - Ensuring Quality in Psychological Support**

This platform, developed jointly by WHO and UNICEF, provides materials supporting governments, training institutions and nongovernmental organizations on training competencies of helpers to deliver effective psychological support to adults and children.



Access to medicines and technologies

Core concepts

Access to neurological medicines involves the timely and reasonable ability for a person to obtain and be able to use a medicine safely to prevent or manage a neurological condition.

Diagnostic tools include investigations such as diagnostic neuroimaging (e.g. computed tomography [CT], magnetic resonance imaging [MRI], ultrasound, positron emission tomography [PET]), electroencephalography and tests such as lumbar puncture and microscopy. These can facilitate early detection of neurological disorders and hence reduce morbidity and slow disease progression.

Assistive products (e.g. aids for hearing, mobility, communication) enable people to live healthy, productive, independent and dignified lives and reduce the need for formal support services.

Lack of access to essential medicines is a major cause of the diagnostic and treatment gap for neurological disorders, despite substantial evidence of their safety, cost-effectiveness and ability to prevent such conditions (Box 9).

Lack of access to essential medicines for neurological disorders is a major cause of the diagnostic and treatment gap

? Why is this important?

➔ Addressing access to essential medicines for neurological disorders will not only improve the health status and outcomes of the population but can also drive socioeconomic development in view of the consequent decrease in social isolation, carer burden, production losses and out-of-pocket spending.

➔ Certain medicines, such as those for epilepsy, headache disorders, Parkinson disease, multiple sclerosis and stroke are effective in preventing, managing or delaying the progression of these disorders, significantly improving the quality of life and health status of people living with neurological disorders.

➔ Improving access to diagnostics and technologies will decrease the diagnostic gap for neurological disorders and enable access to services to manage these conditions. This is particularly relevant in rural and underserved areas.

➔ Many neurological conditions (e.g. stroke, neurotropic infections, traumatic brain injury, spinal cord injury) require rapid access to diagnostic tools and medicines. Timely access to these recourses can decrease the long-lasting severe consequences and mortality associated with these diseases (“time is brain/spine”).

BOX 9.

Key barriers to access to medicines and technologies for neurological disorders are:

- high, multi-level stigma associated with neurological disorders;
- lack of prioritization of neurological disorders;
- outdated and misaligned national essential medicines lists and standard treatment guidelines;
- complex regulatory environments;
- poor health financing and high prices of medicines for neurological disorders;
- lack of local/regional manufacturing of medicines for neurological disorders;
- weak and/or complex supply chain systems, including forecasting, procurement and distribution;
- unavailability of medicines for neurological disorders, particularly in remote and rural areas, and frequent stock-outs;

- lack of qualified or out-of-date workforce across the health system, including health-care professionals and supply chain workers;
- weak pharmacovigilance and poor quality of medicines, including counterfeit and substandard medicines;
- lack of continuity of care beyond the acute setting, despite the critical need for adequate long-term care and rehabilitation services (physiotherapy, ergotherapy, speech and language therapy, cognitive and neurorehabilitation) inherent to many neurological conditions; and
- lack of data on neurological disorders and medicines across the health system.

Tanzania takes the lead in enhancing access to neurological medicines

Population-based prevalence studies in the United Republic of Tanzania estimate that some 450 000 people live with epilepsy, and some 36 000 people live with Parkinson disease. In May 2023, Tanzania was among the first countries to host a workshop on the implementation of IGAP. The workshop brought together policy-makers, service providers, civil society and people with lived experience. The workshop involved sharing the results of an assessment on access to medication for neurological disorders and laid the groundwork for the implementation of IGAP at the national level. Using epilepsy and Parkinson disease as tracer conditions, the participants identified key health system components that influence access and jointly developed a list of actions focused on improving access to these essential neurological medicines. A subsequent workshop in September 2023 ensured the continuity of actions and assessed the progress that had already been achieved.

As part of the formulated actions, Tanzania's Medical Stores Department is conducting special procurements of medicines for neurological disorders in order to address the lack of access to these medicines, including levodopa/carbidopa for Parkinson disease and several antiseizure medicines. In a significant step, Tanzania's National Health Insurance Fund package 2024 (last updated in 2016) now includes several medicines for neurological disorders – such as levetiracetam, donepezil, levodopa/carbidopa, selegiline and baclofen, as well as additional preparations of lamotrigine and carbamazepine. These actions represent a major step towards including Parkinson disease and epilepsy as priorities in the public health agenda of Tanzania.

✔ Actions

To enhance access to medicines, diagnostics and technologies for neurological disorders, a comprehensive approach that involves various sectors is necessary. Some actions apply broadly across sectors, while others focus on specific components of health systems.



Information-gathering:

- Conduct country-level surveys with data disaggregated by key settings on the availability and affordability of neurological medicines, diagnostics and technologies in order to identify gaps.
- Include information on availability, pricing, regulatory status and duration of stock-outs in data that are collected.



Rational selection and use:

- Form a national committee of experts to update lists of essential medicines and diagnostics for neurological disorders regularly in order to align them with the WHO Model Essential Medicines List and Essential Diagnostics lists, keeping in mind local contexts and countries' epidemiological trends (Box 10).
- Review and update standard treatment guidelines for neurological disorders on the basis of global recommendations.
- Review prescribed treatments regularly and consider de-prescribing according to changes in individuals' health.



Strengthen regulatory systems:

- Review legislation to facilitate registration of essential neurological medicines.
- Enhance capacity for pharmacovigilance and surveillance to investigate, monitor and decrease the presence of substandard and falsified/counterfeit medication.
- Actively participate in WHO's collaborative registration procedure.
- Provide guidance and conduct inspections to ensure proper handling practices for neurological medicines, such as appropriate storage of medication, control over expired medicines and prescription control.
- Develop accreditation procedures for laboratories and diagnostic centres by using advanced technologies to ensure quality.



Increase affordability:

- Allocate a separate budget line for neurological medicines in national benefit packages and consider innovative funding mechanisms such as taxation to increase budgets.
- Promote the use of high-quality generic and biosimilar medicines through educational campaigns.
- Establish or update legislation for fair and sustainable pricing of high-quality neurological medicines which does not incur inequitable costs under a rights-based approach.
- Promote publicly funded or supported research and development through fiscal incentives.
- Convene government stakeholders for collaboration on mechanisms for registration of medicines and other health products, pooled procurement and bulk purchasing of neurological medicines as well knowledge-sharing.
- Enhance infrastructure to accommodate advanced and novel clinical investigations for neurological disorders.



Improve availability:

- Provide appropriate options of formulations and strengths to cover the different needs of children, adolescents and elderly populations.
- Ensure that alternative options are available to address the needs of specific populations, such as women and girls who want to or may become pregnant.
- Maintain sufficient stocks across the different care levels and rural/urban areas to ensure continuity of treatment.
- Appropriately plan stocks to improve preparedness for emergencies, as well as for rolling out mass drug administration campaigns.



Capacity of the workforce:⁸

- Train persons working across the supply chain on forecasting, supply chain management, good distribution practices, regulatory compliance and quality assurance.
- Provide training to health-care workers at all levels on safe and appropriate use of medicine, as well as and other important practices such as safe storage, medication individualization, and medication disposal.
- Provide training to specialists and PHC workers on digital health tools (including telehealth, mHealth, digital therapeutics, AI-based health technologies).



Strengthening supply chains:

- Incentivize local/regional manufacturing or coordinate regionally to meet the demand for neurological medicines efficiently.
- Develop forecasting mechanisms using historical data to anticipate the needs for neurological medicines.
- Institutionalize efficient supply chain management through standard operating procedures.
- Conduct strategic procurement to reduce stock-outs and emergency purchases.

⁸ For more information, see “Capacity-building of the health workforce” under section 5.2 on “Diagnosis, treatment and care” in this toolkit.

BOX 10.**WHO Model List of Essential Medicines – 23rd list**

The WHO Model List of Essential Medicines is updated every year and includes the minimum medicine needs of a basic health-care system, listing the most efficacious, safe and cost-effective medicines for priority conditions. Priority conditions are selected on the basis of current and estimated future public health relevance and the potential for safe and cost-effective treatment. Regular updating of the Model List, as well as national essential medicines lists, are key priorities in addressing gaps, responding to the lack of coverage of diseases and medicines as well as to emerging epidemiological trends and emergencies. Continuous expansion of the number and scope of medicines for neurological disorders on the Model List is essential both for addressing the evolving and growing global burden of neurological disorders and for updating evidence on the therapeutic benefits of medicines. The Model List also enables implementation of mhGAP recommendations.

The importance of the inclusion of medicines on the Model List is exemplified in the case of multiple sclerosis and the drive of the Multiple Sclerosis International Federation to add disease-modifying treatments to the 2023 Model List as an initial and important step to increase their availability worldwide, and particularly in LMICs. As a result, rituximab, cladribine and glatiramer acetate were added to the list in 2023. In addition, levetiracetam for treatment of epilepsy and intravenous levetiracetam for the treatment of status epilepticus have been added.

Regular updating of national essential medicine and diagnostic lists for neurological disorders is a key priority for improving treatment access.

Special circumstances

Controlled medicines:

- Review and update national **legislation for controlled medicines** to ensure their safe and appropriate use, while facilitating the procurement of essential neurological medicines with controlled status and ensuring that they remain accessible as needed.
- Provide **training** to relevant supply chain workers (e.g. customs officers and staff of ports/airports/border crossings, staff in distribution centres, warehouses and pharmacies) ensuring that they are aware of the international emergency procedures for flexibility that facilitate procurement and import/export of essential medicines and equipment.

Access during emergencies:

- To improve emergency preparedness, programme managers are encouraged to build up **buffer stocks** and revise their estimates/assessments of medicines to avoid stock-outs.
- To facilitate access during emergency situations, competent authorities should create special procedures to **facilitate importation and exportation** of medicines, including controlled medicines, providing clear guidance to stakeholders on national requirements and procedures, as well as following guidance established by the International Narcotics Control Board when relevant.



Tools and resources



WHO Model List of Essential Medicines - 23rd list, 2023 and **WHO Model List of Essential Medicines for Children - 9th list**

The lists, updated every two years, are intended as guides for countries and regional authorities while developing and updating national essential medicines lists, focusing on a limited number of selected medicines to improve access, support prescribing and lower costs.



Selection of essential medicines at country level. Using the WHO model list of essential medicines to update a national essential medicines list

The guideline proposes best practices and a detailed step-by-step process for developing national essential medicines lists.



WHO: **Priority Assistive Products list**

The list, similar to the WHO Model List of Essential Medicines, includes priority assistive products which improve the quality of life of persons with health conditions and can be used by countries to develop their own national lists.



WHO **Training in assistive products**

The online modules aim to equip community-level personnel working in any context to provide safely and effectively a range of simple assistive products.



The selection and use of essential in vitro diagnostics: report of the fourth meeting of the WHO Strategic Advisory Group of Experts on In Vitro Diagnostics, 2022 (including the fourth WHO model list of essential in vitro diagnostics)

The WHO model list of essential in vitro diagnostics was developed to provide evidence-based guidance to countries for creating or updating their national in vitro diagnostics list and to guide policy on access to clinical laboratory services and in vitro diagnostics testing.



