

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

## **Indicators for measuring progress towards defined targets of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 – 2031**

1. The indicators for assessing progress towards meeting the global targets of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 – 2031 represent a subset of the information and the reporting needs that Member States require to adequately monitor their policies and programmes for neurological disorders. Given that targets are voluntary and global, Member States are not necessarily expected to achieve all the specific targets individually but can contribute to a varying extent towards reaching them jointly.
2. The global targets established for each strategic objective provide the basis for measurable collective action and progress by Member States towards global goals and should not negate the setting of more ambitious national targets, particularly for those countries that have already reached global ones.
3. As indicated under Strategic Objective 4 of the plan, the Secretariat will provide guidance, training and technical assistance to Member States, upon request, for the development of national information systems to capture data on indicators of neurological health system inputs, activities and outcomes. The aim is to keep building on existing information rather than creating new or parallel systems. Existing monitoring and accountability mechanisms for mental health, noncommunicable diseases and infectious diseases will be drawn upon to measure the relevant targets and indicators of the Intersectoral global action plan on epilepsy and other neurological disorders 2022 – 2031.
4. The term “neurological disorders” is used to denote conditions of the central and peripheral nervous systems that include epilepsy, headache disorders, neurodegenerative disorders, cerebrovascular diseases, neuroinfectious/neuroimmunological disorders, neuromuscular disorders, neurodevelopmental disorders, traumatic brain and spinal cord injuries and cancers of the nervous system. The neurological disorders which cause the greatest disability globally are stroke, migraine, dementia, meningitis and epilepsy.
5. Epilepsy can serve as an entry point for accelerating the strengthening of services including information systems for other neurological disorders.

**Table 1: List of global targets**

#	Global Target
1	<p>1.1. 75% of countries will have adapted or updated existing national policies, strategies, plans or frameworks to include neurological disorders by 2031.</p> <p>1.2. 100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders by 2031.</p>
2	<p>2.1. 75% of countries will have included neurological disorders in the UHC benefits package by 2031.</p> <p>2.2. 80% of countries will provide the essential medicines and basic technologies required to manage neurological disorders in primary care by 2031.</p>
3	<p>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.</p> <p>3.2. The global targets relevant for prevention of neurological disorders are achieved, as defined in:</p> <ul style="list-style-type: none"> <li>- the NCD-GAP;</li> <li>- Defeating meningitis by 2030: a global road map; and</li> <li>- Every newborn: an action plan to end preventable deaths.</li> </ul>
4	<p>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.</p> <p>4.2. The output of global research on neurological disorders doubles by 2031.</p>
5	<p>5.1. By 2031, countries will have increased service coverage for epilepsy by 50% from the current coverage in 2021.</p> <p>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.</p>

# STRATEGIC OBJECTIVE 1: TO RAISE THE PRIORITIZATION AND STRENGTHEN GOVERNANCE

Global Target #1.1.	75% of countries will have adapted or updated existing national policies, strategies, plans or frameworks to include neurological disorders by 2031
Indicator-1.1.	Existence of an operational national policy, strategy, plan or framework that has been adapted or updated to address or include neurological disorders.
Means of verification	Existence of a physically available policy, strategy, plan or framework provided by the national authority's response and confirmed on review.
Comments/assumptions/ rationale	<p>Availability of a written organized set of principles, objectives or actions for reducing the burden attributable to neurological disorders in a population in a stand-alone, neurological disorders-specific document or integrated in broader health or other plans. National strategies or plans based on context-specific priorities may also be developed for specific neurological disorders, such as epilepsy or dementia. Again, these may be stand-alone plans or inclusion of specific neurological disorders in the general health plan, and/or within the national mental health plan. They are considered valid if they have been approved/published by the Ministry of Health (or equivalent) or parliament.</p> <p>For countries with a federated system, the indicator will refer to policies or plans of most states or provinces within the country. Policies or plans for neurological disorders may be stand-alone or integrated into other general health or disability policies or plans, for example noncommunicable diseases, infectious disease, mental health, maternal, children and adolescent health, ageing, disability.</p>

