

EPILEPSY 90-80-70¹: A SMART Target

SMART: Specific Measurable Achievable Relevant Time bound²

The statements below are supported by studies and results of demonstration projects detailed in the attached annex. The literature review is not intended to be a systematic review but to provide a snapshot of real-life experiences that help to demonstrate that Epilepsy 90-80-70 target meets the criteria of a SMART target, is feasible, and relevant across all (low to high) resource settings.

Specific

The Epilepsy 90-80-70 target is specific in that it is clearly defined as relating to epilepsy. Although there are many types of epilepsy, the currently widely available diagnostic tools³ (clinical history, smartphone video recording of a seizure, and routine EEG) offer reasonable levels of diagnostic accuracy and demonstrate high levels of specificity in studies across different populations.

Measurable

All parts of the Epilepsy 90-80-70 cascade target are measurable using existing methodologies.

Initial 90% target:

Denominator: The demonstration project in China that began in 2000⁴ showed that it is possible to establish baseline prevalence data through the use of epidemiological surveys, even in large populations and rural/remote settings. This baseline data is needed for any type of target.

Numerator: Can be established by accessing routine health system information +/- triangulation with specific reports from a small number of sentinel sites supplemented with KAP studies as needed.

The 80% target:

This target could be measured through a number of different methods:

- The methodology already in use to assess the availability of essential medicines proposed in the WHO Global Action Plan on the Prevention and Control of Non-Communicable Diseases (see below)
- National pharmaceutical data, as done by the epilepsy programme in Pakistan⁵
- Sentinel sites follow up.

The 70% target:

This target could be measured through surveys of epilepsy professionals and/or people with epilepsy and/or sentinel site surveys. Organizations like ILAE and IBE, with global reach and national and subnational representation, would be able to assist with this type of data collection.

¹ Inspired by and based on the evidence presented in <https://gatesopenresearch.org/articles/3-1502>

² November 1981 issue of *Management Review* by George T. Doran.

³ Widely available refers to those tools found in most part of the world including low resource settings. Additional diagnostic technologies that improve specificity and allow differentiation of categories of epilepsy may only be available in higher resource settings

⁴ [epilepsy_china_report_english.pdf \(who.int\)](#)

⁵ <https://www.ibe-epilepsy.org/wp-content/uploads/2021/07/Roundtable-Report-Final-22-July-v3.pdf>

Achievable

Each component of the cascade target will require intersectoral action and strengthening of different parts of the health system. There is an abundance of evidence to show that the needed actions are possible and have been achieved in real-life demonstration projects and interventional studies. The cost of the majority of these interventions is relatively low, and all areas of strengthening would offer synergistic benefits for other neurological disorders, as well as entry points for broader health system improvement.

90% of all people with epilepsy aware of their diagnosis as a treatable brain disorder

Achieving this goal requires:

- Harmful myths replaced with an understanding that epilepsy is a treatable brain disorder – again a range of studies and longitudinal surveys have shown that myths can be addressed, and that significant and sustained attitudinal and stigma changes are possible.
- Increased public and professional awareness about epilepsy. Demonstration projects and studies throughout the world have shown that it is possible to raise public awareness and understanding of epilepsy as a medical condition, improve positive health-seeking behaviour, and improve knowledge, detection, and diagnostic skills among health professionals. 90% of all people with epilepsy aware of their diagnosis as a treatable brain disorder.
- Improved diagnosis through training and enhanced specialist networks. Smart phone technology and telemedicine are improving the specialized support that can be given to primary care professionals and improve diagnostic accuracy. In specialized centres, EEG machines and other diagnostic tests and technologies are becoming more readily available and shown to be cost effective. Many of these medical technologies are useful for the diagnosis and monitoring of patients with other neurological disorders also.

80% of people diagnosed with epilepsy have access to appropriate, affordable, safe anti-seizure medicines

This is in line with the approved WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2020⁶, which sets a target of 80% availability of affordable essential medicines required to treat major NCDs in public and private facilities.

Achieving this goal requires:

- Strengthened, sustainable essential medicine supply chains. It is possible to significantly strengthen pharmaceutical supply chains, even in low-resource settings and rural areas. Efforts in HIV, tuberculosis, and malaria treatment have shown this to be possible. The pathways, infrastructure, and systems exist to achieve the same goal for anti-seizure medicines.