Diagnosis, treatment and care >

Care pathways
Capacity building of the health workforce
Access to medicines and technologies
Carer support



WHO: Prequalification of Medical Products (IVDs, Medicines, Vaccines and Immunization Devices, Vector Control)

The website on WHO's work in capacity-building for prequalification of medical products describes options and training available for national regulators, manufacturers and quality control laboratories.



WHO guideline on country pharmaceutical pricing policies, second edition

The guideline contains recommendations for 10 pricing policies commonly considered in countries for managing medicine prices, as well as pragmatic considerations for what is required to implement these policies according to the objectives and context of individual health systems.



WHO: Recommendations on digital interventions for health system strengthening

The guideline presents recommendations based on a critical evaluation of the evidence on emerging digital health interventions that are contributing to health system improvements, taking into account benefits, harms, acceptability, feasibility, resource use and equity considerations.



International Narcotics Control Board: Lessons from countries and humanitarian aid organizations in facilitating the timely supply of controlled substances during emergency situations

The publication identifies best practices on how countries and the global community can facilitate the availability of controlled medicines during emergency situations by using these model guidelines.



Carer support

Core concepts

People with neurological disorders often need care to provide for their essential needs, to improve their quality of life and to enable them to participate fully in society. The level of care needed varies and can be highly complex and specialized, placing a significant burden on carers.

Most of the care provided globally comes from non-professionals such as family members, friends and community members. **Role strain** is the result of compounded stressors experienced by carers and may have a severe impact on their quality of life and socioeconomic status and can diminish their opportunities to participate meaningfully in society (Table 1).

Why is this important?

➔ Globally, carers from families and communities provide the vast majority of everyday care for the needs of people with neurological disorders. Typically, these carers are unpaid and the care burden has consequences for economic productivity, mental health, community cohesion and integration into society.

➔ The majority of informal carers around the world are women. The burden of being an informal caregiver increases women's economic risks and hardships, contributing to gender inequities, as evidenced by pension gaps and greater rates of old-age poverty (9).

➔ In many settings there is very little support from institutions and societies for carers despite their important and sustained role.

➔ Support should be directed to upskilling carers, providing psychosocial support and respite (i.e. temporary replacement) care, and providing them with more knowledge, resources and opportunities for role recognition, professional and personal realization and inclusion in the wider society. Targeted support should be provided to specific groups of carers (Table 2).

Table 1. Types of challenges faced by carers of people with neurological disorders

Mental ill-health	This can result from challenges in providing care, together with social isolation, financial stress and other reasons.
Physical demands	The physical demands of caregiving – such as lifting, assisting with mobility, and sleep deprivation – can take a toll on the health of carers.
Lack of knowledge and training	There is often little support and training for unpaid, non-professional carers who care for people with neurological disorders.
Financial burden	This is due to reduced working hours and job loss, as well as medical expenses related to treatment of neurological disorders. It includes old age poverty through diminished formal market participation and subsequent lack of pension.
Reduced life opportunities	Few resources available for vocational and educational training, reduced income, social isolation and stigma influencing relationships can result in little access to opportunities.
Social isolation	The reduced chance to sustain relationships and participate in the community, coupled with societal discrimination, mean that the carer is often isolated.
Stigma and discrimination	These arise from the carer being associated with people with neurological disorders who are often subjected to societal prejudice and discrimination (also known as courtesy stigma).
Bereavement	Caring for people with neurological disorders with terminal conditions can result in deep sadness and depression after their passing.

✓ Actions

✓

Policy:

- Policy-makers should incorporate the **perspectives, views and suggestions** of people with neurological disorders and their carers into policies, programmes, plans and legislation, taking particular care to obtain the views of persons from hard-to-reach groups and to encourage their participation in the planning processes.
- Policies should be created or reviewed through intersectoral engagement to **support carers in their role** through financial and social benefits, including pension funds, while giving carers wider recognition and reducing discrimination.

✓

Education and training:

- Interventions should be developed to **improve carer knowledge and skills** in managing neurological disorders and should be included in service packages for health and social care with the widest possible access, taking into account barriers such as logistics, literacy and financial considerations. Where possible, interventions should include standardized training and certification of carers to ensure standards of care and incorporate evidence-based practices.
- In health care and social care education and training, educators should design **curricula specifically for carers of people with neurological disorders**, catering for both professional and non-professional carers.

✓

Bereavement support:

- Support should be made available through the **health and social care systems** for bereaved carers. Bereavement support should include mental health support, financial support related to long-term care, end-of-life expenses and transition out of the carer role, and opportunities for the vocational training of carers.



Health of carers:

- Interventions and programmes should be developed to improve carers' and families' physical and mental health (e.g. through support groups, peer support initiatives, psychoeducation by health-care practitioners, digital interventions).
- To reduce carer stress, programmes for respite care should be developed and introduced, taking into account the perspectives of people with neurological disorders, carers and families.

Empowering carers of people with dementia: iSupport

iSupport is a skills training programme developed by WHO for carers of people with dementia. It aims to prevent and decrease mental and physical health problems associated with care-giving and to improve the quality of life of those caring for people with dementia. iSupport serves as a self-help tool for carers of people with dementia, including family members, relatives and friends. It can be adapted to national or local contexts and needs. The iSupport manual includes five modules and accompanying exercises, namely: 1) Introduction to dementia; 2) Being a caregiver; 3) Caring for me; 4) Providing everyday care; and 5) Dealing with behaviour changes.

The modules and exercises reflect those included in the virtual course of iSupport which is accessible online. The iSupport manual can be used offline and printed, allowing for a broad reach of the programme particularly in regions of the world with low Internet bandwidth and/or connectivity. Once adapted, learning is self-paced – carers can choose to work through all modules and lessons consecutively, or select the lessons that are the most relevant to their everyday lives. All lessons consist of brief readings, descriptive examples and several exercises. Carers receive feedback as they work through each exercise.

An international iSupport network involves research teams from 40 countries that meet monthly to share their experiences on adapting, developing and implementing iSupport. The network is an organically grown support mechanism for researchers and implementers who share good practices on iSupport implementation for different populations and cultures, foster mutual learning and collaborate on and harmonize research efforts.

Key considerations for specific groups of carers

Table 2. Support for carers will need to be tailored to specific needs

Group of carers	Strategies for carer support
Carers of people with specific neurological disorders such as dementia, where caring responsibilities become more complex and more difficult with the progression of the disorder	<ul style="list-style-type: none"> • Respite care • Psychosocial support • Carer education and training
Carers of people with neurological disorders who are approaching the end of their lives	<ul style="list-style-type: none"> • Psychosocial and bereavement support • Vocational and employment support
Carers of people with complex needs and comorbidities	<ul style="list-style-type: none"> • Carer education and training • Support by an interdisciplinary team • Support with obtaining and using assistive products • Psychosocial support • Flexible work arrangements • Respite care
Carers of children with neurological/ neurodevelopmental disorders	<ul style="list-style-type: none"> • Support by a multidisciplinary team with expertise in care of children • Carer skills training and upskilling • Respite care • Support from special needs educators • Psychosocial support for children and parents, including flexible working arrangements • Support with transition to adult-oriented services, as necessary



Tools and resources



WHO: iSupport for dementia

The package, which consists of a manual and an online tool, provides self-paced skills and a training programme for carers of people with dementia in providing everyday care. iSupport deals with behaviour changes, with brief readings, examples and exercises for which carers receive feedback.



WHO eLearning caregiver skills training for families of children with developmental delays or disabilities

The e-learning modules aim to teach the caregivers of children with developmental delays or disabilities how to use everyday play and home activities for learning and development.



© WHO / NOOR / Sebastian Liste. A young child is receiving rehabilitation at the Down Syndrome Program Center in Karachi, Pakistan.

5.3

**Promotion of brain
health and prevention of
neurological disorders**


Core concepts


Promotion of brain health refers to actions throughout our lifetimes that minimize risk factors and enhance protective factors – i.e. by addressing the determinants of brain health. These determinants are physical health and physical activity, healthy environments, safety and security, learning and social connection, and access to quality services, among others.


Prevention of neurological disorders includes:


- clinical preventive services of neurological consequences of communicable diseases, such as immunization and vaccination of children, adults and older people, as well as vaccination or post-exposure prophylaxis for people exposed to a communicable disease;
- preventive programmes to control risk factors shared across neurological conditions and NCDs, including physical inactivity, hypertension, poor diet, and use of alcohol and tobacco.

Why is this important?

 Promotion of brain health and the prevention of neurological disorders are part of a holistic approach to health that recognizes the interconnections between physical, mental and social factors.

 Promotion of brain health benefits societies and economies by helping people realize their full educational, economic and life potential.

 Prevention can significantly reduce the burden of newly emerging cases of neurological disorders, lessening the impact on individuals and the strain on health-care systems, as well as reducing associated comorbidities and mortality.

 Many neurological conditions can be prevented by simple interventions aimed at reducing modifiable risk factors. For individuals who have a neurological disorder, the trajectory of health and functioning can be shaped by external factors that are influenced by preventive efforts such as physical activity.

Actions

Promotion of brain health and prevention of neurological disorders require an intersectoral platform with integrated policies that address the key risk and protective factors as well as the determinants of brain health. Interventions and services should stem from these policies and focus on increasing opportunities for leisure and physical activity in populations of all ages, eliminating and mitigating harmful exposure to substances and pollutants and enhancing road, sport, communal and labour safety.



Policy actions:

- Prioritize population-wide neurological health promotion strategies through policy initiatives, emphasizing the importance of regular physical activity, good sleep habits, healthy diets, and elimination of tobacco and harmful alcohol use. Draw on NCD prevention programmes considering that “what is good for the heart is good for the brain” (10).
- Implement fiscal policies such as taxes on unhealthy food and beverages, alcohol, and tobacco, healthy lifestyle benefits, and infrastructural improvements to incentivize healthy diets and lifestyle.
- Support population-wide strategies for healthy nutrition for brain development, including food fortification where appropriate, policies for healthy school-based nutrition, and resilient food production systems.
- Review and strengthen environmental policies which reduce air, noise and light pollution, particularly in urban areas.
- Strengthen policies and practices which limit or eliminate exposure to hazardous chemical compounds, including pesticides, lead paint and mercury-containing compounds.
- Align policies and practices with the recommendations set out in the UN’s Decade of Action for Road Safety which aims to prevent at least 50% of road traffic deaths and injuries by 2030.
- Introduce and strengthen protective measures and encourage safe practices in driving, sports and employment.
- Incorporate a One Health approach which considers together sectors such as public health, animal and plant health, and the environment, to design and implement programmes, policies, legislation and research about neurological disorders.



Clinical care:

- Introduce routine newborn screening for early detection and management of neurodevelopmental and neurometabolic disorders.
- Promote perinatal care services, including perinatal mental health, to protect maternal health and prevent neurological disorders in fetal and early life.
- Integrate the prevention of neurological disorders into programmes and interventions for infectious disease screening and treatment with a focus on the identification and management of risk factors.
- Emphasize the importance of vaccination for the prevention of diseases through campaigning and increasing access to routine vaccinations.



