



Dear Dr Kestel,

28 July 2021

Draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders

ILAE/IBE warmly welcome the draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) that WHO released for consultation at the end of June.

The draft IGAP is in line with the wording and intent of Resolution WHA73.10 that was unanimously approved by all Member States during the November 2020 session of the 73rd World Health Assembly. The Resolution mandated WHO to develop a Global Action Plan that would provide a focus on epilepsy as well as other neurological disorders, strengthening prevention, diagnosis, treatment, care, rehabilitation, and palliation in addition to harnessing synergies and opportunities from leveraging epilepsy as an entry point. We congratulate WHO secretariat for achieving this across the five objectives in the draft.

We appreciate the opportunity to provide recommendations on how the detail and aspirations within the draft IGAP can be further strengthened in line with the intent of the Resolution and would like to offer suggestions on three aspects:

- Improving cohesion across the document
- Strengthening the aspirations of the proposed Global Targets and Indicators
- Including further attention to the specialized needs of children, adolescents and young adults transitioning into adulthood

Improving cohesion across the document

The title of both the approved Resolution WHA73.10 and the draft Intersectoral Global Action Plan is 'Epilepsy and Other Neurological Disorders'. In addition, a key approach, endorsed in the Resolution and included in the draft Goal and as Objective 5.3, is to build on the synergies between epilepsy and other neurological disorders.

To ensure that both these aspects are well reflected in the final document and to bring greater cohesion within the document, we would recommend two additions:

Firstly, explanatory paragraph(s) on the synergies between epilepsy and other neurological disorders be inserted into the Overview section. Some suggested text that could be inserted is attached to this letter in Annex 1.

Secondly, the word 'epilepsy' be added into each of the Objectives to align with the title of the Resolution and IGAP and ensure consistency throughout the document. The Objectives would then read as:

Objective 1: To raise the prioritization and strengthen governance for epilepsy and other neurological disorders

Objective 2: To provide effective, timely and responsive diagnosis, treatment, and care for epilepsy and other neurological disorders

Objective 3: To implement strategies for the promotion of brain health and prevention of epilepsy and other neurological disorders [across the life-course – see additional suggestion below]

Objective 4: To foster research and innovation and strengthen information systems for epilepsy and other neurological disorders

More detailed suggestions on other possible amendments that could enhance coherence will be provided through the consultation portal.

Strengthening the aspirations of the proposed Global Targets

Given the declaration by WHO that action to address epilepsy should be considered a *public health imperative*¹, we were very pleased to see a specific target focused on strengthening the public health approach to epilepsy and promoting synergies with other neurological disorders (Target 5).

However, we would like to make two important recommendations:

Firstly, we would suggest that Target 5.1 be reformulated to be more aspirational as well as more concrete. We would like to propose a cascade target - similar to that used globally to address HIV/AIDS – to strengthen the global public health approach to epilepsy:

Target 5.1 Epilepsy 90-80-70²

- (1) 90% of all people with epilepsy aware of their diagnosis as a treatable brain disorder and
- (2) 80% of people diagnosed with epilepsy with access to appropriate, affordable, safe antiseizure medicines and
- (3) 70% of those treated achieve adequate seizure control

Secondly, we would also like to recommend the inclusion of an additional Target Area under Target 5 (new 5.2) to incentivize countries to review their existing legislation and actively address exclusion and discrimination

Target 5.2

All countries have reviewed their existing legislation, particularly in the areas of education, driving, employment, marriage, and fertility, with a view to address and amend clauses that discriminate against people with epilepsy and other neurological disorders by 2031.

Further suggestions for strengthening across all proposed target areas is attached as Annex 2.

¹ <https://www.who.int/publications/i/item/epilepsy-a-public-health-imperative>

² Inspired by and based on the evidence presented in <https://gatesopenresearch.org/articles/3-1502>

Including further attention to the specialized needs of children, adolescents, and young people transitioning into adulthood

Children, adolescents, and young people transitioning into adulthood have physical, social, psychological, and educational needs that differ significantly from those of adults. Disease incidence and prevalence also differ across the life course. Although epilepsy is common across all age groups, other neurological disorders vary with age. Epilepsy, for example, is the most common neurological disorder in childhood while conditions that such as Parkinson's disease are extremely rare before middle age but increase in prevalence with advancing age.