<b>Global Target #1.2.</b>	100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders by 2031.
Indicator-1.2.	Existence of at least one functioning awareness campaign or advocacy programme for neurological disorders.
Means of verification	Inventory of currently implemented and functioning neurological disorders awareness or advocacy campaigns, described project by project, provided by the national authority's response.
Comments/assumptions/ rationale	<p>Existence of national public awareness campaign to improve understanding and reduce stigma and discrimination against people with neurological disorders in the past year.</p> <p>Awareness-raising campaigns may, and preferably should, cover both universal, population-level strategies (e.g., mass media campaigns) and those aimed at locally identified vulnerable groups (e.g., socioeconomically disadvantaged individuals, children, older people, people with physical and intellectual disabilities, and people affected by emergency situations, minority ethnic groups). They should preferably address cross-cutting issues including prevention and promotion.</p> <p>While campaigns can be designed to cover more than one neurological disorder, countries may focus on specific neurological disorders such as epilepsy.</p> <p>The objective of awareness and advocacy campaigns should be to foster an accurate understanding of neurological disorders, reduce stigmatization and discrimination associated with neurological disorders, educate people about the human rights of people with neurological disorders and the UN Convention on the Rights of Persons with Disabilities and enhance the general population's ability to recognize early symptoms and signs of neurological disorders.</p> <p>Functioning is defined as having the following components: dedicated financial resources, programme management, documented evidence of progress and impact.</p>

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

Global Target #2.1.	75% of countries will have included neurological disorders in the UHC benefits package by 2031.
Indicator-2.1.	Existence of a set of evidence informed, prioritized, essential, quality health services and supports for neurological disorders within the universal health coverage benefits package.
Means of verification	Documented universal health coverage – priority benefits package (UHC-PBP) based on information provided by the national authority's response and confirmed on review.
Comments/assumptions/ rationale	<p>A UHC-PBP is a set of evidence-informed prioritized health interventions, services and programmes, including intersectoral actions and fiscal policies, defined through a deliberative process that accounts for economic realities and social preferences. It explicitly defines which programmes, services and interventions should be provided, and financially covered, for the population.</p> <p>Services and supports for neurological disorders include financial risk protection and promotive, preventive, treatment, rehabilitative, and palliative care across the life course. A UHC-PBP should offer services of optimized quality that are effective, efficient, accessible, patient-centred, equitable and safe, supported by fair and sustainable financing arrangements. Interventions must be delivered by qualified providers who are able to provide standard services in a timely manner at the appropriate level of a regulated health system and target specified groups.</p> <p>This indicator is intended to provide evidence that the UHC-PBP contains reference to neurological disorders. Priority neurological disorders such as epilepsy can be specifically identified.</p>

<b>Global Target #2.2.</b>	80% of countries will provide the essential medicines and basic technologies required to manage neurological disorders in primary care by 2031.
Indicator-2.2.	Countries report availability of essential medicines and basic technologies to manage neurological disorders in primary care.
Means of verification	Proportion of countries that report having a core set of relevant essential medicines and basic technologies for neurological disorders available and affordable in primary care facilities on a sustainable basis.
Comments/assumptions/rationale	<p>Essential medicines and basic technologies are intended to be available within the context of functioning health systems at all times, in adequate amounts, in the appropriate dosage forms, with assured quality and at a price the individual and the community can afford. Lists of essential medicines and basic technologies also guide the procurement and supply in the public sector.</p> <p>In this indicator, it is intended to provide a basket that closely reflects the essential medicines and basic technologies used for managing neurological disorders. The proposed basket represents a balanced approach to allow relevant tracer medicines and basic technologies for neurological disorders are monitored yet ensuring a practical and feasible data collection and analysis. The medicines and basic technologies to be included in the basket are meant to be indicative of the access to medicines and basic technologies for neurological disorders but do not serve as a complete or exhaustive list.</p> <p>Anti-seizure medicines can serve as such tracer medicines. A significant portion of the burden of epilepsy in LMIC can be averted by scaling up the routine availability of antiseizure medicines.</p>

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

Global Target #3.1.	80% of countries will have at least one functioning intersectoral programme for brain health promotion and the prevention of neurological disorders across the life course by 2031.
Indicator-3.1.	Existence of at least one functioning intersectoral programme for brain health promotion and the prevention of neurological disorders, across the life course.
Means of verification	Inventory of currently implemented and functioning brain health awareness and neurological disorder prevention/risk reduction programme, described project by project, provided by national authority's response.
Comments/assumptions/ rationale	<p>Many neurological conditions are preventable, including 25% of the global burden of epilepsy cases.</p> <p>Existence of intersectoral brain health promotion and neurological disorder prevention or risk reduction programme in the past year should be reported. While programmes can be designed to cover more than one neurological disorder, countries may focus on specific neurological disorders such as epilepsy</p> <p>Programmes should be national and preferably cover both universal, population-level strategies (e.g., mass media campaigns), life course, and those aimed at locally identified vulnerable groups (e.g., socioeconomically disadvantaged individuals, children, older people, people affected by domestic and gender-based violence, people with low educational attainment, ethnic minorities).</p> <p>Functioning is defined as having the following components: dedicated financial resources, programme management, documented evidence of progress and impact.</p>