Raising awareness:

- Develop culturally relevant brain health promotion messaging and initiatives that leverage innovative evidence-based approaches, including digital and mobile health technologies, educational tools and social media.
- Inform educators about the importance of learning and education in brain development, emphasizing healthy behaviors for children of all ages.
- Provide evidence-based curriculum materials on brain health promotion for professionals in the education, health, and social sectors.
- Incorporate messaging about the importance of early nurturing care and lifelong interventions that promote caregiver skills and address childhood adversities.



Research:

- Emphasize research on the social determinants of brain health to inform evidence-based interventions and policies.
- Conduct research to understand and address disparities in access to preventive health information and services.

How to make brain health a household term: the Norwegian Brain Health Strategy

The first steps towards the Norwegian Brain Health Strategy were taken in 2014 by the Norwegian Brain Council – a collaboration of over 60 patient organizations, medical professional associations and scientific institutions – which advocated with health authorities for more research, better treatment and rehabilitation for neurological disorders, and greater equity within health services. In 2015, a unanimous vote in the Norwegian Parliament set off the development of the strategy. At the request of the Minister of Health, the Norwegian Directorate of Health prepared a status report on brain health together with patient representatives and medical professionals in February 2017. The report concluded that brain health should be promoted because poor brain health represents a major and increasing burden of disease. In 2017, the Norwegian Brain Health Strategy 2018–2024 was launched.

The strategy focuses on prevention and quality of life – especially lifelong brain health promotion from pregnancy to the end of life, including palliative care; increased user participation and peer-oriented health services; high-quality treatment for habilitation and rehabilitation; and stimulation of research, science and innovation.

The lack of concrete measures at all levels is a challenge to implementation of the strategy. For instance, measures of brain disease and brain health should be included in health statistics to ensure appropriate prioritization in policy-making and to increase public awareness. Similarly, better measures are needed that are not disease-specific but that maintain a broad perspective on brain health in line with the national strategy. The current strategy expires in 2024, but its next iteration has already been announced for 2025.



Tools and resources



WHO: **Global action plan for the prevention and control of noncommunicable diseases 2013–2020**

WHO's Global NCD action plan 2013–2020 (extended to 2030) follows commitments made by heads of State and Government, recognizing the primary role and responsibility of governments in responding to the challenge of NCDs and the important role of international cooperation to support national efforts.



WHO: **Optimizing brain health across the life course: WHO position paper**

The position paper provides a conceptual framework for what brain health is and how brain health can be optimized throughout life with actions across the following clusters of determinants: physical health, healthy environments, safety and security, learning and social connection, and access to quality services.



WHO: **Every newborn: an action plan to end preventable deaths**

The action plan presents evidence-based solutions to prevent newborn deaths and stillbirths. It sets out a clear path for action with specific global and national milestones.



WHO: **Preventing disease through healthy environments: a global assessment of the burden of disease from environmental risks**

The analysis, covering more than 100 diseases and injuries, underscores the pressing importance of stronger intersectoral action to create healthier environments that will contribute to improving sustainably the lives of millions around the world.

Promotion of brain health and prevention of neurological disorders



WHO: **Framework Convention on Tobacco Control**

The Convention is an evidence-based treaty that reaffirms the right of all people to the highest standard of health. The Convention represents a milestone for the promotion of public health and provides new legal dimensions for international health cooperation.



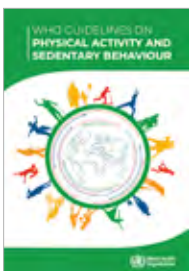
WHO: **Global Strategy for Women's, Children's and Adolescents' Health 2016-2030**

The strategy aims to achieve the highest attainable standard of health for all women, children and adolescents, transform the future and ensure that every newborn, mother and child not only survives but thrives. It is intended as a guide to enable people and communities to drive change, claim their rights and hold leaders to account.



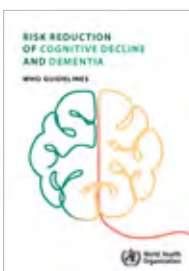
WHO: **Global strategy to reduce the harmful use of alcohol**

The global strategy aims to give guidance for action at all levels, to set priority areas for global action, and to recommend a portfolio of policy options and measures that could be considered for implementation and can be adjusted as appropriate.



WHO: **Guidelines on physical activity and sedentary behaviour**

The guidelines provide evidence-based public health recommendations for children, adolescents, adults and older adults on the amount of physical activity (frequency, intensity and duration) required to offer significant health benefits and mitigate health risks.



WHO: **Guidelines on risk reduction of cognitive decline and dementia**

The guidelines provide evidence-based recommendations on lifestyle behaviours and interventions to delay or prevent cognitive decline and dementia.

5.4

**Research and
information
systems**

◎ Core concepts

Research for neurological disorders encompasses elements such as basic science, clinical research and implementation science. Historically, different research areas have progressed at different paces and received different attention in terms of funding; while progress has been observed in terms of prevention, diagnosis and treatment, other areas such as epidemiology, economic impact, care and support have received less attention despite being equally important. The conversion of research findings and discoveries in neuroscience into practical tools for care and treatment of people with neurological disorders is fundamental for the adequate provision of neurological services.

Health information systems are essential for comprehensive neurology health care, ensuring the secure, sustainable and timely flow of critical information. This encompasses crucial factors such as individuals' medical histories, laboratory examinations, results and treatment plans. Strong health information systems will ensure that essential information is collected and shared for adequate planning and implementation of services.

Strong health information systems are essential for comprehensive neurology health care



? Why is this important?



Investing in research is key to support a **better understanding** of neurological disorders and the determinants of brain health, including: the identification of disease pathological mechanisms; genetic, ethnic and gender differences; resilience and compensation mechanisms; as well as the neurophysiology of brain development and brain health in different settings.



Research and innovation can also support the **development of tools, methods and interventions** to measure brain health, diagnose and treat neurological disorders and provide continuous care and rehabilitation.



Investing in **implementation research** is paramount to the design of implementation strategies that will make interventions relevant to the context in which they are being used and will ensure that equity and diversity measures are taken into account. Implementation research is also needed to optimize the integration of research efforts on neurological disorders with wider efforts on PHC-oriented health systems.



Epidemiological and **cost-of-disease research** are vital to acquiring representative data on brain development, developmental disabilities and neurological disorders, as well as to understanding the impact on health systems, economic impact of neurological disorders and the benefits of investing in prevention, promotion and treatment. This data can, in turn, be used to monitor emerging threats to brain health and support programme planning for the health system.



National health information systems rarely collect information on a defined set of indicators for neurological disorders, resulting in a lack of clarity about the burden of disorders and service use, which in turn has an impact on planning. Routine health information systems for neurological disorders are often either highly fragmented and specific (e.g. monitoring for research purposes, such as stroke or dementia registries) or underdeveloped, especially in low-income countries.



Electronic health records provide interoperability across services and empower individuals with access to their health information. Well-developed health records facilitate the continuity of care across the life course, especially in cases involving multiple health-care providers, and facilitate swift access to critical health data in emergencies.

✓ Actions



Research

- Identify **priorities** in neurological disorder research, taking into account both the health-related needs of the person with neurological disorders and the broader societal needs.
- Facilitate **collaboration** between policy-makers, researchers, health-care providers, civil society, people with neurological disorders and their carers and families in order to understand and respond to research needs. Seek collaboration across sectors, including with the private sector, to drive the search for innovative and scalable solutions for neurological disorders
- Develop sustainable **funding** opportunities for comprehensive, longitudinal studies for neurological disorders, employ mechanisms for joint funding calls for research to ensure sustainable and sufficient funding, and fund innovation for neurological disorders, including novel approaches to treatment and assistive technology.
- Support a multisectoral approach to the creation of **training** programmes on neurological disorders for researchers and for continued education and employment (e.g. tenure-track positions), especially for early career and female researchers.
- Invest in state-of-the-art **research infrastructure** – including laboratories, imaging facilities and data repositories – and support the development of technology platforms that facilitate data-sharing and collaboration.
- Create ethically sound guidelines that anticipate the evidence and requirements necessary for **regulatory review and policy development** in order to fast-track the development and implementation of life-changing scientific advances.
- Review existing laws and regulations concerning **data-sharing and protection** or develop new ones to facilitate exchange between national and international researchers.
- Review and update as necessary **ethical approval processes** for research and innovation to ensure the protection, safety and equitable inclusion of research participants in studies and trials.

- Promote the **responsible and ethical use of data** by research/funding agencies, mandating data-sharing or providing incentives to share data within existing regulations.
- Promote research that can be used to **reduce inequalities** in brain health, focusing on conditions that affect the most disadvantaged populations and on innovation to generate products that would be accessible to these populations.
- Support the **translation of research findings** into evidence-informed policy and practice. Hold regular knowledge-sharing opportunities (e.g. seminars) bringing together researchers and policy-makers for the active dissemination of research findings that can be implemented in the countries' contexts.
- Foster the development of national and international **networks of researchers** in order to promote collaboration, knowledge and skill sharing to enable a holistic approach to implementation.
- Invest research resources in **understanding the disease-causing mechanisms** and risk factors of neurological diseases in order to enhance prevention efforts through predicting and forestalling the occurrence of neurological disorders.



© WHO / Mukhsin Abidzhanov. An elderly couple who receive regular home visits from a family nurse, Tajikistan, 2023.



Information systems⁹

- Develop or improve existing **mechanisms for routine data collection** across health and social care facilities. The mechanisms may include:
 - Implement and integrate **electronic health records** and ensure their interoperability to facilitate seamless data-sharing between different health information systems.
 - Strengthen and expand existing **disease surveillance systems**, incorporating neurological disorders into routine monitoring activities, and implement real-time reporting mechanisms for timely identification of trends and emerging issues.
 - Establish comprehensive **disease registries** for neurological disorders, covering a wide range of conditions, including rare diseases (as separate registries, or combined into one).
 - Ensure that health information systems collect data that can be **appropriately disaggregated** (e.g. age, gender/sex, disease) and able to assess different equity measures.
- Review existing **regulatory frameworks** concerning the routine collection, recording, linkage, disaggregation and sharing of health and administrative data on each encounter of a person with a neurological disorder with the health and social care system.
- Improve data communication across different levels of the health system as well as across other areas (e.g. social care services).
- **Ensure compliance** of health information systems with data privacy and confidentiality regulations, as well as access and network security, protection of the infrastructure and equipment, and regular maintenance of software and hardware.
- Build **system and workforce capacity** for routine data collection, analysis, visualization and reporting

⁹ Information systems are a necessary requirement for monitoring and evaluation; consider this section together with Chapter 6 on “Monitoring and evaluation”.

- Institute regular **cycles of reporting** to senior health-care management and policy-makers in order to incorporate insights and information into decision-making, planning, and the development of policies and strategies for neurological disorders.
- Enable **access to health information system** data to improve utilization of information, creating data-sharing agreements and stipulating open access to research findings on neurological disorders.
- Facilitate periodic **briefing sessions** with all concerned stakeholders on disseminating information and findings based on the data collected through routine health information systems.