While we appreciate the specific mention of children, adolescents, and transition to adulthood in the Overview section, we feel that more is needed to emphasize the specialized nature of care and treatment needed for this age group and would recommend:

- The addition of 'across the life course' be added to Objective 2 such that it would read throughout the document as: Objective 2: To provide effective, timely and responsive diagnosis, treatment and care for epilepsy and other neurological disorders across the life - course.
- The addition of a seventh Guiding Principle on the need for specialized, focused and age-appropriate care for children, adolescents, and transition to adulthood rather than a reliance on adaptation of adult services (Paragraph 23)
- Addition of a paragraph on the need for specific care pathways (including appropriate engagement and involvement with the education sector) for children, adolescents, and transition to adulthood (Section 2.1)
- Addition of a paragraph on the need for specialized training of health care workers who care for children, adolescents and young adults transitioning to adulthood in Section 2.3

Once again we would like to congratulate you and your team on an excellent draft and for incorporating many of the comments that were made on the discussion paper.

We would also like to thank Dr Dua for attending the ILAE/IBE Virtual Roundtable on 16 July 2021. Her presentation was very well received. Attached is a copy of the report on the Roundtable that was attended by over 160 people from 50 countries and included a large number of representatives from Missions and Ministries of Health, Education and Employment globally. We unfortunately did not have time for all interventions but the statements from the Ministries of Health/Missions of Croatia, Lesotho, Russia, and Uruguay clearly showed the support for action to address the unacceptable epilepsy treatment gap and for leveraging the opportunities that utilizing epilepsy as an entry point could bring for people with epilepsy as well as other neurological disorders.

We wish you well as you finalize the IGAP and will provide further, more detailed suggestions from the epilepsy community through the consultation portal that you may find useful.



Prof Sam Wiebe
President, ILAE



Prof. Martin Brodie
President, IBE

Annex 1 – possible language for additional paragraph(s) in the Overview section

Epilepsy occurs in all age groups, across all demographics and in all parts of the world. Nearly all of the known preventable risk factors for epilepsy are common to other neurological disorders. Around 50% of adults with active epilepsy have one or more coexisting neurological, non-communicable or psychiatric condition. Epilepsy is a disorder in its own right, but it can also be a signal of deterioration or change in an underlying neurological condition. Epilepsy and a wide range of other neurological disorders share similar diagnostic and therapeutic technologies as well as similar research, pharmaceutical and psychosocial approaches.

The synergies detailed above lend themselves to epilepsy being an entry point for accelerated strengthening of services and support for both epilepsy and other neurological disorders. Other neurological disorders should be considered concurrently alongside epilepsy treatment and care to achieve the best results for people with epilepsy as well as people with other neurological disorders.

Annex 2: Global Targets and Indicators

Yellow – addition/amendment Red - remove

Strategic Objective	Global Target(s)	Key Indicator(s)	Comments
SO1. To raise the prioritization and strengthen governance for epilepsy and other neurological disorders	<u>Global target 1.1:</u> 75% of countries will have adapted or updated existing national policies, strategies, plans or frameworks to include neurological disorders by 2031	Existence of an operational national policy, strategy, plan, or framework that has been adapted or updated to include neurological disorders (for instance, on noncommunicable diseases, mental health, maternal, children and adolescent health, ageing and disability)	For countries with a federated system, the indicator will refer to policies/plans of the majority of states/provinces within the country.
	<u>Global target 1.2:</u> 100% of countries will have at least one functioning awareness campaign or advocacy programme for epilepsy and other neurological disorders by 2031	Existence of at least one functioning awareness campaign or advocacy programme for neurological disorders	Campaigns and programmes should be national and preferably cover both universal, population-level awareness strategies as well as those aimed at locally identified vulnerable groups. Campaign should actively address harmful myths and misunderstandings about epilepsy and other neurological disorders that are common within the country and/or specific subpopulations
SO2. To provide effective, timely and responsive diagnosis, treatment and care for epilepsy and other neurological disorders across the life course	<u>Global target 2.1:</u> 75% of countries will have neurological disorders across the life course within universal health coverage benefits package	Existence of a set of evidence-informed, prioritized, essential, quality health services and supports for neurological disorders within the universal health coverage benefits package	Services and supports include financial risk protection and promotive, preventive, treatment, rehabilitative, and palliative care across the life-course
	<u>Global target 2.2:</u> 80% of countries will provide essential medicines and basic technologies required to treat neurological disorders in primary care	Countries report availability of essential medicines and affordable basic technologies to treat neurological disorders in primary care	This is part of the health system for integration of care for neurological disorders into primary health care and includes description of availability of medicines and basic technologies at primary care level