⁶ World Health Assembly, 66. Resolution and decisions. Annex 4. Global action plan for the prevention and control of noncommunicable diseases 2013–2020. Geneva: World Health Organization; 2013 (http://apps.who.int/gb/ebwha/pdf_files/WHA66-REC1/WHA66_2013_REC1_complete.pdf, accessed 15 April

- Proper financing and pricing to ensure that anti-seizure medicines are affordable. Most first-line anti-seizure medicines are inexpensive to produce and highly cost effective. However, public financing and proper pricing are needed to ensure that the public health and economic benefits are fully realized. Both of these issues can be addressed, and projects in some parts of the world have shown that this aim can be achieved.
- Reclassification of certain anti-seizure medicines to allow production and importation. Undue regulation is a significant but under-reported barrier that can be surmounted with strong international and national coordination.

70% of those treated achieve adequate seizure control

Achieving this goal requires:

- Investment in primary and community care and support. A range of studies have shown that taking a primary care approach is an effective means of ensuring sustainable care and support for people with epilepsy and that this improves long-term compliance with medication and seizure control
- Informing, engaging, and empowering people with epilepsy. Self-care has been shown to improve seizure control, as well as a self-esteem and social integration.
- Continued research to improve treatment options. Research over the past two decades has resulted in more than 14 new anti-seizure medicines being developed over the past two decades⁷. In addition, surgical techniques, wearable and implantable devices, and the ketogenic diet provide other treatment options for people with epilepsy. However, continued research is needed to find expand further the options available particularly for people who do not respond to first line medicines and to reduce side effects⁸.

Relevant

Action to address the unacceptable treatment gaps for epilepsy has been declared a public health imperative. Epilepsy is a treatable brain disorder with interventions that can significantly reduce the physical, mental, social, and exclusion burdens experienced by over 50 million people with epilepsy worldwide. Demographic and epidemiological shifts around the world, as well as overall population growth, are likely to result in increasing numbers of people with epilepsy over the next decade. Setting an aspirational but SMART cascade target that incentivized intersectoral action and system building across the health sector is needed and relevant.

Time bound

The target is clearly time bound – 2021 to 2031 – and there is evidence that with sufficient government commitment and investment it could be achieved in this time period.

⁷ [Pharmaceuticals | Free Full-Text | Therapeutic Drug Monitoring of the Newer Anti-Epilepsy Medications | HTML \(mdpi.com\)](#)

⁸ <https://www.bmj.com/content/371/bmj.m3658>

Annex Selected Literature

90% of all people with epilepsy aware of their diagnosis as a treatable brain disorder

Selected examples of successes in raising awareness and addressing stigma and myths:

An Evaluation of the Impact of Health Worker and Patient Education on the Care and Compliance of Patients with Epilepsy in Zimbabwe

Adamolekun, B, et al. *Epilepsia* 1999; 40:507.

<https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1528-1157.1999.tb00749.x?sid=nlm%3Apubmed>

A six-month intervention programme in Zimbabwe demonstrated that community health worker education increased patient recruitment by 74%, and increased medication adherence.

Knowledge, attitudes, and stigma towards epilepsy in different walks of life: a study in Georgia.

Gzirishvili N., et al. *Epilepsy Behav.* 2013;27(2):315.

<https://www.sciencedirect.com/science/article/abs/pii/S1525505013000619>

In a demonstration project in Georgia, a substantial level of stigma, erroneous beliefs and low public awareness caused people with epilepsy to hide the condition. However, barrier can be overcome through public and professional education and awareness raising.

Community perceptions and attitudes regarding epilepsy and disease cost after implementation of a community-based epilepsy treatment program in onchocerciasis-endemic communities in the Democratic Republic of Congo

Dusabimana A, et al. *Epilepsy Behav.* 2021;116.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7960634/>

One year of community education, free anti-seizure medicine, and monthly follow-up of people with epilepsy resulted in:

- Reduced belief that epilepsy is contagious
- People with epilepsy now prefer to seek care first at a health center, rather than a traditional healer
- Epilepsy-related costs to family decreased by 95%, increased adherence to anti-seizure medication and reduced felt stigma

Determinants of felt stigma in epilepsy

Aydemir N, et al. *Epilepsy Behav.* 2016;58:76.