Innovations in measuring childhood development: GSED

The Global Scales for Early Development (GSED), published in 2023, were developed by WHO to answer the need for a universal measure to quantify development in the earliest period of childhood. GSED is an open access package specifically designed to provide a standardized method for measuring the development of children up to 36 months of age at population and programmatic levels globally. The GSED measures (short form and long form) capture child development holistically through a common unit – the Developmental score (D-score). The open access measures that are part of GSED were created by an expert team to serve as a population-level assessment of early childhood development across diverse cultures and contexts. In the process, over 100 000 observations on children were used to develop the items. A rigorous and standardized method was deployed to evaluate the psychometric properties of the newly-created GSED measures in seven countries. However, the measures have not yet been tested within the context of clinical use and should therefore not be used for screening individual children for developmental delays or impairments or for diagnosis.

Key considerations for inclusivity in research and data collection

Certain populations are underrepresented in neurological research and data collection, leading to a lack of evidence on causal mechanisms, risk factors, care pathways and the social and economic impact of neurological disorders. Such populations include women, children, older adults, migrants, refugees, minorities and indigenous people, socioeconomically disadvantaged people, persons with cognitive impairments and disabilities, and people living in rural or low-resource areas. Steps should be taken to encourage their inclusion in all data collection and research initiatives through the following:

- Assess and address the barriers to participation in research such as transportation, childcare or work schedules.
- Provide communication materials and research instruments in easily accessible formats, including multiple languages as needed. This includes consent forms, surveys/questionnaires and information materials.
- Target recruitment strategies to the cultural context of underrepresented populations, using community leaders and other community resources.
- Research funding and governance should encourage and require accountability of inclusive research through additional funding, incentives and educational materials for researchers.
- Collect and analyse data in a way that allows for disaggregation by demographic factors, ensuring that underrepresented populations are accurately considered.
- Analyse gaps and missing subpopulations in routine health information collection efforts and conduct concerted outreach efforts to contact and follow up hard-to-reach groups.



Tools and resources



Evidence, policy, impact: WHO guide for evidence-informed decision-making

The guide and its associated tool repository provide government stakeholders and partner organizations with vetted methods and tools to enable better leverage of diverse forms of evidence for more effective policy and practice in the clinical, public health and health system fields.



Supporting the routine use of evidence during the policy-making process: a WHO checklist

The WHO checklist is for any organization supporting the routine use of evidence in the process of policy-making. Government stakeholders, knowledge intermediaries and researchers who are focused on strengthening evidence-informed policy-making will find in it key steps and tools in the checklist to help their work.



WHO: Regulatory considerations on artificial intelligence for health

The document describes the key regulatory considerations on artificial intelligence (AI) for health which stakeholders working with medical devices are urged to examine in the development of frameworks and best practices for the use of AI in health care.



WHO: SCORE for Health Data Technical Package

The package is intended to assist in strengthening country data systems and capacity to monitor progress towards the health-related Sustainable Development Goals (SDGs), WHO's triple billion targets, and other national and subnational health priorities.

Research and information systems



WHO: **A blueprint for dementia research**

The blueprint for dementia research summarizes the current state of dementia research across six broad themes, identifies existing knowledge gaps, and outlines 15 strategic goals with actions and timebound milestones to address these gaps.



PAHO: **Monitoring and Evaluation Framework on Information Systems for Health**

The digital transformation toolkit facilitates the adequate implementation of policies, recommendations, data governance frameworks, monitoring and evaluation frameworks, analysis, and other rapid evaluation tools for countries' information systems for health.



WHO: **Global Scales for Early Development (GSED) v1.0**

GSED is an open-access package specifically designed to provide a standardized method for measuring development of children up to 36 months of age at population and programmatic level globally.



5.5

Approach to specific neurological disorders



Introduction

While the toolkit emphasizes an integrated approach, it acknowledges the importance of addressing specific neurological conditions individually.

This section of the toolkit highlights six specific neurological disorders due to their high global burden of disease and public health significance. (brain infections, dementia, epilepsy, migraine and headache disorders, neurodevelopmental disabilities and stroke). The toolkit, however, is applicable to all neurological disorders as described in the International Classification of Diseases, Eleventh Revision (11). The actions suggested below are given as a template of key considerations to be analysed when planning an effective response to a prominent public health concern in a specific setting.

The set of suggested actions for each condition can serve as guidance for focusing efforts on managing and mitigating issues related to specific conditions. Each country has the flexibility to decide which neurological conditions to prioritize on the basis of its specific circumstances. For example, dementia, a disorder typically associated with older age, is progressively becoming a public health concern globally as populations are ageing.

The public health challenges vary widely across these different neurological conditions and present opportunities to plan actions at different points in the life course and health system. For stroke, prevention is a key consideration. For headache disorders and brain infections, the burden will be reduced significantly through health service

improvements for prevention, detection, diagnosis and treatment. Capacity-building of the health workforce will make a significant difference to the diagnosis and management of epilepsy. In the case of dementia, research and investment have the potential to contribute to new care pathways which would reduce its economic impact.

Despite different presentations and sequelae, neurological disorders are interdependent. Improving services for one condition or cluster could lead to advances in the management and care for all. Thus, interventions should target synergistic effects which will produce the greatest return for the limited resources and will create entry points for diagnosis and treatment of all neurological disorders.

Brain infections

Public health significance

Brain infections (such as meningitis encephalitis and meningo-encephalitis) are life-threatening conditions caused by infection of the membranes that surround the brain and spinal cord or the brain tissue, predominantly caused by bacteria, viruses, parasites or fungi.

Common sequelae following brain infections include seizures, hearing and vision loss, cognitive impairment, neuromotor disability and memory and behavioural changes, as well as scarring and limb amputations after meningococcal sepsis. Many people will also experience a range of less serious after-effects that are not always immediately apparent, such as difficulties with emotion regulation and learning challenges in children.

Many brain infections are preventable. Enhanced efforts are needed to encourage all recommended immunizations and to promote high levels of vaccine coverage at the national and subnational levels.

Aftercare is expensive and may not be affordable for families. Policies and services for the assessment of sequelae, treatment, rehabilitation and follow-up, including those in communities, are often absent or insufficient, and access to them is uneven, especially in LMICs. Appropriate training for health care professionals and community workers on timely identification, management of disability and bereavement is limited, with inadequate numbers of trained staff at all levels of care.

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

✓ Actions



Policy:

- Implement infectious disease management, eradication/elimination/control and immunization programmes based on WHO guidance, such as the roadmap for defeating meningitis by 2030, WHO's roadmap for neglected tropical diseases 2021–2030, WHO's guidelines on management of *Taenia solium* [pork tapeworm] neurocysticercosis, and the WHO initiatives relevant to encephalitis, One Health and the WHO Global Arbovirus Initiative (see Tools and Resources below).
- Support and promote the availability of rapid and affordable diagnostics for infections of the nervous system with tests for pathogens relevant to each setting (e.g. lumbar puncture, cerebrospinal fluid microscopy, molecular-genetic and biochemical analyses, neuroimaging).
- Promote access to therapeutics and review and update mandatory and recommended vaccinations, removing barriers to access to vaccines.
- Promote services such as rehabilitation and palliative care, as outlined in the WHO *Package of interventions for rehabilitation*.¹⁰
- Strengthen partnerships between government and civil society organizations, including organizations for persons with disabilities and other networks, so that people with sequelae or disabilities and their families/carers have access to quality and effective services that are in line with international human rights standards and frameworks.

¹⁰ For more information, see Tools and resources under "Care pathways" in section 5.2 on "Diagnosis, treatment and care".



Clinical care:

- Increase timely collection and testing of cerebrospinal fluid, blood and other specimen samples by; ensuring the availability of sterile kits and laboratory test equipment; supporting national policies that promote cerebrospinal fluid (of adequate volume and quality) and blood sampling; training of clinical and laboratory staff; and increasing acceptance of lumbar puncture among communities.
- Establish appropriate training and supervision of health workers at each level of care for timely identification, diagnosis, referral and management of brain infections in all age groups.¹¹
- Develop and implement best practice guidelines for LMICs on the detection, monitoring and management of brain infection sequelae after discharge from hospital, at all levels of health care and in community settings – e.g. schools (including disability sensitization and communication skills).
- Promote community-based programmes to:
 - identify sequelae and disabilities, based on standardized instruments (especially for child development and hearing) and refer for assessment and appropriate care; and
 - provide care, support and aftercare to individuals, families and communities affected by brain infections (e.g. psychosocial support, disability support).
- Provide relevant, up-to-date information to people and carers affected by brain infections about access to services such as rehabilitation for managing sequelae as well as information about the rights of people with disabilities, as guaranteed under national policies and laws and through global human rights instruments.
- Regularly review and solicit the perspectives and views of people with brain infections and neurological disability when introducing interventions.

¹¹ For more information, refer to “Capacity-building of the health workforce” under section 5.2 on “Diagnosis, treatment and care”.



Prevention:

- Promote vaccination campaigns and knowledge-sharing about the usefulness of vaccination as a method of reducing neurological disabilities caused by brain infections.
- Raise awareness of infection control and surveillance mechanisms (e.g. centralized reporting of index cases, appropriate handling of infectious tissue) as well as standard contact precautions and isolation procedures (including provision of PPE) to reduce the risk of neurotropic communicable disease spread.
- Implement vector control strategies such as minimizing standing water for mosquitoes (dengue, chikungunya, Japanese encephalitis) and leptospirosis control, and avoiding outdoor defecation to prevent scrub typhus and water-borne infections such as typhoid.



Research and monitoring:

- Alongside researching medical aspects of brain infections, study the community understanding of the risk of brain infections and the factors that facilitate or act as barriers to healthseeking behaviours, and integrate corresponding actions for raising awareness into country plans.
- Implement new methods, such as geospatial data, for monitoring and data collection on transmission, sequelae and disabilities from brain infections, available support and specialist services.

KEY MESSAGES

Training health workers in prompt identification, diagnosis, referral and management of brain infections can save lives and reduce disabling sequelae.



Identification of sequelae and disabilities following brain infections and provision of care, support and aftercare to individuals and families are essential elements in planning of infectious disease programmes and services.



Tools and resources



WHO: **Defeating meningitis by 2030 roadmap**

The roadmap sets a comprehensive vision for 2030 “Towards a world free of meningitis”. and charts a path to achieve goals through concerted actions across five interconnected pillars: prevention and epidemic control; diagnosis and treatment; disease surveillance; care and support of those affected by meningitis; and advocacy and engagement.



WHO: **Why encephalitis matters? Report of the virtual meeting, 28–29 June 2022**

The report describes the proceedings of the virtual meeting “Encephalitis as a public health priority” which discussed mechanisms to strengthen countries’ capacity to respond to the public health challenge posed by encephalitis and reduce the burden faced by individuals, families, communities and societies.



WHO: **Guidelines on the management of *T. solium* neurocysticercosis**

These guidelines were developed to assist health-care providers in appropriate, evidence-based management of parenchymal neurocysticercosis in order to improve decision-making, ensure appropriate patient care and avoid misdiagnoses and inappropriate treatment.



