GLOBAL EPILEPSY NEEDS STUDY
GENS

IBE International Bureau for Epilepsy

Global Epilepsy Needs Study

Policy Advocacy Report

© International Bureau for Epilepsy, 2026.
This work is available under the Creative Commons Attribution-ShareAlike 4.0 International licence (CC BY-SA 4.0).

To view a copy of this licence, visit: https://creativecommons.org/licenses/by-sa/4.0/

Suggested citation:

Global Epilepsy Needs Study: Policy Advocacy Report. Washington DC: International Bureau for Epilepsy; 2026. Licence: CC BY-SA 4.0.

Under the terms of this licence, this work may be copied, redistributed, and adapted, provided the new work is issued using the same or equivalent Creative Commons licence and it is appropriately cited as indicated below. In the use of this work, there should be no suggestion that the International Bureau for Epilepsy (IBE) endorses any specific organization, product, or service. The use of the IBE logo is not permitted.

If this work is translated, the following disclaimer should be added along with the suggested citation: “This translation was not created by the International Bureau for Epilepsy (IBE). IBE is not responsible for the content or accuracy of this translation.”

If this work is adapted, the following disclaimer should be added along with the suggested citation: “This is an adaptation of an original work by the International Bureau for Epilepsy (IBE). Views and opinions expressed in the adaptation are the sole responsibility of the author(s) of the adaptation and are not endorsed by IBE.”

Publication

Baker GA, Bagga SK, Walsh D, Nolan C, Sharma S, Hooker C, Parrao PG, Sofia F, Cross JH, Bertone MM, García I, Janneh AJ, Kukla A, Montero EV, Ding D, Friedrich L, Pinto LF Singh G, Triki CC, Raj L, Reese A.
The Global Epilepsy Needs Study
A mixed-methods, multi-country exploration of the unmet psychosocial and everyday needs of people with epilepsy. Epilepsia Open. 2026;00:1–19. (GENS): https://doi.org/10.1002/epi4.70237

Scan the QR code below to access the publication

Contents

Foreword

Dear friends,

It is a pleasure for me to write this foreword on behalf of the International Bureau for Epilepsy (IBE). We are a global network of over 160 national epilepsy organisations – in more than 100 countries – that serve and support people with epilepsy and their caregivers.

In this policy advocacy report, IBE is proud to share with you the results of our most ambitious research undertaking ever: The Global Epilepsy Needs Study (GENS).

GENS came about in response to the unanimous approval, by the member states of the World Health Assembly, of the World Health Organisation's 10-year Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP), 2022-2031. IGAP was the culmination of international advocacy efforts led by IBE, and the International League Against Epilepsy, which was kick-started by the 1997 'Out of the Shadows' global campaign against epilepsy. IGAP contains two strategic objectives which calls on governments worldwide 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.

Global target 5.2: 80% of countries will have developed or updated their legislation to promote and protect the human rights of people with epilepsy by 2031.

It is essential that we see epilepsy as a human rights concern. Across the world, people – of all ages - with epilepsy, and those who care for them, are denied equal opportunities to play, to learn, to work, to travel, to marry, or to parent.

Policies, plans, and programmes to address epilepsy as a public health priority are ultimately pointless unless they address the real, everyday unmet needs of people living with the condition.

Through GENS, IBE aims to better understand global priorities for those with epilepsy, ensuring that lived experience authentically informs policy, research, and healthcare innovation.

In this report, we examine ten key areas of life to identify the priority needs of people with epilepsy. We amplify the voices of our experts by experience — sharing their stories alongside the numbers — to provide a roadmap for change through best practices and actionable policy advice.

Whilst our recommendations, here, are targetted to policy-makers; addressing these needs will require multi-stakeholder collaboration. IBE remains committed to cross-sector partnerships that turn these findings into reality.

Already, we are rolling out projects that we believe can have an impact. Externally, our global advocacy continues apace and awareness is raised via campaigns such as #50millionsteps and International Epilepsy Day. Internally, we are facilitating peer to peer learning via our Global Exchange and regional chapter conventions. We are developing advocates through our Global Epilepsy Leaaders programme and driving meaningful engagement with our Lived Experience Project. We partner with the International League Against Epilpesy to deliver international and regional congress where speakers with lived experience are ensuring healthcare professionals are trained to address their real needs.

No single organisation, though, can address these needs alone. This report must be a shared starting point from which we can, and must, build a more inclusive future together. Therefore, I want to thank everyone who helped bring this study to fruition. Such a massive undertaking would not have been possible without our chapter working group, our expert advisory group, our research partners at MediPaCe, our sponsors, and the entire IBE staff. It took our whole community to launch GENS, and it will take our whole community to ensure it truly changes lives.

DR FRANCESCA SOFIA
President, IBE

Structure Of The Report

The Global Epilepsy Needs Study explored the priority needs of people with epilepsy across ten domains of life [1]. This report has been developed by analysing these domain-specific findings and developing recommendations for action.

1
Executive summary

2
Policy recommendations for policy-makers and other key stakeholders.

3
Introduction highlighting the global burden of epilepsy, and its related policy frameworks.

4
Overview of GENS outlining who we heard from and the key findings, with a link to the publication in Epilepsia Open.

The main body of the report is divided into 10 sections, representing the GENS life domains. Each section presents findings from the survey and semi-structured interviews and includes:

1. A short explanation of the domain.
2. The top five most frequently selected needs.
3. Statistically significant survey findings, reflecting the odds ratios i.e. how much more likely one group is to experience something compared to other group(s).
4. A snapshot of qualitative themes, including sub themes and key issues identified.
5. Illustrative quotes.
6. Reflections on the importance and relevance of the findings from our global epilepsy community.
7. Domain-specific policy recommendations.
8. Global best practice examples demonstrating how some of these needs are being addressed. These summary examples reflect the initiatives of our global epilepsy community, including IBE chapters and partners, and were selected to reflect representation across our 7 regions.

All policy recommendations are based on priority unmet needs identified through GENS and were developed with input from members of IBE's Community Council, drawing on their lived experience of epilepsy, as well as IBE's Regional Committees on behalf of national epilepsy organisations worldwide.

The recommendations are aligned with the targets of the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders [2] and linked to broader global frameworks, including the United Nations Sustainable Development Goals [3], the United Nations Political Declaration on Non-Communicable Diseases [4], and the Universal Declaration of Human Rights [5].

These global recommendations are intended to be adapted to local contexts, taking into account national norms, cultural realities, and political priorities, with the aim of advancing social inclusion, reducing stigma, and improving quality of life for people with epilepsy worldwide.

Target audiences of this report

This report is intended for use by the following stakeholders:

- policy-makers, decision-makers, and officials of national and subnational government sectors.
- program managers and service planners in the health, social, education, economic, justice, environment, and other relevant sectors.
- public health professionals and researchers working in national ministries, in subnational offices, or at the district level.
- health and social care professionals involved in service planning for epilepsy.
- civil society organisations, professional societies, advocacy groups, academic and research institutions, and other epilepsy community representatives.
- people living with epilepsy, their carers and their families.
- donors and funders of programmatic work.
- IBE and its chapters.

Executive Summary

The International Bureau for Epilepsy (IBE) launched the Global Epilepsy Needs Study (GENS) [1] to address a longstanding and critical gap in epilepsy research: the limited understanding of the psychosocial and everyday needs of people living with epilepsy.

While epilepsy advocacy has advanced globally - evidenced by the unaminous adoption of WHO's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) [2] - the voices and lived experiences of people with epilepsy remain insufficiently reflected in research, policy, and service design.

Building on these global advocacy efforts, GENS sought to establish a robust, representative evidence base on unmet needs beyond seizure control, with the aim of driving more inclusive, person-centred approaches to care, research, and policy development.

Using a mixed-methods approach and involving people with lived experience throughout the research process, GENS gathered 5,296 survey responses and conducted 75 semi-structured interviews across 15 countries. The study explored the lived realities of people with epilepsy across 10 key domains of everyday life, presented below.