<b>Global Target #3.2.</b>	<p>The global targets relevant for prevention of neurological disorders are achieved, as defined in the:</p> <ul style="list-style-type: none"> <li>- The NCD-GAP<sup>1</sup>;</li> <li>- Defeating meningitis by 2030: a global road map<sup>2</sup>; and</li> <li>- Every newborn: an action plan to end preventable deaths<sup>3</sup>.</li> </ul>
Indicator-3.2.	<p>Relevant indicators as defined in:</p> <p>The NCD-GAP:</p> <ul style="list-style-type: none"> <li>• A 10% relative reduction in prevalence of insufficient physical activity.</li> <li>• At least a 10% relative reduction in the harmful use of alcohol, as appropriate, within the national context.</li> <li>• A halt in the rise in diabetes and obesity.</li> <li>• A 25% relative reduction in the prevalence of raised blood pressure or contain the prevalence of raised blood pressure according to national circumstances.</li> <li>• A 30% relative reduction in prevalence of current tobacco use in persons aged 15+ years.</li> </ul> <p>Defeating meningitis by 2030: a global road map:</p> <ul style="list-style-type: none"> <li>• Vaccine coverage of the full immunization schedule for <i>Neisseria meningitidis</i> (Nm), <i>Streptococcus pneumoniae</i> (Spn), <i>Haemophilus influenzae</i> type B (Hib) maintained or achieved in all countries.</li> <li>• Global policies on Nm, Spn, Hi and group B streptococcus (GBS) vaccines updated or developed as new vaccines and evidence become available.</li> <li>• A training programme on identification, diagnosis, referral and treatment of meningitis, including potential sequelae, established and integrated into existing training in &gt;80% of countries.</li> <li>• Evidence-based guidelines and recommended tools developed on treatment and care of bacterial meningitis and implemented in 80% of countries.</li> <li>• Community services for people with long-term impairments from meningitis integrated into existing disability inclusion initiatives in &gt;50% of countries.</li> </ul> <p>Every newborn: an action plan to end preventable deaths:</p> <ul style="list-style-type: none"> <li>• 95% of women will give birth with a skilled attendant, and every woman and her newborn will receive effective high-quality and respectful care.</li> <li>• At least 75% of babies who do not breathe spontaneously at birth after thorough drying and stimulation will be resuscitated with bag and mask ventilation; at least 75% of stable preterm newborns or babies weighing less than 2000 g will receive kangaroo mother care and other supportive care; and at least 75% of newborns with possible serious bacterial infection will receive antibiotic therapy.</li> <li>• 90% of women and newborns will receive early postnatal care of high quality within two days of birth.</li> </ul>
Means of verification	<p>Reporting to WHO's governing bodies as provided for in the Global action plan for prevention and control of noncommunicable diseases 2013–2030, Defeating meningitis by 2030: a global road map, Every newborn: an action plan to end preventable deaths.</p>



Comments/assumptions/ rationale	<p>Series of definitions for relevant indicators as included in:</p> <ul style="list-style-type: none"> <li>- Global action plan for prevention and control of noncommunicable diseases 2013-2030;</li> <li>- Defeating meningitis by 2030: a global road map;</li> <li>- Every newborn: an action plan to end preventable deaths.</li> </ul>
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<sup>1</sup> World Health Organization and others. *Global action plan for the prevention and control of noncommunicable diseases 2013-2020*. [www.who.int/about/licensing/copyright\\_form/en/index.html](http://www.who.int/about/licensing/copyright_form/en/index.html) (2013)

<sup>2</sup> World Health Organization. *Defeating meningitis by 2030: a global road map (26th October 2020 draft)*. (World Health Organization, 2020)

<sup>3</sup> World Health Organization. *Every newborn: an action plan to end preventable deaths*. (World Health Organization, 2014)