WHO: **Japanese encephalitis**

This page provides key information on Japanese encephalitis, including symptoms, transmission, diagnosis, treatment, prevention and control.



Approach to specific neurological disorders: Brain infections



WHO: Package of interventions for rehabilitation: module 5: neurodevelopmental disorders

This package outlines the most essential interventions for rehabilitation for 20 health conditions, including information on the required assistive products, equipment and consumables, and the workforce that is usually skilled to deliver these interventions. This module comprises specific packages for autism spectrum disorders and disorders of intellectual development.



WHO: Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021-2030

The roadmap sets global targets and milestones to prevent, control, eliminate or eradicate 20 diseases and disease groups as well as cross-cutting targets aligned with the SDGs.



WHO: One Health in action against Neglected Tropical Diseases

A One Health approach recognizes the relationship between human, animal and environmental health, which is key to sustainably addressing NTDs. The OpenWHO course provides practical ideas, tools and examples to facilitate action towards the global goal of substantially reducing the burden of NTDs by 2030.

Dementia

Public health significance

In 2019, approximately 55 million people were living with dementia worldwide, with over 60% living in LMICs. The forecast for 2050 is that there would be 139 million people living with dementia worldwide. The economic cost of dementia was calculated at US\$ 1.3 trillion in 2019, where informal care accounted for more than half of this (13).

Dementia is the world's seventh leading cause of death and one of the leading causes of care dependence and disability in old age, both in LMICs and in high-income countries (14).

In 2021, only 26% of countries had a national dementia plan instead of the 75% required to meet the global target outlined in the Global action plan on the public health response to dementia (15).

A growing evidence base demonstrates that there are clear risk and protective factors that affect the cognitive health of adults. Up to 40% of dementia cases can potentially be prevented if modifiable risk factors are addressed throughout the life course (16).

Globally, there is a lack of awareness and understanding of dementia, resulting in stigmatization and discrimination against people living with dementia, ultimately having an impact on diagnosis and care.

Dementia disproportionately affects women, both directly and indirectly, as women shoulder a greater disease burden and also tend to act as caregivers to people living with dementia. Women are responsible for some 70% of informal care hours globally.



Approach to specific neurological disorders: Dementia

Dementia is often underdiagnosed and untreated in certain populations, such as people in low-income and rural settings, refugees and migrants. This is a result of multiple barriers such as low awareness of dementia in these populations, disruptions in the continuity of care, and limited adoption of cross-cultural cognitive assessment tools.

In 2021, relative dementia research output was low globally (0.68% of total research output). Much research is also focused on interventions for cognitive symptoms, which constitute only a part of the clinical picture of dementia.

KEY MESSAGES

Carer strain for those caring for people with dementia, especially informal carers, can be significantly reduced through appropriate psychosocial, financial and logistical support and skills training.



Early diagnosis is the first step to accessing dementia care pathways and maintaining good quality of life. Raising public awareness and improving diagnosis in primary care are two of the most promising ways to achieve this.



✓ Actions



Policy:

- Aligning with the WHO global action plan on the public health response to dementia,¹² develop and resource a national dementia plan with clear implementation targets, using tools such as *Towards a dementia plan: a WHO guide*.¹³
- Implement well-resourced public awareness campaigns (developed in partnership with civil society, people with dementia, their carers and other relevant stakeholders) to increase public knowledge and understanding about dementia and to promote life-course preventative campaigns.
- Support the implementation of dementia-friendly initiatives to help create more supportive societies using WHO guidance, such as WHO's *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives* (see Tools and Resources below).
- Develop or strengthen the protection of carers, particularly women, with social, financial and disability benefits, and support them beyond their caregiving role in all settings.
- Include people living in rural settings, people living with HIV, minority populations, refugees and migrants in relevant national and subnational policies, legislations, plans and frameworks on dementia.
- Encourage health system preparedness in anticipation of potential upcoming diagnostics and disease modifying treatments, while strengthening care services and support as equal components of an integrated dementia treatment pathway.

12 See "Policy, plans and legislation" under the section on "Prioritization and governance" for more information and resources on the action plan.

13 See Tools and resources for "Policy, plans and legislation" under the section on "Prioritization and governance".



Clinical care:

- Develop national and local clinical guidelines for dementia, relying on established guidelines such as WHO's mhGAP.
- Integrate dementia services within primary care and support capacity-building and workforce training so that individuals are more likely to receive a timely diagnosis and appropriate post-diagnostic support.
- Develop infrastructure and skills at the secondary level of care to diagnose dementia and provide interdisciplinary care (e.g. by integrating dementia screening as part of routine care for people living with HIV).
- Strengthen referral and back-referral pathways to ensure post-diagnostic support and continuity of care for people with dementia.
- Provide access to programmes to mitigate cognitive decline and maintain physical function for people with dementia – such as physical activity for balance and strength to prevent falls.¹⁴
- Implement effective caregiver training programmes – such as WHO's iSupport training programme for carers of people living with dementia.
- Improve access to services and development of diversity-sensitive care for minority populations, refugees and migrants with dementia.



© WHO / Fatoumata Diabaté. An older man sitting in front of his home in Ménaka, Mali, 2022.

14 For more information on rehabilitation, see “Care pathways” under the section on “Diagnosis, treatment and care”.



Prevention:

- Link dementia with programmes, policies and campaigns on NCD risk reduction and health promotion.
- Develop national and local dementia risk reduction guidelines, relying on established guidelines such as WHO's guidelines on risk reduction of cognitive decline and dementia.¹⁵
- Design and implement evidence-informed, multisectoral and culturally sensitive interventions aimed at dementia risk reduction.
- Support the delivery of population-level health education on dementia risk reduction, such as mDementia (see Tools and Resources below), including information about the interrelatedness of dementia risk with that of other neurological, mental health and substance use conditions, as well as other NCDs.



Research and monitoring:

- Allocate appropriate and sustainable funding to dementia research.
- Make dementia research more inclusive and independent of age, sex, comorbidities, and clinical and social complexity to ensure that the most vulnerable persons are also represented.
- Engage people with lived experience throughout the entire research process to ensure that projects are relevant to them.
- Promote in LMICs the scientific research of dementia, access to science, capacity-building and knowledge transfer,
- Use WHO's blueprint for dementia research to guide research planning (see Tools and Resources below).
- Implement effective and routine monitoring of dementia-related indicators to support the formulation and implementation of evidence-based policy, service planning and delivery, and to track progress at national and subnational levels. To measure national responses to dementia, Member States are encouraged to contribute to the Global Dementia Observatory, WHO's monitoring and accountability mechanism for the Global action plan on the public health response to dementia.

¹⁵ See Tools and resources under the section on "Promotion of brain health and prevention of neurological disorders".



Tools and resources



WHO: **Global dementia observatory**

The observatory is the monitoring and accountability mechanism for the Global action plan on the public response to dementia 2017–2025. The observatory collates data from WHO Member States on 35 key dementia indicators to strengthen countries' ability to respond to the needs of people with dementia, their carers and families.



WHO: **Global dementia observatory knowledge exchange platform**

The platform contains key resources to support the implementation of the Global action plan on the public health response to dementia and its seven action areas. The platform supports policy-makers to strengthen policies, as well as health and social care systems, and to undertake evidence-based planning for managing dementia.



WHO: **Global status report on the public health response to dementia**

The report takes stock of actions driven by countries, WHO and civil society since the adoption of the global action plan, identifies barriers to its implementation, especially in light of the COVID-19 pandemic, and highlights areas where urgent, accelerated action is required.



Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives

The toolkit provides practical guidance and tools that can support communities and countries in raising awareness of dementia and empowering people living with dementia to remain in, and be a significant part of, their community.



WHO: **A blueprint for dementia research**

The blueprint for dementia research summarizes the current state of dementia research across six broad themes, identifies existing knowledge gaps, and outlines 15 strategic goals with actions and timebound milestones to address these gaps.

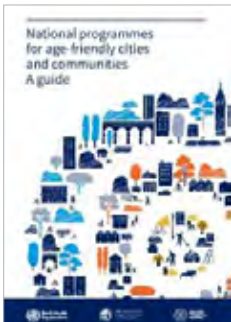


Approach to specific neurological disorders: Dementia



WHO: **iSupport for dementia**

The package (a manual and an online tool) provides self-paced skills and a training programme for carers of people with dementia providing everyday care and dealing with behaviour changes. The package includes with brief readings, examples and exercises on which carers receive feedback.



WHO: **National programmes for age-friendly cities and communities: a guide**

This guide provides direction to national authorities and stakeholders responsible for or involved in forming or sustaining national programmes for age-friendly cities and communities.



WHO: **Be healthy, be mobile: a handbook on how to implement mDementia**

The handbook provides guidance on how to develop, integrate, implement and evaluate a national mDementia programme in five key areas: operations management; content development and adaptation; promotion participation and retention; technology specifications; and monitoring and evaluation.



Alzheimer's Disease International: **Forgotten in a crisis: addressing dementia in humanitarian response**

This report by Alzheimer's Disease International analyses existing tools and guidelines which mandate inclusive support for people at risk, concluding that better implementation of such tools is urgently needed for people with dementia in humanitarian settings.

Epilepsy

Public health significance

Epilepsy is a chronic condition that affects around 50 million people worldwide (17). It is characterized by recurrent seizures which occur as a result of a change in the electrical activity of the brain due to abnormally excessive or synchronous neuronal activity.

There is great variation in seizure etiology as well as manifestation depending on the area/extent of brain involved. There are temporary symptoms, such as loss of awareness or consciousness, and disturbances of movement, sensation (including vision, hearing and taste), mood, behaviour or cognitive functions. Seizures are unpredictable in occurrence, duration and severity and can also vary in frequency, from less than one per year to several per day.

While epilepsy may have many different underlying mechanisms, the cause of the disease is still unknown in about 50% of cases globally. With appropriate diagnosis and access to medicines, 70% of persons could achieve adequate seizure control (18).

People with epilepsy tend to have more physical problems (such as fractures and bruising from injuries related to seizures), as well as higher rates of psychological conditions, including anxiety and depression (17). Similarly, the risk of premature death in people with epilepsy is up to three times higher than in the general population, with the highest rates of premature mortality found in LMICs and in rural areas (19).

Many causes of death related to epilepsy, such as falls, drowning, burns and prolonged seizures, are potentially preventable.



Approach to specific neurological disorders: Epilepsy

Epilepsy has significant economic implications in terms of health-care needs, premature death and lost work productivity. There is also a human rights rationale for a focus on epilepsy. People with epilepsy often experience stigma and discrimination, can be denied social, educational and work opportunities, may be prevented from obtaining a driving license or entering certain occupations, and have reduced access to health and life insurance.

In many countries legislation relating to epilepsy reflects centuries of misunderstanding – for instance, discriminatory laws and practices which permit the annulment of a marriage on the grounds of epilepsy and laws that deny people with seizures access to restaurants, theatres, recreational centres and other public buildings. A form of institutional stigma, such discriminatory legislation can perpetuate the multi-level stigma commonly faced by people with epilepsy and can exacerbate internalized (self-)stigma and interpersonal stigma.