Globally, the most frequently identified needs emerged across 5 of the 10 life domains (refer to pages 8-9): **Healthcare & Wellbeing, Safety & Survival, Knowledge & Advice**, **Community & Household**, and **Mental Health & Wellbeing**. These findings underscore urgent priorities for action, including improving access to epilepsy care, increasing public awareness of epilepsy and seizure first aid, strengthening protection of the rights of people with epilepsy, and addressing the broader impacts of epilepsy on mental health, wellbeing, and daily life.

Thematic analysis of the interviews, combined with the survey data, generated 5 overarching themes reflecting core realities of people with epilepsy and their families, presented on the next page.

5,296 people across 15 countries shared epilepsy experiences

5 major themes identified by the Global Epilepsy Needs Study

1.	**Navigating uncertainty and redefining daily life**	The unpredictable nature of epilepsy increases vulnerability, disrupts routines, and impacts daily participation and future planning. This ongoing uncertainty creates instability in everyday life, and requires individuals and families to continually adapt their activities, plans and expectations.
2.	**Living with risk, social exclusion and misunderstanding**	Stigma, judgement, societal misconceptions and safety risks shape participation and relationships, often leading to exclusion, withdrawal, strained connections and barriers to personal development.
3.	**Challenges in navigating inaccessible systems**	People with epilepsy often face healthcare, education, employment, and transport systems that lack the flexibility, resources, or understanding required to accommodate their needs, leaving them to adapt within inflexible environments.
4.	**Consequences of inaccessible or inadequate information**	A lack of timely, relevant, and accurate information about epilepsy, at individual, healthcare professional, and societal levels, creates uncertainty reinforces stigma, and limits the ability to make informed decisions and access appropriate support.
5.	**Complex epilepsy needs demand more than standard approaches**	People with rare or complex epilepsies face persistent challenges unmet by standard care, including fragmented healthcare pathways, unmet cognitive and emotional needs, gaps in specialist medical and psychosocial support and heavy caregiving burdens.

The survey found greater needs among respondents from low-income countries, as well as among women, people with complex epilepsy, those who viewed epilepsy as a disability, and individuals who self-identified as minorities. These findings are highlighted in the 10 sections of the report that explore the findings across our GENS life domains.

It is of significance that 2 of the 10 most frequently selected needs called for the recognition and protection of the human rights of people with epilepsy, a thread that ran across all domains, and was of relevance for low- and high-income countries.

The findings highlight the importance of providing support for people with epilepsy across all domains of life. The cross-cutting global recommendations [6,7] overleaf are outlined for policy-makers to address these concerns through coordinated action with key stakeholders, including people with lived experience, healthcare professionals, patient and medical organisations.

The 10 GENS Life Domains

- Knowledge & Advice
- Safety & Survival
- Healthcare & Wellbeing
- Learning & Education
- Work & Income
- Transport & Driving
- Community & Household
- Mental Health & Wellbeing
- Sexual & Reproductive Health
- Achieving Life Goals

Top 10 Cross-Cutting, Global Recommendations

1

Strengthen human rights-based legal and policy frameworks, ensuring non-discrimination; and offering recourse mechanisms when human rights are violated.

2

Develop and implement national epilepsy plans and programmes, and/or ensure epilepsy is integrated in national plans on neurology, rare disease, NCDs, and all other relevant policies.

3

Run nationwide epilepsy awareness campaigns focused on stigma reduction and seizure safety; mandating seizure first aid training for community gatekeepers (educators, employers, sports coaches, etc.).

4

Ensure meaningful involvement of people with lived experience of epilepsy in policy and programme design, implementation and evaluation.

5

Support and resource national epilepsy and community-based organisations to deliver services and supports locally.

6

Develop integrated, person-centred and cross-sectoral systems of care across the life course; improving coordination between health, education, employment, transport, and social protection systems.

7

Increase health workforce capacity in epilepsy care, including integrated mental health and sexual & reproductive health care; leveraging innovation.

8

Ensure continuous access to essential medicines and services, particularly in times of conflict and crisis.

9

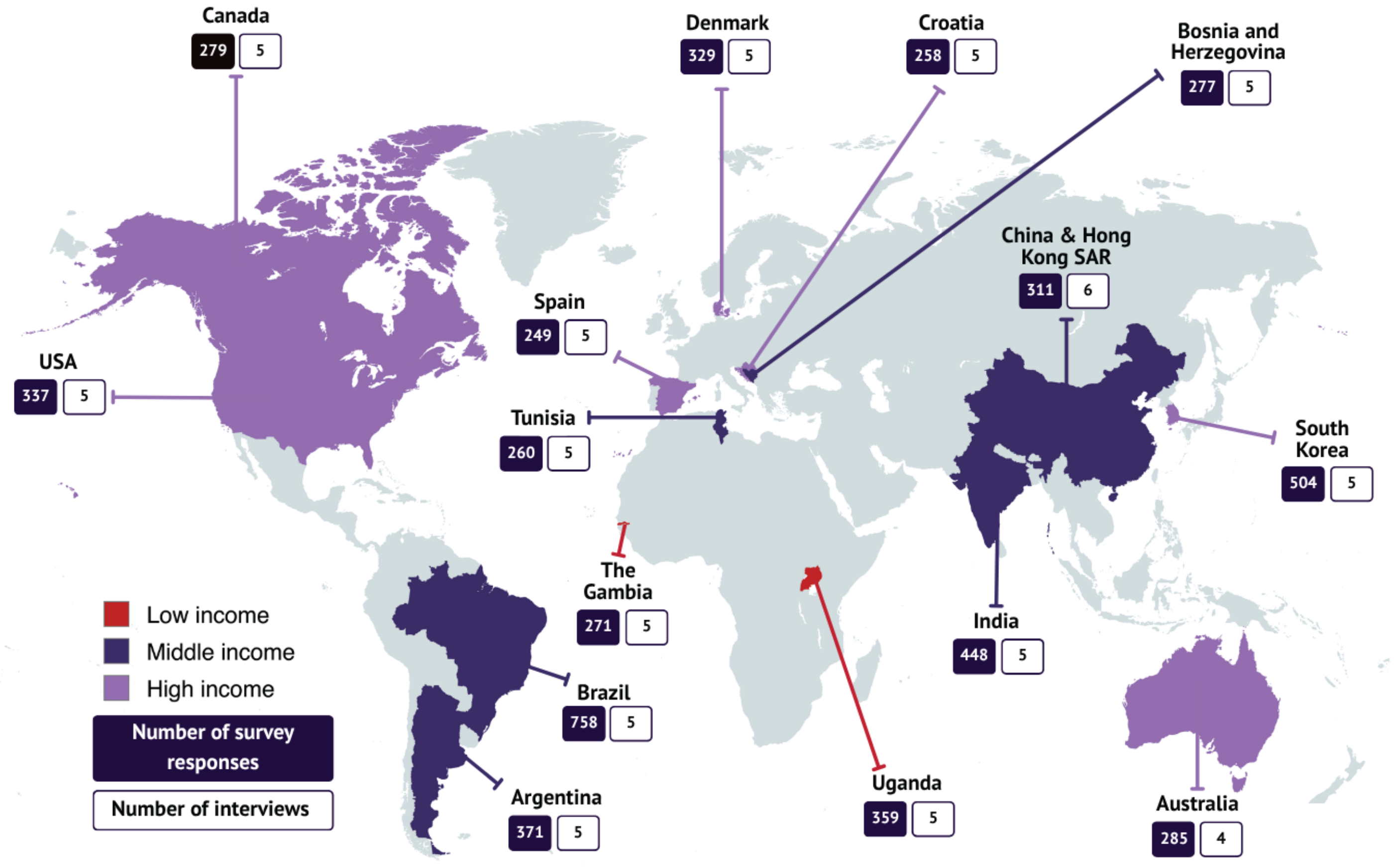
Advance urban planning and design of the built environment to enhance safety, accessibility, and inclusion.

10

Support evidence generation through intersectoral research funding, support for innovative R&D, and the creation of national registries, epidemiological data, socio-economic analyses, etc. to inform political prioritisation and action.