<p>SO3. To implement strategies to promote brain health and development and prevent epilepsy and other neurological disorders.</p>	<p><u>Global target 3.1:</u> 80% of countries will have at least one functioning multisectoral programme for brain health promotion and the prevention of neurological disorders, across the life course by 2031</p>	<p>Existence of at least one functioning multisectoral programme for brain health promotion and the prevention of neurological disorders, across the life-course</p>	<p>Programmes should be national and should preferably cover both universal, population-level strategies as well as those aimed at locally identified vulnerable people</p>
	<p><u>Global target 3.2:</u> The global targets relevant for prevention of neurological disorders are achieved as defined in: - the Global action plan for prevention and control of noncommunicable diseases 2013-2020 - Defeating meningitis by 2030: a global road map - Every newborn: an action plan to end preventable deaths - UN General Assembly adopted resolution 74/299 “Improving global road safety”, proclaiming the Decade of Action for Road Safety 2021-2030 - Road Map for Neglected Tropical Diseases 2021-2030</p>	<p>Relevant indicators as defined in: - the Global action plan for prevention and control of noncommunicable diseases 2013-2020 - Defeating meningitis by 2030: a global road map - Every newborn: an action plan to end preventable deaths - UN General Assembly adopted resolution 74/299 “Improving global road safety”, proclaiming the Decade of Action for Road Safety 2021-2030 - Road Map for Neglected Tropical Diseases 2021-2030</p>	<p>Reporting to WHO’s governing bodies as provided for in the aforementioned action plans.</p>
<p>SO4. To foster research and innovation and strengthen information systems for epilepsy and other neurological disorders</p>	<p><u>Global target 4.1:</u> 50% of countries routinely collect and report on a core set of indicators for epilepsy and other neurological disorders through their national health data and information systems every two years by 2031</p>	<p>Countries have functioning health data and information systems to routinely collect and report on a core set of indicators for epilepsy and other neurological disorders</p>	<p>Reporting and submission of core set of indicators for epilepsy and other neurological disorder to WHO every two years. Core indicators include those relating to specified targets of this action plan, together with other essential indicators of health system actions (e.g., training and human resource capacity, availability of essential medicines for neurological disorders, out-patient and in-patient visits)</p>
	<p><u>Global target 4.2:</u> 70% of countries have integrated epilepsy and other neurological disorders</p>	<p>Existence of a current research plan or programme in which epilepsy and other neurological disorders are integrated</p>	<p>For countries with a federated system, the indicator will refer to plans or programmes of the majority of</p>

	into existing research plans or programmes by 2031		states/provinces within the country.
SO5. To strengthen the public health approach to epilepsy and promote synergies with other neurological disorders	<p>Global target 5.1: 90-80-70 (i) 90% of all people with epilepsy are aware of their diagnosis as a treatable brain disorder; (ii) 80% of people diagnosed with epilepsy have access to appropriate, affordable, safe antiseizure medicines and (iii) 70% of those treated achieve adequate seizure control</p>	As described in each component of the composite cascade target	<p>Composite cascade of care target to support progress towards a world where no person's life is limited by epilepsy. Data may be derived from administrative sources, electronic records and registries. This will be a relative, globally combined measure. Numerators: Derived from routine information systems or, if unavailable, a baseline and follow-up survey of health facilities in one or more defined geographical areas of a country. Denominator cascade (i): estimated prevalence of epilepsy derived from national surveys or, if unavailable, subregional global prevalence estimates. (ii) numerator of (i) (iii) numerator of (ii)</p>
	<p>Global target 5.2: All countries have reviewed their existing legislation, particularly in the areas of education, driving, employment, marriage, and fertility, with a view to address and amend clauses that discriminate against people with epilepsy and other neurological disorders by 2031.</p>	<p>Two step target: By 2025: Evidence derived from government records that countries have undertaken a review of existing legislation to identify possible areas for amendment By 2031: Evidence from government records that plans have been developed and activated to address any needed legislative changes</p>	