IGAP recognizes the shared preventive, pharmacological and psychosocial approaches between epilepsy and other neurological disorders that can serve as valuable entry points for accelerating and strengthening services and support for these conditions overall.

KEY MESSAGES

It is essential to address the pervasive myths and misconceptions about epilepsy that contribute to social exclusion and isolation of people with epilepsy. Dismantling these barriers and promoting inclusivity across domains such as education and employment can create opportunities for people with epilepsy to participate fully in society and lead fulfilling lives.



By prioritizing access to diagnosis and treatment, the treatment gap that affects more than 75% of individuals with epilepsy in LMICs can be bridged. This includes improved training of health-care workers and access to anti-seizure medicines.



Actions



Policy:

- Develop and resource an integrated national response to epilepsy to achieve the targets set out in IGAP.
- Ensure that the integrated plan includes a focus on the 11 levers for change outlined in WHO's publication *Improving the lives of people with epilepsy: a technical brief*. These include:
 - political commitment and leadership
 - governance and policy frameworks
 - funding and allocation of resources
 - engagement of community and other stakeholders
 - models of care
 - health-care workforce
 - medicines and other health products
 - monitoring and evaluation
 - research
 - systems for improving quality of care
 - digital technologies for health.
- Prevention, diagnosis, treatment and care of epilepsy require an intersectoral approach. Engage a broad group of government stakeholders beyond health, especially in civil affairs, education, employment, transport and infrastructure, organizations of people with disabilities, societies for epilepsy and similar entities.
- Ensure that policies provide support for people with epilepsy, their families and carers with regard to health, social issues, economic, educational, employment, recreational and legal justice.
- Ensure that legislation, plans and policies relating to people with epilepsy are updated and discriminatory laws are removed to promote and protect the rights of people with epilepsy, in accordance with the UN Convention on the Rights of Persons with Disabilities.



Clinical care:

- Establish national standards and practices to ensure that the quality of clinical care is maintained, overseen, evaluated and improved in engagement with people with epilepsy, their carers and families.
- Extend the role of primary health-care practitioners, providers and allied health professionals in diagnosing and managing epilepsy, especially in low-resource settings, based on WHO's mhGAP guidelines and derivative products.
- Improve training of medical and allied health professionals in the diagnosis, treatment and management of epilepsy, with appropriate job support, and include people with epilepsy, their perspectives, views and preferences in developing training curricula.
- In many LMICs, there is low availability of antiseizure medicines for both acute and chronic care. This can be alleviated by developing and regularly updating national essential medicines lists on the basis of the local context and needs and aligned with WHO's Model List of Essential Medicines.
- Ensure provision of essential diagnostic tools which include electroencephalogram (EEG) and neuroimaging.
- Develop reliable procurement, supply, storage and distribution systems for antiseizure medicines that minimize waste and stock-outs, remove substandard and falsified products, and guarantee equitable access to the necessary medicines, devices and treatments at all levels of care, including in emergencies and crises.



Research and monitoring:

- Incorporate data collection on epilepsy into health information systems and include indicators related to the quality of health services and care for epilepsy, as well as their demand and utilization.
- Identify and support a research agenda for epilepsy based on the priorities at the national or sub-national level, including intervention and implementation research, research into the social aspects of epilepsy, and research on innovation in epilepsy care, especially in low-resource settings.



Prevention:

An estimated 25% of epilepsy cases are potentially preventable (20). Actions to reduce the risk of epilepsy include the following:

- Preventing head injury (e.g. by reducing falls, road traffic accidents, violence and sports injuries) is the most effective way to prevent post-traumatic epilepsy.
- Provision of adequate perinatal care can reduce new cases of epilepsy caused by birth-related injury or infections.
- Information and guidance can advise on the use of medicines and other methods to lower the body temperature of a feverish child to reduce the chance of febrile seizures.
- Implementation of cardiovascular risk factor reduction strategies can help to prevent epilepsy associated with stroke (e.g. measures to prevent or control high blood pressure, diabetes and obesity, the promotion of physical activity, and the avoidance of tobacco and excessive alcohol use).
- Programmes for the control of communicable diseases should target central nervous system infections in areas where these are endemic. This includes bacterial meningitis and viral encephalitis, tubercular meningitis, neurocysticercosis (where *Taenia solium* [pork tapeworm] can cause up to 70% of epilepsy cases in affected communities) and cerebral malaria. Additionally, encourage active feedback and synergies on prevention and treatment between programmes for the control of communicable diseases and treatment of neurological disorders.
- Integrate the prevention of epilepsy into all sectors (e.g. health, education, social services, justice, sports, employment health and safety, transport and infrastructure).



Tools and resources



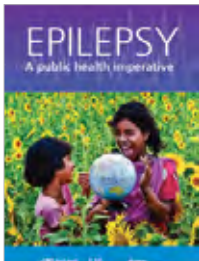
WHO: **Improving the lives of people with epilepsy: a technical brief**

The brief presents the key information on epilepsy and identifies actions on the policy and operational levels to strengthen services for people with epilepsy using a person-centred approach based on human rights and universal health coverage.



International Bureau for Epilepsy: **Advocate's Toolkit for Reducing Epilepsy Stigma in Africa**

The toolkit contains resources, ideas and practical guidance for addressing and dismantling stigma in the various communities on the African continent. The toolkit was developed to help advocates to be proactive in shaping inclusive communities.



WHO: **Epilepsy: a public health imperative**

The report summarizes the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels.



International League Against Epilepsy: **ILAE gateway to EPI-ACT resources**

The website is a comprehensive online resource. It offers tools and examples for epilepsy advocates to use while developing country-specific goals to improve engagement, plans, information, access, care pathways, and training and education in order to achieve IGAP targets.



WHO: **mhGAP Intervention Guide - Version 2.0**

The Intervention Guide presents the integrated management of priority MNS conditions using algorithms for clinical decision-making. It is for use by doctors, nurses and other health workers as well as health planners and managers.



International Bureau for Epilepsy: **eLearning Modules on Health Diplomacy**

The online learning modules provide epilepsy advocates with a deeper understanding of health diplomacy and policy advocacy, including engagement of relevant global health actors and utilization of key policy frameworks such as IGAP, the SDGs and WHO's epilepsy technical brief.

Migraine and other headache disorders

Public health significance

A headache is a painful and disabling feature of primary headache disorders, namely migraine, tension-type headache and cluster headache. Headaches can also be caused by, or occur secondarily to, a long list of other conditions, the most common of which is medication-overuse headache.

Headache disorders, which are characterized by recurrent headaches are ranked third (after stroke and dementia) in accounting for the overall neurological disease burden, as measured by age-standardized DALYs in 2019 (21).

Headaches are associated with personal and societal burdens of pain, disability, diminished quality of life and financial cost.

Many governments, seeking to constrain health-care costs, do not acknowledge the substantial burden of headache on society. They might not recognize that the direct costs of treating headache are small in comparison with the huge indirect cost savings that might be made (e.g. by reducing lost working days) if resources were allocated to treat headache disorders appropriately.



✓ Actions



Policy:

- Implement programmes to raise awareness among health-care providers and the general public of headache disorders and effective treatments because many affected people are unaware that effective treatments exist.
- Support the establishment and maintenance of national professional organizations for headache disorders and their roles in promoting education, producing locally relevant management aids, including guidelines, and importing knowledge and international standards through links to international groups.
- Emphasize and add headache disorders to undergraduate curricula and training in medical schools, followed by continuing medical education for general practitioners.



Clinical care:

- Train the health workforce and strengthen capacity of the health system, particularly at the primary care level, to prevent, diagnose and control migraine and other headache disorders in all people, including children and adolescents, across the life course.
- Address medication gaps to ensure access to the main classes of drugs to treat headache disorders – analgesics, anti-emetics, specific anti-migraine medications (such as sumatriptan) and prophylactic medications such as propranolol.
- Health-care providers can help in identifying and keeping track of potential headache triggers, such as specific foods, environmental factors, or activities, and in taking steps to minimize exposure.
- Support people with migraine and headache disorders in the workplace through education, improving diagnosis and optimization of treatment.



Prevention:

- Support the delivery of population-level interventions to educate people on medication-overuse headaches, migraine triggers and lifestyle modifications that are highly effective.
- Provide lifestyle advice on prevention of headache occurrence and relapse. Restricting or eliminating alcohol, having regular sleep and exercise schedules, healthy diets, managing stress, staying hydrated and using a headache calendar to identify other triggers are often all that is needed to provide relief.
- Raise awareness on other prevention measures, including limiting screen time, maintaining good posture, and regular eye and health check-ups to address underlying conditions.



Research and monitoring:

- Incorporate appropriate indicators into routine health system information collection to monitor the epidemiology of migraine and headache disorders.
- Raise awareness and mobilize resources for more research into the causes, care pathways and prevention of migraine and headache disorders.

KEY MESSAGES

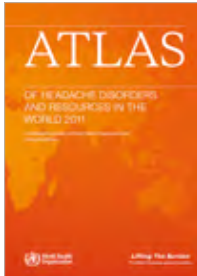
Supportive and inclusive workplace environments for people with migraine and headache disorders will improve health outcomes and increase overall productivity.



Appropriate treatment of headache disorders requires training of health professionals, accurate diagnosis and recognition of the conditions, provision of cost-effective medications, simple lifestyle modifications and education.



Tools and resources



WHO: **Atlas of headache disorders and resources in the world 2011**

The atlas describes the epidemiology and impact of headache disorders on society, health-care utilization, diagnosis, assessment and treatment, and professional training related to headache disorders.



WHO: **Fact sheet on headache disorders**

The fact sheet provides basic information on headache disorders and their impact, treatment, barriers to care and the WHO response to identified needs.



Global Patient Advocacy Coalition: Migraine Wellness Initiative Toolkit

This toolkit from the aims to help advocacy groups to align with employer programmes on the best goals and milestones based on migraine wellness programme needs, timing, scale and preferred tactics.



Global Campaign against Headache

The campaign aims to reduce the burden of headache worldwide by working with local policy-makers and principal stakeholders to plan and implement health-care services for headache, ensuring they are appropriate to local systems, resources and needs.

Neurodevelopmental disabilities

Public health significance

Neurodevelopmental disabilities are common; global estimates based on the 2019 GBD study indicate that 316.8 million children and adolescents experience a health condition contributing to neurodevelopmental disability.

The most prevalent conditions contributing to neurodevelopmental disabilities include idiopathic developmental intellectual disability, attention deficit hyperactivity disorder (ADHD), cerebral palsy, and hearing and vision loss, based on the 2019 GBD study.

Globally, individuals with neurodevelopmental disabilities have unmet health care needs due to weak, fragmented health-care systems. They are more likely to have poor health than their peers and experience obesity, diabetes, heart and respiratory diseases, and mental health conditions, and have a higher risk of premature death.

Some of the negative aspects of the health status of people with neurodevelopmental disabilities seem to be associated with the biological basis of the health condition (e.g., congenital cardiac defects and early-onset dementia in people with Down syndrome). But other negative aspects are due to health inequities and the increased risk of exposure to well-established social determinants of poor health and well-being, such as poverty, social exclusion, violence and discrimination, and access to health promotion, healthcare and education. These negative effects are unjust, unfair and partly avoidable.