Overview of GENS

15 COUNTRIES | **12** LANGUAGES | **10** LIFE DOMAINS | **75** IN-DEPTH INTERVIEWS | **5296** SURVEY RESPONSES



Respondent Type

59% person with epilepsy
41% caregiver

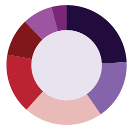
Epilepsy Type

80% non-complex epilepsy
20% complex epilepsy

Sex

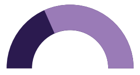
♂ **35%** male
♀ **63%** female
1% other
1% prefer not to say

Age



- **24%** Under 18 years
- **16%** 18-24 years
- **21%** 25-34 years
- **16%** 35-44 years
- **10%** 45-54 years
- **8%** 55-64 years
- **4%** 65 years or older

Location



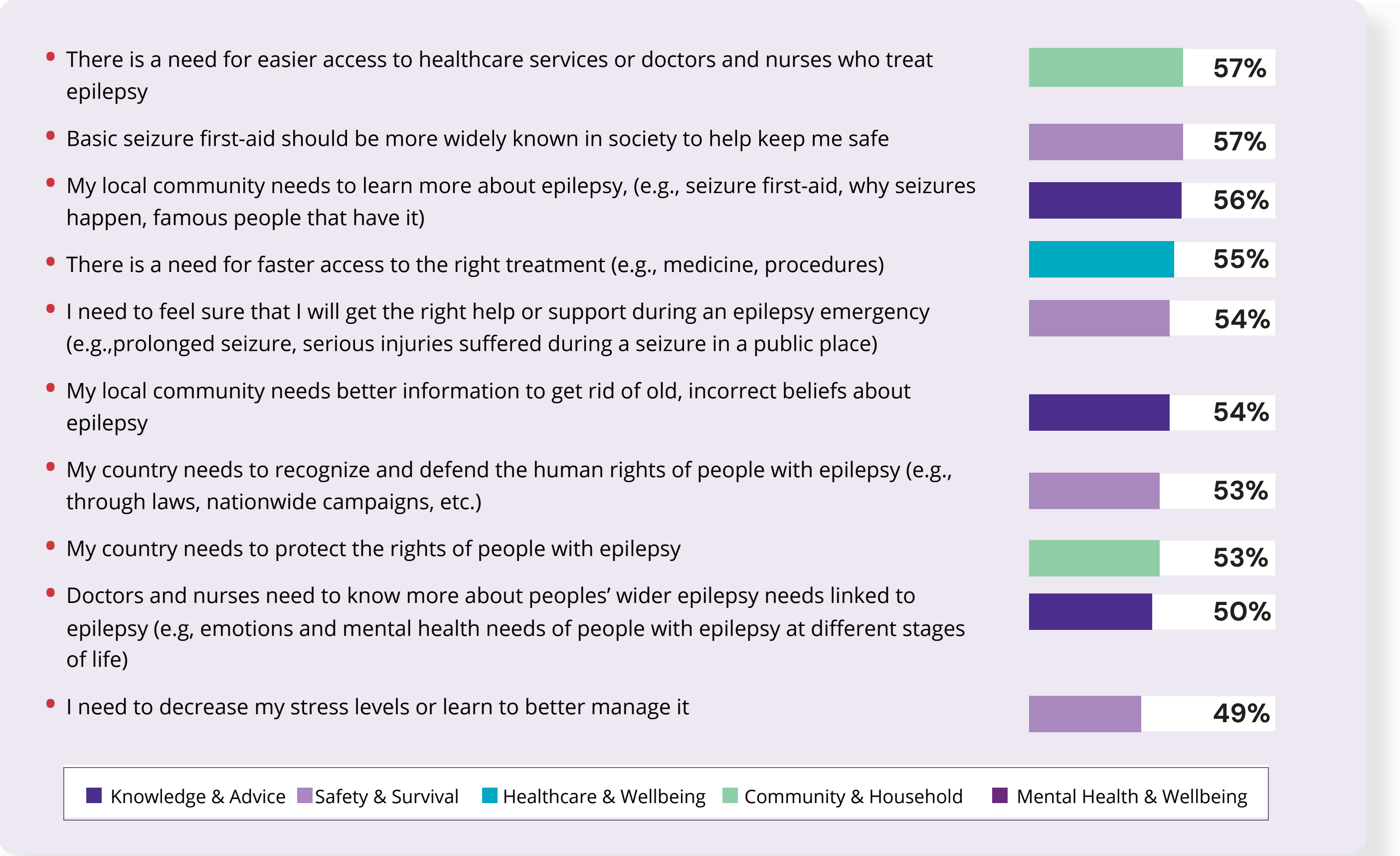
38% urban
62% rural/suburban

Research Tools & Processes

- Literature review & lived experience consultation
- Survey & interview guide development; pilot testing
- Recalibration & data collection
- Data analysis & results validation, with lived experience input
- Manuscript development, with lived experience feedback
- Ongoing dissemination, with lived experience involvement

Survey & Interview Results

The top 10 most frequently selected needs across eight domains are presented below. For two domains, 'Learning and Education' and 'Work and Income,' survey routing was applied. Survey questions were shown only to respondents who were either currently in, or planning to enter, education, and those who were currently working or seeking employment. Findings and identified needs within these two domains were therefore analysed separately.



There is a need for easier access to healthcare services or doctors and nurses who treat epilepsy	57%
Basic seizure first-aid should be more widely known in society to help keep me safe	57%
My local community needs to learn more about epilepsy, (e.g., seizure first-aid, why seizures happen, famous people that have it)	56%
There is a need for faster access to the right treatment (e.g., medicine, procedures)	55%
I need to feel sure that I will get the right help or support during an epilepsy emergency (e.g.,prolonged seizure, serious injuries suffered during a seizure in a public place)	54%
My local community needs better information to get rid of old, incorrect beliefs about epilepsy	54%
My country needs to recognize and defend the human rights of people with epilepsy (e.g., through laws, nationwide campaigns, etc.)	53%
My country needs to protect the rights of people with epilepsy	53%
Doctors and nurses need to know more about peoples' wider epilepsy needs linked to epilepsy (e.g, emotions and mental health needs of people with epilepsy at different stages of life)	50%
I need to decrease my stress levels or learn to better manage it	49%

Analysis of the interview data identified sub-themes, which were merged with the survey findings and used to generate five overarching themes that reflect the core needs of people with epilepsy across all geographic and demographic settings (refer to page 7). The figures below illustrate how the 10 GENS life domains map onto these themes.

Navigating uncertainty and redefining daily life

- Safety & Survival
- Transport & Driving
- Community & Household
- Mental Health & Wellbeing
- Sexual & Reproductive Health
- Achieving Life Goals

Living with risk, social exclusion and misunderstanding

- Safety & Survival
- Learning & Education
- Work & Income
- Community & Household
- Sexual & Reproductive Health
- Achieving Life Goals

Challenges in navigating inaccessible systems

- Healthcare & Wellbeing
- Learning & Education
- Work & Income
- Transport & Driving
- Mental Health & Wellbeing

Consequences of inaccessible or inadequate information

- Knowledge & Advice
- Mental Health & Wellbeing

Complex epilepsy needs demand more than standard approaches

- Knowledge & Advice
- Safety & Survival
- Healthcare & Wellbeing
- Transport & Driving
- Community & Household
- Mental Health & Wellbeing
- Achieving Life Goals

Global Burden Of Epilepsy

Epilepsy is a neurological, non-communicable disease characterised by recurrent seizures and neurobiological, cognitive, psychological, and social consequences [8]. The associated global burden [6-9] is highlighted below.

51.7m

people living with epilepsy.

14.4m

disability adjusted life years (idiopathic epilepsy).

125k

annual global epilepsy mortality.

3x

higher risk of premature death for PWE compared to the general population.

$100b

global economic burden (excluding costs for untreated epilepsy, non-optimal treatment & loss of productivity and earnings).

5th

among neurological causes of disability adjusted life years (DALYs).

80%

live in low-middle income countries.

75%

treatment gap in low-income countries.

70%

PWE could become seizure free with the appropriate us of anti-seizure medicines.

~50%

prevalence of other physical or mental health conditions.

25%

of epilepsy cases are potentially preventable.

0.5%

of the global burden of disease.

Global Advocacy for Epilepsy

In recent decades, epilepsy has gained long-overdue recognition in global policy frameworks. The adoption of the World Health Organization's 10-year Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) in 2022 marked a major milestone for global advocacy [2].