[https://www.epilepsybehavior.com/article/S1525-5050\(16\)00124-4/fulltext](https://www.epilepsybehavior.com/article/S1525-5050(16)00124-4/fulltext)

In a Turkish study, those who hid their epilepsy condition from others were more likely to seek nonmedical treatments and were more likely to report higher levels of stigma.

Pediatric Epilepsy Training course – British Paediatric Neurology Association

<https://courses.bpna.org.uk/index.php?page=paediatric-epilepsy-training>

Paediatric Epilepsy Training (PET) is a series of face-to-face 1 and 2-day courses developed by the British Paediatric Neurology Association (BPNA) in response to concerns about standards of care for children with epilepsy in the UK. PET has been running in the UK since 2005 and is now being established worldwide.

PET is aimed at paediatricians, medical officers and emergency department professionals. It aims to improve the diagnosis of epileptic and non-epileptic events; improve the standard of care; and raise awareness of when to liaise with a Paediatric Neurologist, a children's epilepsy expert.

The International League Against Epilepsy (ILAE) endorses PET.

Results from a 2017 survey of PET trainees found that:

Results from the 2017 PET1 Outcome Measures:

- 85% report improved ability to distinguish between epileptic and non-epileptic events
- 82% report they have improved history taking
- 80% report PET has prompted them to try to improve the way clinical services are set up to support children with epilepsy
- 75% report they have made moderate or significant changes to their practice, diagnosis and caring for children and young people with epilepsies
- 63% report they recognise more quickly when a patient needs to be referred to an expert
- Many have introduced or improved teaching about epilepsy to parents and families (88%), undergraduates (70%), post graduates (63%), professional colleagues (65%)

Selected examples of accuracy of common diagnostic tools that could be made available in most resource settings:

Assessment of the Predictive Value of Outpatient Smartphone Videos for Diagnosis of Epileptic Seizures

Tatum WO, et al. *JAMA Neurol.* 2020;77(5):593.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2758655>

This diagnostic study conducted at 8 tertiary care epilepsy centers found that video reviewed by experts predicted a final diagnosis with an accuracy of 89% for epileptic seizures and 86% for

psychogenic nonepileptic attacks. The findings also confirmed the ability to perform a secure exchange of smartphone videos among multiple institutions.

Sensitivity and specificity of electroencephalography (EEG) among patients referred to an electrophysiology lab in Bangladesh

Chowdhury AH, et al. *J Dhaka Med Coll.* 2014; 23(2): 215.

<https://www.banglajol.info/index.php/JDMC/article/view/25394>

Among 1,154 patients, age varied from birth to 75 years, though most study participants were children. The overall sensitivity of EEG for diagnosing epilepsy was 66% (range 62% - 68%) and specificity was 79% (range 72%- 84%).

The diagnostic accuracy of routine electroencephalography after a first unprovoked seizure.

Bouma HK, et al. *Eur J Neurol.* 2016 Mar;23(3):455.

<https://onlinelibrary.wiley.com/doi/10.1111/ene.12739>

In pooled adult studies, routine EEG had a sensitivity of 17.3% and specificity of 94.7%. In studies in children, the pooled sensitivity and specificity were 57.8% and 69.6%.

80% of people diagnosed with epilepsy with access to appropriate, affordable, safe anti-seizure medicines

Selected literature on cost-effectiveness of anti-seizure medicines and economic benefits of improved supply, pricing and public financing:

Cost-effectiveness of first line antiepileptic drug treatments in the developing world: a population-level analysis.

Chisholm D, WHO-CHOICE. *Epilepsia.* 2005;46(5):751.

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2005.52704.x>

A cost– effectiveness analysis of epilepsy treatment in nine WHO subregions found that first-line medicines, such as phenobarbital, represent a highly cost-effective use of resources. Extending coverage of anti-seizure medicines to 50% of primary epilepsy cases would avert 150–650 disability-adjusted life-years per million population, at an annual cost per capita of US\$ 0.20–1.33. (The disability-adjusted life year is a measure of overall disease burden, expressed as the number of years lost due to ill health, disability, or early death.)