Stigma against people with neurodevelopmental disabilities affects their mental health and life opportunities; as an example, young people with these conditions are 51% more likely to consider themselves unhappy and 41% more likely to feel discriminated against.

Limited opportunities to participate in society, interact with peers and access learning and health care are a reality for many persons with neurodevelopmental disabilities.



Approach to specific neurological disorders



© WHO / Sergey Volkov. A young couple enjoying nature in Russia, 2007.

✓ **Actions**

Develop and resource an **action plan** for improving health outcomes for people with neurodevelopmental disorders. Ensure that the integrated plan includes a focus on the ten **action areas** outlined in the WHO-UNICEF Global report on children with developmental disabilities (12), as follows:

1.

Strengthen coordination and accountability mechanisms

As a priority, establish multisectoral programmes to meet holistically the needs and preferences of persons with neurodevelopmental disabilities and their families. This should take place through strengthened interagency cooperation and budget allocation across all relevant sectors according to identified needs and targets.

2.

Deepen commitment at all levels

Direct investments towards enhancing services and systems. Focus on education and community-based health care, improving supports and opportunities at family and community levels.



KEY MESSAGES

There is a wide range of interventions and actions with focus of policy development, care systems strengthening and stigma reduction which can create the conditions for inclusive and enabling environments and responsive care for persons with neurodevelopmental disabilities.



To ensure that the rights of persons with neurodevelopmental disabilities to enjoy the highest standards of health, well-being and participation are realized, collective and sustained efforts and greater investment in changing social and care systems are needed.

3.

Promote participation in advocacy, leadership, policy, programming and monitoring

As experts with lived experience, adults, children and young people with developmental disabilities and their caregivers must be included in developing policy and programming relevant to their lives and in implementation and evaluation.

4.

Address the social determinants of health, well-being and participation

Eliminate risks and adversities that often affect persons with neurodevelopmental disabilities in particular, including exposure to violence, by introducing policy provisions and legal frameworks to guarantee access to affordable health care, social services, education and assistive technologies and to safeguard their human rights and social protection.



5.

Strengthen multisectoral policy-making to address inequities in healthcare

Incorporate or update policies, laws and health financing mechanisms with a rights-based approach to ensure UHC for persons with neurodevelopmental disabilities. Equitable access to health promotion, prevention and care for all persons with neurodevelopmental disabilities should be reflected in mainstream policies and plans for health, disability, social protection and education.

6.

Strengthen services for inclusive and people-centred evidence-based care

Mainstream services in all sectors that are inclusive and accessible to persons with neurodevelopmental disabilities and their families. Strengthen systems to provide specialized services for the specific, evolving needs of children, youth and adults with neurodevelopmental disabilities and their caregivers. Particular attention should be paid to strengthening early identification and access to care; to managing co-occurring problems and diseases; to improving support during transitions, such as from preschool to school and from school to independent living; and to promotion of health throughout the life-course.

7.

Inform, empower and support caregivers

Tailor policy provisions and strategies to ensure access to information on treatment options, support for navigating care, psychoeducation and financial and social assistance, according to the needs of persons with neurodevelopmental disabilities and their caregivers.



8.

Address stigmatization and foster inclusive and enabling environments

Consider approaches to adjust the built environment in all services and sectors and in the community; to promote diversity, inclusion and respect; and to ensure access to education and opportunities for learning across the life-course. Barriers to service delivery (including barriers to physical access, information, communication and coordination) must be removed in all health-care programmes.

9.

Strengthen data and research

Establish processes to ensure that data regarding persons with neurodevelopmental disabilities are collected at various levels, including monitoring of inequalities in health and education outcomes and exposures to risks, disparities in access to opportunities and services, harmful practices and human rights violations in all sectors. Research priorities should include a focus on accessing life-long services for health promotion and care and on improving the understanding of health inequalities among persons with neurodevelopmental disabilities.

10.

Develop inclusive plans and protocols for health emergency preparedness and response

Persons with neurodevelopmental disabilities require specific attention and tailored strategies in emergency preparedness and response frameworks to avoid unnecessary distress, delays in access to information and support, and discrimination.



Tools and resources



WHO-UNICEF: **Global report on children with developmental disabilities**

The report provides principles and approaches to include intentionally the needs and aspirations of children and young people with developmental disabilities in policy, programming and public health monitoring, proposing 10 priority actions to accelerate changes.



WHO: **Fact sheet on autism**

The fact sheet provides basic information on autism spectrum disorders and their impact, epidemiology, care and human rights of people with autism, as well as the WHO response to identified needs.



WHO: **Caregiver skills training for families of children with developmental delays: adaptation and implementation guide**

The guidance aims to provide caregivers with skills that they can use at home to improve their child's engagement in activities and communication, and to promote positive behaviour and skills for daily living.

Stroke

Public health significance

Stroke is the largest contributor (over 35%) of neurological DALYs globally according to GBD2021 (1).

Strokes are usually acute events, mainly caused by a blockage that prevents adequate blood supply to brain tissue. The most common reason for this is a build-up of fatty deposits on the inner walls of the blood vessels that supply the heart or brain (ischaemic stroke). Strokes can also be caused by bleeding from a blood vessel into the brain (haemorrhagic stroke) or from blood clots (cardioembolic stroke).

Strokes result from a combination of genetic, physiological, environmental and behavioural factors. People of all age groups, regions and countries can be affected by stroke. Many cases of and deaths from stroke are preventable. Millions of lives can be saved from stroke by treating and controlling hypertension (22). Children, adults and older people are all vulnerable to the risk factors that contribute to stroke, whether unhealthy diets, physical inactivity, exposure to tobacco smoke, the harmful use of alcohol or air pollution.

Strokes have a profound impact on individuals, families and communities. People with stroke experience problems with perception, memory, language and communication, muscle power, muscle tone and motor control, and thus movement and mobility. Because of these impairments, independence in self-care activities, interactions with others, and participation in meaningful activities, such as work and social life, are often restricted.

Due to the chronic course of stroke, people who have experienced stroke often require long-term care, provided largely by informal carers. Challenges for carers include stress, role strain, financial burden, social isolation and bereavement in the event of loss of loved ones.

✓ Actions



Policy:

- Assess national capacity for the prevention and control of stroke and develop and implement a national multisectoral policy.
- Prioritize and increase budgetary allocations for stroke prevention and control, recognizing the economic and health burden associated with strokes. Invest in training programmes to enhance the capacity of the health workforce in stroke prevention, diagnosis, treatment and rehabilitation.
- Integrate stroke into the social and development agenda and poverty alleviation strategies.
- Raise public and political awareness, as well as understanding and practice of prevention and control of stroke.
- Strengthen partnerships between government and civil society organizations, including organizations for persons with disabilities and other networks, so that people with disabilities from stroke, their families/carers and those bereaved due to stroke have access to quality and effective services that are in accordance with international human rights standards and frameworks.



Clinical care:

- Establish national guidelines to include the treatment of acute ischaemic stroke with intravenous thrombolytic therapy, and/or mechanical thrombectomy, in an experienced facility and within defined time windows, and low-dose acetylsalicylic acid within 24–48 hours for secondary prevention of ischaemic stroke as per the NCD Appendix 3 update (see Tools and resources at the end of this section).
- Ensure adequate provision of neuroimaging infrastructure (CT scanners, mobile CT units) which is essential to guide the management of stroke in the acute setting – i.e. differentiation of ischaemic versus haemorrhagic stroke.
- Implement comprehensive care of people who have had an acute stroke in stroke units. This includes strategies such as staffing by a specialist stroke multidisciplinary team, and access to equipment for monitoring and rehabilitation.
- Establish accreditation of health-care facilities for stroke management to ensure standards,



promote the training of staff and strengthen referral pathways.

- When possible, care pathways should include neurosurgical facilities for surgical procedures that are important for the treatment of some cases of acute ischaemic stroke (e.g. malignant media infarcts) and haemorrhagic stroke (e.g. cerebellar haemorrhage).
- Establish rehabilitation (inpatient and at home) as one of the essential health services for shortening recovery time, preventing complications related to stroke, and improving physical and mental functioning and well-being.¹⁶
- Tertiary health-care facilities should establish stroke units that include post-stroke rehabilitation to enable people with stroke to reach their optimal physical, cognitive, emotional, communicative and social activity levels
- Educators for health and social care should develop and implement best practice guidelines for LMICs on the detection, monitoring and management of stroke at all levels of health care and in community settin



Prevention:

- Promote and emphasize brain health across the life course, including a focus on healthy behaviour, considering the strong interrelationships between stroke and NCDs such as hypertension, diabetes, obesity and other related disorders as well as the links with behavioural risk factors such as physical inactivity, unbalanced diets, tobacco use and the harmful use of alcohol.
- Integrate cost-effective stroke interventions and risk reduction into the basic PHC package with referral systems to all levels of care
- Expand the use of digital technologies to increase health service access and efficacy for stroke prevention, promote healthy lifestyles and reduce the costs in health care delivery.

¹⁶ For more information see Tools and resources in “Care Pathways” under the section on “Diagnosis, treatment and care”.



Research and monitoring:

- Support operational research and knowledge translation to continually improve stroke prevention and management strategies.
- Enhance monitoring and surveillance systems to track the incidence, prevalence and outcomes of strokes.

KEY MESSAGES

Raising awareness of the symptoms of stroke and the necessity of seeking urgent medical care as soon as possible are crucial steps to decreasing neurological damage, considering that effective treatment for acute ischaemic stroke is possible only within a short time window.



Interventions that prevent stroke through modifying lifestyle factors, including prevention and management of hypertension, are a key tool for reducing incidence and disease burden.



© WHO / NOOR / Sebastian Liste. People engaged in a cognitive exercise for rehabilitation in Russia, 2020.



Tools and resources



WHO global action plan on physical activity 2018–2030

The action plan provides updated guidance and a framework of effective and feasible policy actions to increase physical activity at all levels.



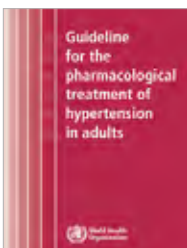
Updated Appendix 3 of the WHO Global NCD Action Plan 2013–2030

This document supports countries in implementing, as appropriate for the national context, actions to achieve the nine voluntary global targets for NCD prevention and control through the six objectives of the WHO global NCD action plan.



WHO: **HEARTS: technical package for cardiovascular disease management in primary health care**

The technical package, which comprises six modules and an implementation guide, provides a strategic approach to improving cardiovascular health in countries. The package supports ministries of health to strengthen management of cardiovascular disease in PHC settings.



WHO: **Guideline for the pharmacological treatment of hypertension in adults**

The guideline provides the most current and relevant evidence-based global public health guidance on the initiation of treatment with pharmacological agents for hypertension in adults.



© WHO / Daiana Valencia. A mother is holding her young son diagnosed with autism in Argentina, 2020.