Unanimously approved by all World Health Assembly member states, the plan commits governments to strengthening the public health response to epilepsy. However, policies, plans, and programmes must translate into meaningful improvements in the everyday lives of people with epilepsy.

To better inform such efforts, IBE designed and delivered the Global Epilepsy Needs Study. The study provides critical insight into the priority needs of people with epilepsy worldwide, and aims to inform global and local policy and decision-making.

The policy recommendations in this report were developed in collaboration with leading epilepsy advocates and organisations, and focus on practical, achievable solutions to address the identified needs.

1997

Global Campaign Against Epilepsy – "Out of the Shadows" (WHO/ ILAE/IBE)

First major global advocacy campaign on epilepsy; raised awareness, reduced stigma and highlighted the treatment gap [10].

2015

WHA68.20 – Global Burden of Epilepsy Resolution

Established epilepsy as a global public health priority; called for strengthened national policies, services, and stigma reduction [11].

2019

WHO "Epilepsy: a public health imperative" report

Provided the strongest global evidence base for epilepsy policy and investment; reinforced need for system-level action [12].

2020

WHA73.10 – Global actions on epilepsy and other neurological disorders

Expanded focus from epilepsy alone to integrated neurological care; led to development of IGAP [13].

2022

WHO IGAP on Epilepsy and Other Neurological Disorders (2022–2031)

Provides a global roadmap with targets to improve epilepsy prevention, diagnosis, treatment, and care [2].

2024

WHO IGAP Implementation Toolkit

Supports countries to translate IGAP into action, including epilepsy service planning and monitoring [14].

2025

UN's Political Declaration of Non-Communicable Diseases

Recognises neurological disorders, including epilepsy, within the broader NCD agenda; calls for strengthened health systems, prevention, access to treatment and efforts to reduce stigma[4].

WHO's Global Status Report on Neurology

Provides findings from WHO's IGAP monitoring mechanism; establishes baseline values for IGAP's 10 global targets for 2022, 2 of which are specific to epilepsy[6].

Knowledge & Advice

This domain explored the knowledge and advice needs of people with epilepsy.

It focused on access to high-quality information about epilepsy management, advice for effective communication with healthcare professionals, and improving awareness among families and communities to address misconceptions and promote seizure first-aid and safety.

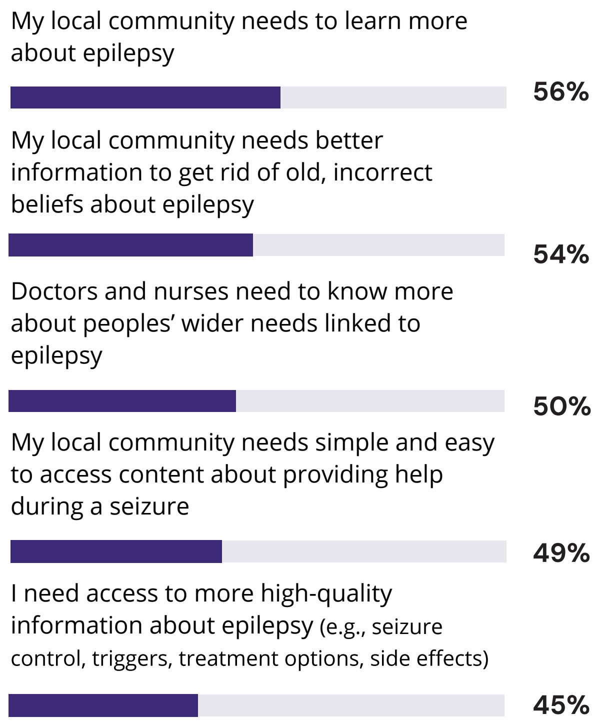
> *"I went to a neurologist who asked, 'What is it? Tell me, what is it?' He wanted me to tell him what epilepsy is. Okay, but uh...the person who should be telling me about epilepsy is...it's him, right? It's the doctor, right?"*
>
> **BRAZIL**

> *"She also says to make the person having a seizure smell onion to stop his/her seizure and make them fine. I had seen her making that kid smell onion when she was having a seizure...someone from the community might have told her."*
>
> **INDIA**

> *"This knowledge went against my earlier in school myths and preconceptions that if someone with epilepsy got a seizure and passed gas, you catching a whiff of it would automatically give you epilepsy too. We were also told that its hereditary and rooted in ancestral spirits."*
>
> **UGANDA**

Knowledge & Advice

Top 5 Most Frequently Selected Needs



Key Survey Insights

1. Income

Respondents from low-income countries were more likely than those from middle-income and high-income countries to report the need for:

- access to high-quality information about epilepsy (e.g., seizure control, triggers, treatment options, side effects)
  77% vs. 46% vs. 35%
- family and those who care for them to learn more about epilepsy (e.g., tips to stay safe, seizure first-aid, seizure
  80% vs. 34% vs. 29%
- greater awareness among doctors and nurses of people's wider needs related to epilepsy (e.g., emotional and mental health needs across different stages of life)
  77% vs. 46% vs. 49%
- advice on how to have effective conversations with doctors and nurses
  69% vs. 27% vs. 25%
- advice on how to tell key people in their life about their epilepsy (e.g., about their diagnosis, how it affects their life)
  68% vs. 25% vs. 27%
- better information within their local communities to get rid of outdated and incorrect beliefs about epilepsy
  80% vs. 53% vs. 50%

Interview Themes That Emerged

THEME 4: CONSEQUENCES OF INACCESSIBLE OR INADEQUATE INFORMATION	
Health information shortfalls	Misinformation, burden on individuals to access epilepsy knowledge, missed education opportunities by healthcare professionals, and knowledge gaps among healthcare providers.
Knowledge gaps in everyday and future planning	Limited knowledge about epilepsy among people with epilepsy and caregivers, low awareness of government support, and unfamiliarity with epilepsy organisations.
Widespread misunderstanding of epilepsy	False cultural beliefs and knowledge gaps in families, workplaces, educational settings, healthcare systems, and wider society.
THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES	
Burden of caregiving	Broader social and economic pressures (caregiver need).

Community Lived Experience Reflections

"One of the greatest challenges is not only the lack of information, but the quality, accessibility, and consistency of that information throughout the patient journey. People with epilepsy and their families are often forced to become "experts" themselves, navigating multiple and sometimes contradictory sources while managing an already complex condition. This creates uncertainty and directly impacts decision-making, relationships with healthcare professionals, and how epilepsy is understood in society. This is why this domain is so important: it shows that access to reliable and meaningful information is not secondary, but a fundamental condition for safety, autonomy, and quality of life."

ELVIRA, **SPAIN**

"This domain is very important to me because of my own early experience with epilepsy care. When I first saw a doctor around the age of 11, my mother was given some medication and simply told to give it to me every night, without any explanation of what it was, why it was being prescribed, or how long it needed to be continued. No diagnosis or context was explained to her at the time. As a result, she believed I had experienced a hypoglycemic episode and thought the medication was just a multivitamin."

AMEENA, **PAKISTAN**

"...When I was first diagnosed, I was given antiseizure medication without any clear explanation of my condition. It was only after going home and searching online that I discovered I had epilepsy. That moment was painful and confusing—it made me realize how critical it is for healthcare providers to communicate openly, honestly, and compassionately with patients."

FRED, **KENYA**

Policy Recommendations

The policy recommendations for this domain mirror the cross-cutting recommendations found on pages 8-9. Policy-makers should implement the following measures:

1. **Increase public awareness,** rolling-out ongoing national campaigns to equip the public with accurate knowledge to improve health literacy on epilepsy, dispel harmful misconceptions, and empower people with epilepsy and their families.
2. **Mandate seizure first-aid training,** including standardised and consistently applied guidance across key sectors of society (e.g. education, law enforcement, first responders, community services).
3. **Require healthcare services to adopt a holistic, person-centred approach,** going beyond clinical diagnosis to address the wider needs of people living with epilepsy.
4. **Formally involve people with epilepsy and their carers in the design and delivery of medical education** curricula to incorporate lived experience.
5. **Strengthen provider competencies in effective communication,** shared decision making, and eliciting patient preferences.
6. **Support and resource national epilepsy and community-based organisations** to act as credible and accessible information providers.