Health and economic benefits of public financing of epilepsy treatment in India: an agent-based simulation model.

Megiddo I et al. *Epilepsia.* 2016;57:464.

<https://onlinelibrary.wiley.com/doi/10.1111/epi.13294>

Covering costs for both first- and second-line therapy and other medical costs alleviates the financial burden from epilepsy and is cost-effective across wealth quintiles and in all Indian states.

Mapping the availability, price, and affordability of antiepileptic drugs in 46 countries.

Cameron A et al. *Epilepsia*. 2012;53(6):962.

<https://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2012.03446.x>

Data from 46 countries was examined showed that the availability of anti-seizure medicines is lower in low- and middle-income countries, compared with high-income countries. As well, the costs of these medicines are highest where the treatment gap is largest. This study supports the need for more effective pricing negotiations as well as appropriate public financing and strengthened supply chains.

Selected literature on regulatory barriers:

Undue regulatory control on phenobarbital - an important yet overlooked reason for the epilepsy treatment gap.

Bhalla D et al. *Epilepsia*. 2015;56(4):659.

<https://onlinelibrary.wiley.com/doi/10.1111/epi.12929>

Regulatory hurdles at national and international level need to be – and can be addressed – to improve availability and reduce prices.

70% of those treated achieve adequate seizure control
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Selected literature on the impact of investment in primary and community care and informing, engaging, and empowering people with epilepsy:

Demonstration project on epilepsy in Brazil: outcome assessment

Li LM, et al. *Arq. Neuro-Psiquiatr* 2007;65(suppl 1)

<https://www.scielo.br/j/anp/a/RhYmPmCjG6Xqps7Dqywbdt/?lang=en>

Staff and patients in primary health units underwent information training in epilepsy, and 181 people with epilepsy visiting these primary health units were followed for 1 to 38 months. Following training of professionals and people with epilepsy, the median seizure frequency dropped from one to three seizures per month to one to three seizures per year. Patients and their families indicated that, in most cases (78%), health status had improved.

Treatment access intervention: the Epilepsy Manager Program of the Philippine League Against Epilepsy. Soto MF. *Neurology Asia*. 2013;18(suppl 1):61-65.

[http://www.neurology-asia.org/articles/neuroasia-2013-18\(s1\)-061.pdf](http://www.neurology-asia.org/articles/neuroasia-2013-18(s1)-061.pdf)

The success in gaining good seizure control for hundreds of people with epilepsy in remote and rural areas of the Philippines program is detailed in this paper.

Models of community-based primary care for epilepsy in low- and middle-income countries

Singh G, et al. *Neurology* 2020;94(4):165

<https://n.neurology.org/content/94/4/165.long>

Meta analysis of community-based interventions that have reduced the epilepsy treatment gap.

Care delivery and self-management strategies for adults with epilepsy.

Bradley PM, et al. *Cochrane Database Syst Rev* 2016, Issue 2. Art. No.: CD006244

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006244.pub3/full>

The review provided growing evidence of the importance of dedicated self-management education strategies and highlighted the need for more comprehensive research in this area.

Evidence that adequate seizure control is possible with anti-seizure medicines:

Treatment Outcomes in Patients with Newly Diagnosed Epilepsy Treated with Established and New Antiepileptic Drugs: A 30-Year Longitudinal Cohort Study.

Chen Z, et al. *JAMA Neurol* 2018;75(3):279.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2666189>

A total of 1795 individuals who were newly treated for epilepsy with AEDs between July 1, 1982, and October 31, 2012, were included in this analysis. All patients were followed up for a minimum of 2 years (until October 31, 2014) or until death, whichever came sooner. The study found that 63.7% of participants had been seizure free for at least one year. Among these people, 86.8% were on monotherapy and 90% achieved this level of control with their first or second medication regimen.

The costs of epilepsy in Australia: A productivity-based analysis

Foster E., et al. *Neurology* 2020;95(24): e3221.

<https://n.neurology.org/content/95/24/e3221.long>

Modelling shows that increasing seizure freedom would significantly prevent excess deaths, improve quality of life and bring enormous return on investment from a health care perspective and societal gains in terms of reducing productivity losses.