Monitoring and evaluation

Core concepts

Monitoring and evaluation (M&E) is an essential part of any implementation programme for neurological disorders, irrespective of its size and scope. M&E provides information to improve service delivery, to help plan and allocate resources, and demonstrates results for accountability purposes. Data collected through M&E can inform whether any adjustments are necessary to the operational workplan or to resource allocation for neurological disorders.¹⁷ In this context, M&E is defined as follows:

- “Monitoring” refers to the systematic and continuous collection of information to assess how a plan for neurological disorders is being implemented. Using a core set of indicators and targets linked to national priorities and objectives, monitoring provides information on the IGAP implementation progress and performance, as well as detecting over- and under-spending.
- “Evaluation” comprises the assessment of specific information at predetermined times to determine whether the actions taken have achieved the intended results and impact. It also informs future planning and budgeting for neurological disorders.

Systematic data collection and analysis of a core set of measures related to neurological disorders is essential for the strategic planning and M&E of activities aimed at strengthening services, including insight into current service needs, barriers to accessing such services and future trends.

¹⁷ Information systems are a necessary requirement for monitoring and evaluation; consider this chapter together with the section on information systems under 5.4 “Research and information systems”.

The key components of M&E are shown in Box 11, while M&E at global level is described in Box 12.

BOX 11.

Key components of an M&E system

The four components of a strong M&E system are:

- sound policy and institutional environment;
- well-functioning data sources;
- strong institutional capacity for data collection, management, analysis, use and dissemination; and
- effective mechanisms for review and action.

Why is this important?



M&E will provide a baseline (i.e. support a situational analysis) and trends of the burden, needs, service utilization uptake and available resources. This in turn will guide the setting of priorities and goals as well as the utilization and efficient distribution of limited resources. M&E will provide government officials, health authorities, development managers and civil society with information: 1) to improve service delivery, planning and allocation of resources for neurological disorders, and 2) to present results as part of their accountability to key stakeholders.



Further, M&E that places at its core the key values, wishes and preferences of people living with neurological disorders, their families and carers will provide the basis for addressing unmet needs and reducing the burden of neurological disorders.

✓ Actions



Establish foundation and governance

- Include a framework for monitoring and evaluation in national plans and strategies that include neurological disorders, setting out what the improvement targets will be, what the interval of data collection will be, and how the analysis will be used as feedback.
- Incorporate M&E at the various levels of operation of the health system (e.g. district, regional, national) by creating quality improvement teams to support data collection, dissemination of information and feedback of results to everyone working with neurological disorders.
- Actively involve people with neurological disorders, their families and carers in planning and carrying out the data collection, in the analysis of data and interpretation of results, and in sharing and disseminating the information.
- Allocate an appropriate budget for M&E for neurological disorders as a proportion of programmatic financing.



Promote continuity

- Develop feedback mechanisms and guidance that allow health-care providers and administrators working with neurological disorders to receive insights from the data, fostering a continuous improvement cycle.
- Review regularly (recommended annually) processes for monitoring and evaluation to streamline, innovate and adjust in order to reflect needs.



Streamline data collection

- Collect data on neurological disorders using robust indicators that balance detail with efficiency, and disaggregate by sex, age, location and other relevant characteristics. A logic model will identify how inputs into the system lead to neurology-related outputs, outcomes and impacts as well as delineating the indicators that will be used to measure these.
- Ensure that indicators align with international standards while remaining adaptable to local contexts and feasible for collection.
- Establish partnerships with other stakeholders working in neurological disorders, such as nongovernmental organizations that are implementing programmes, academic institutions conducting research and analysis, and the private sector (such as pharmaceutical manufacturers) to maximize the information collected and set up mechanisms to utilize it. Encourage active feedback and interaction between programmes that involve neurological disorders, including other sectors such as social services, education, environment, finance, employment, justice and housing.
- The integration of relevant data into routine health information systems allows for regular monitoring, improves accountability, and can increase efficiency.¹⁸



Disseminate results

- Analyse data and ensure dissemination of results at each level of data collection through quality improvement teams and share the results with all stakeholders and sectors participating in the M&E process.
- Present results to senior managers and policy-makers to support revisions and updates to policies, plans and legislation, providing a forum for discussion with the involvement of people with neurological disorders, their families and carers.
- Make data accessible to researchers and institutions working with neurological disorders through secure and user-friendly platforms to enable complementary analysis. Implement data visualization techniques to facilitate easy interpretation of complex information.

¹⁸ For more information see section 5.4 on "Research and information systems".

BOX 12.

Monitoring and evaluation at the global level

- **IGAP questionnaire and completion guide.** The IGAP questionnaire and completion guide provide indicators (and their suggested metadata) that may be used to measure the progress of IGAP implementation at country (and global) level. A key function of data collected with the IGAP questionnaire is to support decision-making that will improve services for neurological disorders.
- **GDO e-tool 2.0 and GDO reference guide, second edition.** The Global Dementia Observatory (GDO) assists countries in collating relevant national-level dementia data on a core set of indicators that are used to monitor global actions towards reaching the targets outlined in the Global action plan on the public health response to dementia. The GDO reference guide provides detailed definitions, rationale, method of estimation and potential data sources for each indicator.
- Countries can use sample indicators to collect key information on neurological disorders and to monitor relevant actions at the national level. Specific indicators can also measure individual countries' contribution towards achieving the global targets of IGAP.



Tools and resources



WHO: **Health inequality monitor**

The toolkit and platform allow users: 1) to explore patterns of inequality easily by using disaggregated data and summary measures of inequality; 2) to compare inequality between settings; and 3) to create and export customized graphs, maps and tables.



Institute for Health Metrics and Evaluation (IHME): **Brain health atlas**

The atlas aims uses a science-based approach to quantify the present burden, future trends and economic impact of brain health conditions so that data can be used to guide policy change.



WHO: **Special Initiative for Mental Health - Cross-country Monitoring and Evaluation: Baseline Summary Report**

The report provides a breakdown of proposed country-specific indicators to monitor progress in improving coverage for MNS conditions in the 12 countries included in the WHO Special Initiative for Mental Health.

References

1. Steinmetz JD, Seeher KM, Schiess N, Nichols E, Cao B, Servili C et al. Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *Lancet Neurol.* 2024;23(4):344–81.
2. Optimizing brain health across the life course: WHO position paper. Geneva: World Health Organization; 2022 (<https://iris.who.int/handle/10665/361251>, accessed 26 April 2024).
3. Operational framework for primary health care: transforming vision into action. Geneva: World Health Organization & United Nations Children's Fund (UNICEF); 2020 (<https://iris.who.int/handle/10665/337641>, accessed 24 April 2024).
4. Executive Board, 138. (2016). Framework on integrated, people-centred health services: report by the Secretariat. World Health Organization. <https://iris.who.int/handle/10665/250704>
5. IASC Reference Group for Mental Health and Psychosocial Support in Emergency Settings. Who is where, when, doing what (4Ws) in mental health and psychosocial support: manual with activity codes. 2012 ; (<https://interagencystandingcommittee.org/sites/default/files/migrated/2014-10/IASC%20RG%204Ws%20MHPSS%20.pdf>, accessed 26 April 2024).
6. Gustavsson A, Svensson M, Jacobi F, Allgulander C, Alonso J, Beghi E et al. Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol.*
7. Feigin VL, Owolabi MO, Feigin VL, Abd-Allah F, Akinyemi RO, Bhattacherjee NV et al. Pragmatic solutions to reduce the global burden of stroke: a World Stroke Organization – Lancet Neurology Commission. *Lancet Neurol.* 2023;22(12):1160–206. 2011;21(10):718–79.
8. Chisholm D, Lee YY, Baral PP, Bhagwat S, Dombrovskiy V, Grafton D et al. Cross-country analysis of national mental health investment case studies in sub-Saharan Africa and Central, South and South-East Asia. *Front Health Serv.* 2023;3: <https://doi.org/10.3389/frhs.2023.1214885>.
9. Roig M, Mariuchi D. Old-age poverty has a woman's face. Policy Brief No. 142. New York (NY): United Nations Department of Economic and Social Affairs; 2022 (https://www.un.org/development/desa/dpad/wp-content/uploads/sites/45/publication/PB_142.pdf, accessed 26 April 2024).
10. Gardener H, Wright CB, Dong C, Cheung K, DeRosa J, Nannery M et al. Ideal cardiovascular health and cognitive aging in the Northern Manhattan Study. *J Am Heart Assoc.* 2016;5(3):e002731.
11. International Classification of Diseases, Eleventh Revision (ICD-11), World Health Organization (WHO) 2019/2021 <https://icd.who.int/browse11>.
12. Global report on children with developmental disabilities: from the margins to the mainstream. Geneva: World Health Organization & United Nations Children's Fund (UNICEF); 2023 (<https://iris.who.int/handle/10665/372864>, accessed 24 April 2024)
13. Wimo A, Seeher K, Cataldi R, Cyhlarova E, Dielemann JL, Frisell O et al. The worldwide costs of dementia in 2019. *Alzheimers Dement.* 2023;19(7):2865–73.
14. Dementia. Fact sheet. Geneva: World Health Organization; 2023 (<https://www.who.int/news-room/fact-sheets/detail/dementia>, accessed 26 April 2024).

15. From Plan to Impact VI. Making every step count. London: Alzheimer's Disease International; 2023 (<https://www.alzint.org/resource/from-plan-to-impact-vi/>, accessed 26 April 2024).
16. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413–46.
17. GBD 2016 Epilepsy Collaborators. Global, regional, and national burden of epilepsy, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019 Apr;18(4):357–375. [https://doi.org/10.1016/S1474-4422\(18\)30454-X](https://doi.org/10.1016/S1474-4422(18)30454-X)
18. Winter SF, Walsh D, Amos A, Secco M, Sofia F, Baker GA. The WHO intersectoral global action plan and epilepsy cascade target: towards a roadmap for implementation. *Seizure*. 2022;103:148–50.
19. Watila MM, Balarabe SA, Ojo O, Keezer MR, Sander JW. Overall and cause-specific premature mortality in epilepsy: a systematic review. *Epilepsy Behav*. 2018;87:213–25.
20. Thurman DJ, Begley CE, Carpio A, Helmers S, Hesdorffer DC, Mu J, Touré K, Parko KL, Newton CR. The primary prevention of epilepsy: A report of the Prevention Task Force of the International League Against Epilepsy. *Epilepsia*. 2018 May;59(5):905–914. <https://doi.org/10.1111/epi.14068>
21. Ding C, Wu Y, Chen X, Chen Y, Wu Z, Lin Z, et al. Global, regional, and national burden and attributable risk factors of neurological disorders: The Global Burden of Disease study 1990–2019. *Front Public Health*. 2022 Nov 29;10:952161.
22. Global report on hypertension: the race against a silent killer. Geneva: World Health Organization; 2023 (<https://iris.who.int/handle/10665/372896>, accessed 27 April 2024).

For more information please contact:

Brain Health Unit
Department of Mental Health and Substance Use

World Health Organization
Avenue Appia 20
CH-1211 Geneva 27
Switzerland

Email: brainhealth@who.int

Website: <https://www.who.int/health-topics/brain-health>