Best Practice Examples

Fundación Epilepsia y Juventud (Epilepsy and Youth Foundation)
CHILE

'My Journey with Epilepsy' Podcast

RATIONALE & APPROACH	The podcast was conceived in October 2025, as a digital space for communication and learning aimed at raising awareness, educating, and increasing understanding about epilepsy, while addressing stigma and promoting empathy. Through 10 main episodes and 2 special episodes, the project explored medical, social, emotional, and family-related topics, integrating the voices of professionals, people with epilepsy, caregivers, and relevant stakeholders.
OUTCOMES & IMPACT	The podcast broadened the public conversation about epilepsy and generated active participation on digital platforms through an accessible format. Qualitative analysis showed strong audience engagement, particularly among women. It has therefore become not only an educational tool, but also a space of listening, belonging, and shared experience.

EDYCS Epilepsy Group
MAURITIUS

Educational Comic Book: 'Savane Bien'

RATIONALE & APPROACH	In Mauritius, treatment barriers include a lack of knowledge and stigma surrounding epilepsy, particularly among children. The project aimed to assess the effect of reading an educational comic *Savane Bien* on the knowledge, attitudes, and practices (KAP) related to epilepsy among public school children. The study was initiated by the University of Limoges in collaboration with the Ministry of Education and EDYCS Epilepsy Group. A quasi-experimental study was conducted in 16 public schools across rural and urban areas, involving grade 5 pupils aged 10–11 years. Data were collected using a structured questionnaire before and immediately after reading the comic, with mean KAP scores compared at baseline and post-reading.
OUTCOMES & IMPACT	A 2025 publication highlighted that *Savane Bien* improved knowledge, attitudes, and practices related to epilepsy across different environments, regardless of sociodemographic or cultural characteristics. It can help support early knowledge acquisition and influence school environments and broader community perceptions by reducing stigma and promoting positive attitudes towards those living with epilepsy.

Safety & Survival

This domain explored the safety and survival needs of people with epilepsy.

It focused on preventing seizure-related injuries and death, ensuring safety in public spaces, during travel, and in emergencies, promoting awareness of seizure first aid and human rights, and preventing physical or emotional harm.

> *“I think people should have basic knowledge on how to behave if someone in their environment experiences a seizure....a few years ago, when a guy had a seizure in my town, and due to the inadequate help from those present, the guy unfortunately passed away.”*
>
> **BOSNIA AND HERZEGOVINA**

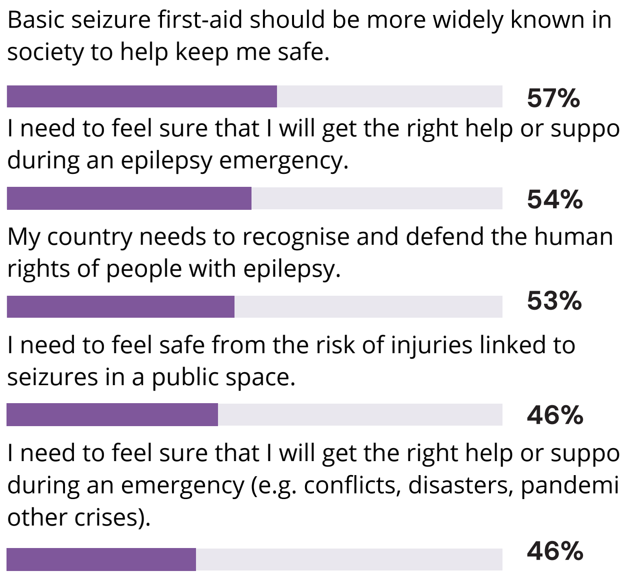
> *“It’s important that if someone has a seizure, those around them don’t panic or freeze, not knowing what to do— or worse, end up traumatised for life just from witnessing it.”*
>
> **BRAZIL**

> *“I was bullied from the time I started school to the end. It was really serious bullying, my parents had windows smashed and I got beaten up and death threats. It was every day. It was because of my epilepsy. The others called me ‘the crooked one’.”*
>
> **DENMARK**

> *“People have weird ideas about it [epilepsy], it’s not contagious. Don’t put a spoon in somebody’s mouth who’s having a seizure, people are still doing that.”*
>
> **USA**

Safety & Survival

Top 5 Most Frequently Selected Needs



Basic seizure first-aid should be more widely known in society to help keep me safe.
57%

I need to feel sure that I will get the right help or support during an epilepsy emergency.
54%

My country needs to recognise and defend the human rights of people with epilepsy.
53%

I need to feel safe from the risk of injuries linked to seizures in a public space.
46%

I need to feel sure that I will get the right help or support during an emergency (e.g. conflicts, disasters, pandemic, other crises).
46%

2. Income

Respondents from low-income countries were more likely than those from middle-income and high-income countries to report the need for:

- their country needs to recognise and defend the human rights of people with epilepsy (e.g., through laws, nationwide campaigns, etc.)
  78% vs. 59% vs. 42%
- feeling safe from being physically hurt by others because of their epilepsy
  73% vs. 31% vs. 22%

Key Survey Insights

1. Sex

Female repsondents were more likely than male to report the need for:

- feeling safe from the risk of injuries linked to seizures in a public space
  49% vs. 42%
- reducing the risks of life-changing injuries or dying from epilepsy (e.g., SUDEP)
  47% vs. 40%
- feeling safe when traveling to different places (e.g., visiting family, holidays)
  46% vs. 38%
- advice on how to cope with changes in weather that may impact them (e.g., extreme heatwaves)
  42% vs. 35%
- basic seizure first-aid to be more widely known to help keep them safe
  60% vs. 52%
- their country needs to recognise and defend the human rights of people with epilepsy (e.g., through laws, nation-wide campaigns, etc.)
  57% vs. 47%
- feeling safe from being physically hurt by others because of their epilepsy
  34% vs. 29%
- feeling safe from being emotionally hurt by others because of their epilepsy
  44% vs. 36%
- feeling sure they will get the right help or support during an emergency (e.g., during conflicts, disasters, pandemic and other crises)
  49% vs. 42%
- feeling sure they will get the right help or support during an epilepsy emergency (e.g., prolonged seizure, serious injuries suffered during a seizure in a public place)
  57% vs. 49%

Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING DAILY LIFE	
Physical risk inherent to epilepsy	Living with everyday physical dangers.
THEME 2: LIVING WITH SOCIAL EXCLUSION, AND MISUNDERSTANDING	
Vulnerability and safety risks	Humiliation, ridicule and emotional harm, vulnerability to harm from others during seizures, and mistreatment and exploitation in healthcare settings.
Inadequate emergency response	Stigma and misunderstanding prevent safe responses.
THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES	
Cognitive, developmental, and emotional needs	Safety risks related to developmental needs, social vulnerability and relational risk.

Community Lived Experience Reflections

“I have been living away from my family for the past five years. Knowing that most people in the general public are not aware of how to respond to seizures, I often fear having a tonic-clonic seizure in public or alone, where I may not receive appropriate help. This fear is also linked to the post-ictal state, where I would be confused, vulnerable, and unable to remember or advocate for myself. As a woman in Pakistan, this sense of vulnerability feels even greater, and it often leaves me feeling constantly alert and on guard in public spaces.”

AMEENA, **PAKISTAN**

“Societies in a lot of countries are not ready to provide adequate care, and epilepsy patients feel insecure when they are outside their homes and have a seizure. In my particular case, I remember once when I was walking along a rather dangerous street in the city center. Just as I was about to cross the road, I had an absence. I felt terrified that someone might steal my belongings, and right after that, I had a seizure and lost all awareness.. The constant feeling of unease and insecurity is something people with epilepsy live with whenever they are outside of their safe environment.”

CAROLINA, **COLOMBIA**

“Safety is not just about preventing physical injury, it is also about dignity, awareness, and timely support. The fear of being misunderstood, judged, or not receiving the right help during a seizure is very real. These findings highlight the urgent need for better awareness, especially around seizure first-aid and creating safer, more inclusive environments for people with epilepsy.”