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

Global Target #4.1.	80% of countries routinely collect and report on a core set of indicators for neurological disorders through their national health data and information systems at least every three years by 2031.
Indicator-4.1.	Countries have functioning health data and information systems to routinely collect and report on a core set of indicators for neurological disorders.
Means of verification	Can occur by means of a patient registry, aggregate data or medical records from various sources measured at a system level (national, subnational or local level). Responses provided by the national authority.
Comments/assumptions/rationale	<p>Systematic monitoring and evaluation of health data provides evidence for policy development and service delivery, improve accessibility to, and coordination of, care for people with neurological disorders, and allow a better understanding and detection of population-level changes and trends.</p> <p>Core set of indicators for neurological disorders include those relating to specified targets of this action plan, together with other essential indicators of health and social system actions (for example, training and human resource capacity, and service availability and utilization). Data should include information on specific neurological disorders as prioritised by the country for policy development and service delivery.</p> <p>The data need to be disaggregated by sex and age groups as well as specific neurological disorders (i.e. epilepsy). Where needed, surveys can also be used to complement data from routine information systems. Data will be collected, analyzed and reported by WHO as part of its Neurology Atlas.</p>

<b>Global Target #4.2.</b>	The output of global research on neurological disorders doubles by 2031.
Indicator-4.2.	Number of published articles on neurological disorders research (defined as research articles published in an indexed and peer-reviewed journal). The indicator measures the output of neurological disorders research as defined by national published research studies.
Method of verification	Literature searches centrally-conducted every three years, stratified by country of origin, topics and types of research, using bibliometric data sourced for the most recent calendar year.
Comments/assumptions/ rationale	<p>The indicator measures the output of neurological disorders research as defined by national published research studies.</p> <p>The annual published research output in peer-reviewed and indexed journals is a proxy for the amount (and quality) of neurological disorders research being conducted in a country. It indirectly assesses a country's commitment to neurological disorders research, which will ultimately have an impact on outcomes for people with neurological disorders.</p> <p>Where feasible, the research output will be stratified for different neurological disorders such as epilepsy, Parkinson disease, etc.</p>

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

Global Target #5.1.	By 2031, countries will have increased service coverage for epilepsy by 50% from the current coverage in 2021.
Indicator-5.1.	Proportion of persons with epilepsy who are using services over the past 12 months (%).
Method of estimation/ calculation	<p>Coverage of services for epilepsy calculated as the number of people receiving defined services by the population in need of the intervention.</p> <p>Service coverage =</p> $\frac{\text{Number of people in receipt of services}}{\text{Number of people with epilepsy}} \times 100\%$ <p><i>Numerator:</i> number of people with epilepsy in receipt of services, derived from routine information systems or a baseline and follow-up survey of health facilities in one or more defined geographical areas of a country.</p> <p><i>Denominator:</i> total number of people with epilepsy in the sample population, derived from national surveys or, if unavailable, based on subregional prevalence estimates.</p>
Comments/assumptions/rationale	<p>Estimates of service coverage are needed for all neurological disorders but are restricted here to epilepsy as tracer indicator to make the measurement effort feasible. Health facilities range from primary care centres to general and specialized hospitals; they may offer social care and support as well as psychosocial and/or pharmacological treatment on an outpatient or inpatient basis. To limit measurement effort, and where needed, countries may restrict the survey to hospital-based and overnight facilities only (with some loss of accuracy due to omission of primary care and other service providers).</p> <p>Countries may choose to measure effective coverage using a household survey and taking a cascade approach to provide information on percentage of people with epilepsy who are diagnosed; percentage of people diagnosed with epilepsy who have access to appropriate, affordable, safe antiseizure medicines; and percentage of those treated who have achieved adequate seizure control.</p>

<b>Global Target #5.2.</b>	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.
Indicator-5.2.	Existence of national legislations relevant to epilepsy that are in line with international and regional human rights instruments.
Method of estimation/ verification	Physically available legislations relevant to epilepsy and confirmation that they accord with international and regional human rights standards
Comments/assumptions/ rationale	<p>Confirmation that available legislations accord with international and regional human rights standards particularly in the areas of education, employment, driving, marriage and fertility, with a view to addressing discrimination against people with epilepsy.</p> <p>For countries with a federated system, the indicator will refer to the laws of most states/provinces within the country. Laws may be stand-alone or integrated into other general health or disability laws. Human rights standards will be based on the UN Convention for the Rights of Persons with Disabilities and include provisions for education, employment, driving, marriage and fertility.</p>