POOJA, **INDIA**

One of the most difficult aspects is knowing that in many situations, safety depends not on medical care, but on the awareness of others. When people do not know how to respond to a seizure, the risk increases - not only of physical harm, but also of fear, stigma, and inappropriate reactions.. These findings strongly reflect that reality, particularly the need for broader knowledge of seizure first aid and the importance of feeling confident that help will be available in an emergency.

MARIA MARTA, **ARGENTINA**

Policy Recommendations

Policy-makers should take coordinated action to reduce preventable harm and improve survival for people with epilepsy through the following measures:

1. **Increase public awareness,** Rolling-out ongoing national campaigns to equip the public with accurate knowledge to improve health literacy on epilepsy, dispel harmful misconceptions, and empower people with epilepsy and their families.
2. **Mandate seizure first-aid training,** including standardised and consistently applied guidance across key sectors (e.g. education, law enforcement, first responders, community services), and promotion of seizure emergency response protocols.
3. **Create an epilepsy-friendly built environment,** mandating more inclusive urban planning and strengthening safety in public places including transport and recreational settings, to reduce injury risks associated with seizures.
4. **Protect vulnerable sub-populations,** including women, minority groups, and people with rare or complex epilepsies, ensuring responsive safeguarding, protection from harm, and equitable access to targeted support services.
5. **Ensure continuity of access to essential medicines during emergencies,** through resilient supply chains,monitoring systems and contingency planning.
6. **Leverage digital health solutions,** to improve and maintain access to care and specialist support in crisis, remote or under-served settings.

Best Practice Examples

EpiStop
CZECH REPUBLIC
Integrating Rapid and Early Seizure Termination (REST) and Seizure-Safe School Policies

RATIONALE & APPROACH

The absence of nationally standardised seizure response protocols in schools in the Czech Republic created avoidable safety risks and delayed emergency care for children with epilepsy. Between 2021–2022, EpiStop launched a teacher training course, followed by an awareness-raising and media campaign. This laid the foundation for an intersectoral working group involving patient organisations (EpiStop, Society E), medical societies (CLAE, SPN), education authorities (Ministry of Education), and policymakers (Ministry of Health, Office of the Government, Office of the Public Defender of Rights, Senate Committee on Social Politics). Together, they developed a methodological guidance aligned with Rapid and Early Seizure Termination (REST) principles, including seizure first-aid training for school staff, authorization for non-medical personnel to administer rescue medication, and Health Support Plans.

OUTCOMES & IMPACT

The Czech Republic established nationally endorsed methodological guidance for schools, including seizure response protocols and Health Support Plans, to strengthen inclusion and safety for children with epilepsy. Implementation and dissemination to clinicians, teachers, parents, and schools are underway, alongside inclusion of the topic in the Teacher magazine and the newly published EpiStandards 2026. The model may now serve as a best-practice example for implementing IGAP and integrating REST principles into community and education settings across Europe.

UCB supported cross-European collaboration and co-supported key resources (e.g., EpiStandards), while the initiative was independently led by EpiStop and other stakeholders.

Japan Epilepsy Association
JAPAN

Disaster Response Manual

RATIONALE & APPROACH

Japan is one of the world's most earthquake-prone countries. Serious difficulties were faced by people with epilepsy regarding medication procurement and seizure response at evacuation shelters during the 2011 Great East Japan Earthquake. There was an urgent need to systematise these lessons as a "guideline for survival". Information for the manual was consolidated from medical professionals and local governments in affected areas with the inclusion of an emergency contact card as an appendix. The first edition was compiled over two years following the 2011 disaster.

OUTCOMES & IMPACT

The project led to the inclusion of national notifications (emergency alerts) on emergency medical care. The manual now functions as a safety guideline for initial response and daily medication maintenance for people with epilepsy during natural disasters.

Healthcare & Wellbeing

This domain explored the healthcare and wellbeing needs of people with epilepsy.

It focused on timely access to specialised services, personalised and effective treatment, management of medication side effects and co-morbidities, and access to affordable insurance to support long-term health and care.

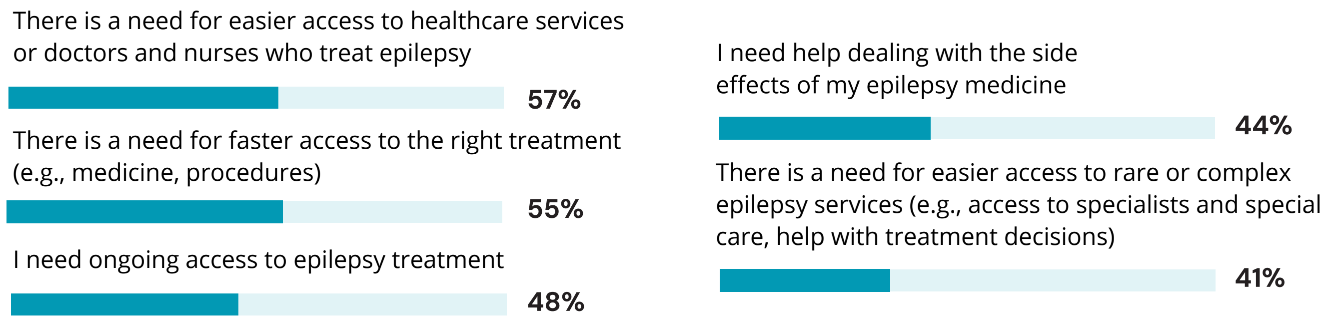
> *“When I go to the hospital and there is no medication, I run the risk of getting a seizure, to or from the hospital. There are extremes where I go even two months without the medication being available. .”*
>
> **UGANDA**

> *“Unfortunately, not all medications available in the EU are available in the Republic of Croatia. Some medications are on the list, but you can’t get them without medical committees. Automatic medications that go to committees are not prescribed because doctors don’t want complications. That’s completely bad.“*
>
> **CROATIA**

> *“I wish the medical staff could have a moment to exchange detailed information about the patient’s illness. I can’t even ask questions properly right now. Rather, when I try to speak as a patient carer, [HCP] sighs deeply and stops me from asking questions.“*
>
> **SOUTH KOREA**

Healthcare & Wellbeing

Top 5 Most Frequently Selected Needs



Key Survey Insights

1. Income

Respondents from **low-income countries** were more likely than those from **middle-income** and **high-income** countries to report the need for:

- faster access to the right treatment (e.g., medicine, procedures)
  85% vs. 56% vs. 48%
- ongoing access to epilepsy treatment (e.g., seizure medicines)
  83% vs. 49% vs. 39%

2. Epilepsy Type

Respondents affected by **complex epilepsy** were more likely than those affected by **non-complex epilepsy** to report the need for:

- easier access to healthcare services or doctors and nurses who treat epilepsy
  66% vs. 55%
- healthcare that addresses their own specific needs (e.g., having a personal care plan)
  47% vs. 37%
- help managing other health problems alongside their epilepsy (e.g., comorbidity)
  48% vs. 37%
- easier access to complex epilepsy services
  53% vs. 38%

3. Minority

Respondents from who identified as belonging to a **minority group** compared to those who did **not** were more likely to report the need for:

- ongoing access to epilepsy treatment (e.g., seizure medicines)
  53% vs. 38%
- healthcare that addresses their own specific needs (e.g., having a personal care plan)
  46% vs. 37%

4. Disability

Respondents who view **epilepsy as a disability** compared to **those who do not**, were more likely to report the need for:

- help managing other health problems alongside their epilepsy (e.g., comorbidity)
  47% vs. 32%

Interview Themes That Emerged

THEME 3: CHALLENGES IN NAVIGATING INACCESSIBLE SYSTEMS	
Barriers to accessible healthcare	Barriers to accessing care and information, under-resourced healthcare services, and the economic impact of epilepsy.
Gaps in quality of care and support	Healthcare professionals knowledge and support, quality of medical practice, and treatment challenges.
THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES	
Access to epilepsy care	Barriers to accessing care and information, and quality of medical practice.
Cognitive, developmental, and emotional needs	Gaps in specialist medical support.
Burden of caregiving	Broader social and economic pressures (caregiver need).

Community Lived Experience Reflections

"This domain is deeply important because it touches on the exhaustion of navigating a system that often feels like it's designed to be difficult. These findings give a voice to that struggle, proving that we aren't just looking for a prescription; we are looking for a partnership in our long-term wellbeing."

JESSIE, **UK**

"Access to the right treatment is a problem in Australia. I feel that it is relatively easy to access epilepsy medications (pharmaceuticals). However, it is much more challenging to find services, doctors and nurses that can assist with other treatment such as surgery, diet therapy and neuromodulation. There is also a delay overall in accessing appointments even with general practitioners (GPs) with people waiting days to weeks. This wait is even longer for specialists. This also depends on whether you go through the public or private system."

MATISSE, **AUSTRALIA**

"From the start, I had to rely entirely on private healthcare to receive timely consultations and even then, waiting two to three weeks for a neurology appointment is the norm. I am not registered on any national epilepsy list, and no one ever informed me that such a thing existed. The medication prescribed to me was not available on the Albanian market, I source and purchase it from Greece, as I do not trust the quality of medications available locally. This is not a sustainable solution, and not everyone is in a position to do the same. To make matters worse, my private health insurance explicitly excludes epilepsy. Any cost related to my condition is entirely out of pocket. These are the everyday realities of living with epilepsy in a country where the condition is simply not adequately recognised or supported."

ELISA, **ALBANIA**

Policy Recommendations

Policy-makers should strengthen health systems to ensure equitable access to quality care and improved wellbeing for people with epilepsy through the following measures:

1. **Integrate epilepsy into primary healthcare within Universal Health Coverage (UHC) frameworks** to ensure equitable access to early diagnosis, treatment, and long-term management, and to reduce financial hardship.
2. **Strengthen the health workforce through training and task-sharing approaches**, equipping non-specialist providers to diagnose and manage epilepsy using evidence-based tools, particularly in resource-limited settings.
3. **Ensure reliable access to essential medicines** by strengthening procurement and supply chain systems, supported by health information systems to improve forecasting, availability and continuity of care.
4. **Establish clear, evidence-based care pathways** across all levels of the health system, including diagnosis, referral mechanisms, and structured transition of care, to improve care coordination and timely access to appropriate services.
5. **Promote comprehensive models of care that include psychosocial support**, ensuring access to services such as counselling alongside medical treatment to address the broader impacts of epilepsy on wellbeing.
6. **Expand access to specialist care** through regional centres of expertise and internationally networked specialist services, strengthening referral pathways and multidisciplinary collaboration to improve management of complex epilepsy cases.
7. **Advance equitable digital innovation** in epilepsy care through interoperable electronic health records, clinical data registries, telehealth, and responsible AI-enabled tools, ensuring global equity in access, data sharing, and quality of care.

Best Practice Examples

Kiserem Epilepsy Foundation

KENYA

Train the Trainer Project

RATIONALE & APPROACH

Many people with epilepsy purchase medication over-the-counter without proper diagnosis or guidance. Others experience severe side effects from medications, often because treatment is not properly monitored by qualified healthcare professionals. Most women are not given adequate counselling on safe anti-seizure medications during pregnancy, which can increase the risk of miscarriages and complications. To address this, the Kiserem Foundation organised medical camps where doctors provided consultations and engaged with patient groups and community members to educate them about epilepsy, side effects of anti-seizure medications, and sexual and reproductive health, while an EEG specialist assessed patients and supported proper diagnosis.

OUTCOMES & IMPACT

Over 1 year, 50 community health promoters were trained, 100 people received antiseizure medication, 40 EEGs were conducted, and 400 people were taught about epilepsy. As a result, the project improved community awareness, access to specialist care, proper diagnosis, safer medication guidance, understanding of treatment effects, and information on reproductive health.

Japan Epilepsy Association

JAPAN

Free Epilepsy Consultation Dial-in

RATIONALE & APPROACH

In Japan, there is a lack of nationwide consultation windows outside of outpatient clinical visits. To address this, the Free Epilepsy Consultation Dial-in expanded its service from a once-a-week window run by association officers to a three-day-a-week service delivered by specialists. The consultation window was established at the organisation's founding, with a free regular service finalised in the 2000s.

OUTCOMES & IMPACT

The expanded service now supports 1,000 annual consultations and has contributed to consultant skill improvement, increased referrals to specialised institutions, and the provision of learning opportunities. Further expansion to five days a week and inclusion of web-based and online training are planned.

Learning & Education

This domain explored the needs of people with epilepsy within education and training settings.

It focused on reducing stigma, improving awareness among teachers and staff, ensuring reasonable adjustments and inclusive learning environments, and strengthening legal and policy protections to support equitable access to education.

> *"There is no general protocol for emergencies where some children in an educational institution would be given medicine to stop a seizure."*
>
> **CROATIA**

> *"She wants to become like everyone else. She wants to be active like others. She wants to work and do a job like my sister, brother and other girls of my age. But she can't do much. She only has to do this. She had to drop out of school in class 10th as she started having more seizures. She has completed class 9th but for the job an individual should have completed 10th or 12th class. There are no jobs in the market, not even a peon for someone who has only completed class 8th."*
>
> **INDIA**

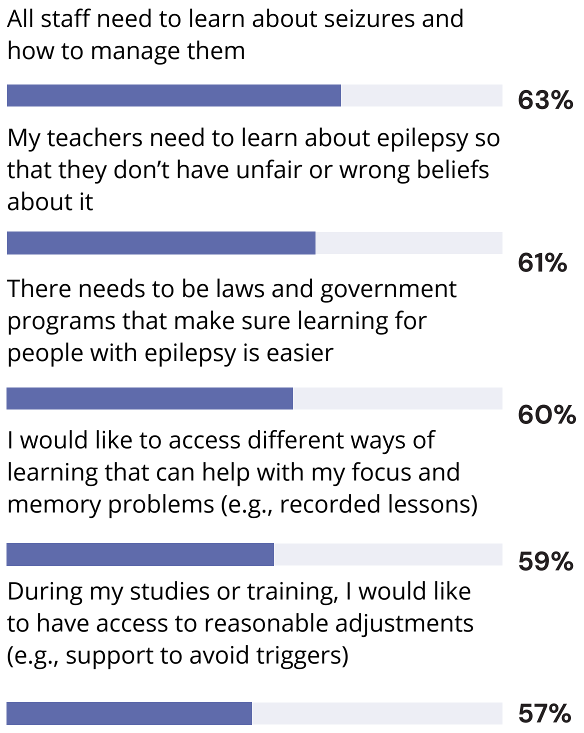
> *"Most importantly, other than medication is access to education. The government should help those living with epilepsy to have equal opportunity to education as any other child this is very important and is my concern. I will be very happy if my children can go to school online."*
>
> **THE GAMBIA**

Learning & Education

Through survey routing, only those currently attending or planning to attend formal education selected needs in this domain, which was:

37% of respondents (n=1980)

Top 5 Most Frequently Selected Needs



Key Survey Insights

1. Income

Respondents from low-income countries were more likely than those from middle-income and high-income countries to report the need for:

- teachers to learn about epilepsy so that they do not hold unfair beliefs
  78% vs. 59% vs. 60%
- being free from stigma and negative attitudes from fellow students
  80% vs. 44% vs. 46%
- feeling more included in the learning setting (e.g., teachers letting all students know that differences are normal)
  77% vs. 44% vs. 40%

Interview Themes That Emerged

THEME 2: LIVING WITH RISK, SOCIAL EXCLUSION AND REDEFINING EVERYDAY LIFE

Barriers to personal growth and development	Missed opportunities for learning and career development.

THEME 3: CHALLENGES IN NAVIGATING INACCESSIBLE SYSTEMS

Barriers to equitable education	Equitable access to education, lack of institutional support, limited awareness and stigma in education settings, and the need for reasonable adjustments.

Community Lived Experience Reflections

> *“Lack of awareness, fear, and absence of clear protocols can lead to exclusion, overprotection, or decisions that limit a child or young person’s educational development. This affects not only learning, but also self-esteem, socialisation, and future opportunities. This is why this domain is key: education is not only a right, but a fundamental driver of inclusion and long-term development for people with epilepsy.”*
>
> ELVIRA, **SPAIN**

> *“For those of us who navigated the education system with epilepsy, these findings really hit home. Academia is not built for complex conditions. I have experienced challenges at all levels. This domain is really important as it has the ability to dictate future opportunities.”*
>
> JESSIE, **UK**

> *“I fully agree with the first need, ‘All staff need to learn seizures and how to manage them’. I do believe that teachers need to have a broader understanding of epilepsy, including the impacts it can have on learning and education, for example memory, fatigue and comprehension. It can sometimes feel like pulling teeth to get adjustments.”*
>
> MATISSE, **AUSTRALIA**

> *“My lived experience with epilepsy has shown me how deeply stigma affects people in everyday settings, especially in schools. In some cases, teachers lack understanding and respond with discrimination, labelling learners as “mad” or “stupid,” and even encouraging other students to laugh at them. I have witnessed a child having daily seizures being punished instead of supported, which deeply affected me and required intervention. These experiences highlight the urgent need for teacher training and awareness on epilepsy. This domain is important to me because education settings should be safe and supportive, not places where stigma and misunderstanding cause further harm.”*
>
> FRED, **KENYA**

Policy Recommendations

Policy-makers should take coordinated action to promote the inclusion of people with epilepsy in education through the following measures:

1. **Strengthen legal and policy frameworks** to prohibit discrimination and ensure equal access to education and work, in line with international human rights standards, including the UN Convention on the Rights of Persons with Disabilities.
2. **Mandate reasonable accommodations across educational and workplace settings** to support full participation, including flexible approaches that address health, cognitive and environmental needs; and offer grants or incentives to support educators.
3. **Establish minimum standards for safe and supportive learning environments,** including seizure first-aid preparedness, clear protocols for the administration of rescue medications where appropriate, and risk reduction measures.
4. **Integrate epilepsy into national education and health policies,** promoting coordinated, cross-sectoral approaches to support inclusion across the life course.
5. **Ensure access to effective accountability and redress mechanisms** to address discrimination and exclusion in education settings.

Best Practice Examples

Epilepsy Ireland
IRELAND

Reasonable Accommodations

RATIONALE & APPROACH	Prior to 2023, young people in Ireland who experienced a seizure during their state exam could not access a resit within the same exam cycle and instead had to wait until the following year. This longstanding issue was addressed through sustained advocacy between 2021–2023, including meetings with policymakers and Ministers, submitting parliamentary questions, and sharing stories through media and social media.
OUTCOMES & IMPACT	The advocacy resulted in the establishment of a new deferred exam system so that students experiencing a medical emergency during exams, including seizures, can now apply for a deferred sitting within the same exam cycle.

FundHemi
ARGENTINA

Salud cerebral y epilepsia (Brain Health and Epilepsy Program)

RATIONALE & APPROACH	The program was developed to educate adolescents in their final year of pre-university education on core concepts of brain health and epilepsy through interactive, evidence-based learning. Conceived as a long-term public health investment, the program is structured as a 10-year capacity-building strategy. The aim is to provide accurate information, reduce stigma, and foster more inclusive educational communities. The program implemented interactive educational workshops on brain health, epilepsy, seizure first aid, and stigma reduction, in partnership with 5 Argentine universities, more than 15 pre-university schools, and the Argentine ILAE chapter. It also engaged university authorities, educators, health professionals, patient organisations, and local public institutions.
OUTCOMES & IMPACT	More than 1,600 adolescents were trained across multiple provinces, with formal arrangements established with 3 universities, with further expansion planned. The project identified the baseline knowledge gap - that 53% of students had never previously received information about epilepsy. Following the training, 97% answered correctly on seizure first aid, 94% reported improved understanding and skills. The program also contributed to a significant reduction in misconceptions related to employability, participation in sports, and social integration for people living with epilepsy.

Work & Income

This domain explored employment and financial security needs of people with epilepsy.

It focused on workplace adjustments, inclusion, protection from stigma and discrimination, job security and career progression, as well as supportive laws, policies, and stable income to promote economic independence.

> *"Epilepsy excludes you from many public job competitions...in every competition for police positions, when you look at the list of medical conditions that disqualify candidates, epilepsy is almost always one of the first on the list under nervous system disorders...there isn't the same kind of inclusion policy that I see in other countries."*
>
> **BRAZIL**

> *"Even by my former boss. I can see that he did not count the work I did on an equal footing with others. I wasn't allowed to use the skills that I actually had. I was quickly broken down and told that you can't. There were things like that."*
>
> **DENMARK**

> *"I have lower vitality because of the seizures my energy levels are lower than I'd typically expected to be. My ability to work is significantly reduced because of having epilepsy. I'm a barber but still I don't get as much work as I would have if I didn't have the condition."*
>
> **UGANDA**

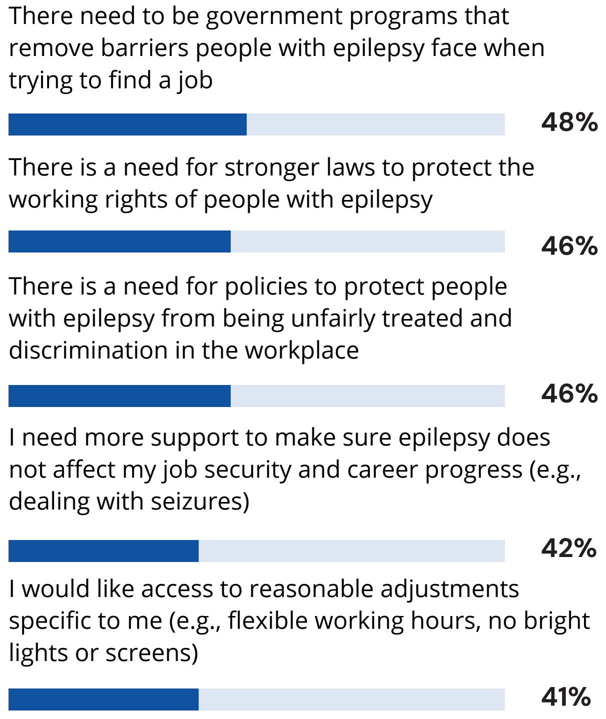
Work & Income

Through survey routing, only those currently working or seeking employment selected needs in this domain, which was:

53% of respondents (n=2816)

13% were unable to work due to disability

Top 5 Most Frequently Selected Needs



Key Survey Insights

1. Income

Respondents from low–income countries were more likely than those from middle–income and high–income countries to report the need for:

- feeling more included in the workplace and be able to build relationships
  55% vs. 24% vs. 19%

2. Disability

Respondents who view epilepsy as a disability compared to those who do not, were more likely to report the need for:

- a stable income and learning how to manage their money so they can better provide for themselves
  45% vs. 34%

Interview Themes That Emerged

THEME 2: LIVING WITH RISK, SOCIAL EXCLUSION, AND MISUNDERSTANDING	
Barriers to personal growth and development	Missed opportunities for learning and career development.

THEME 3: CHALLENGES IN NAVIGATING INACCESSIBLE SYSTEMS	
Structural barriers to employment and retention	Barriers to employment for people living with epilepsy.
Everyday challenges of epilepsy in the workplace	Disclosure dilemmas, impact of epilepsy on work performance, workplace pressures related to epilepsy management, and workplace stigma and misconceptions.

Community Lived Experience Reflections

“*I have also chosen not to disclose my condition to my manager, as I do not want to be seen or treated differently. That in itself says something about the environment many of us navigate quietly every day. In Albania, remote work remains largely unavailable in most companies, which is a real barrier. Workplace flexibility is not a luxury for people with epilepsy, it is a practical necessity.*”

ELISA, **ALBANIA**

“*My lived experience with epilepsy has deeply affected my employment and financial security. I previously worked as a chef, but I had to change my career and working environment to better manage my condition. Epilepsy often influences how employers and colleagues perceive you, and at times, people treat you with pity rather than respect. This can limit opportunities for growth, independence, and career progression.*”

FRED, **KENYA**

“*Workplace disclosure remains one of the greatest challenges for people with epilepsy, as it frequently leads to bullying or the threat of being fired. When a company understands epilepsy, the ‘risk’ disappears and is replaced by informed support. We must bridge the gap between labor rights and medical reality, ensuring that no professional has to choose between their health and their livelihood due to a lack of employer education.*”

IVANA, **ARGENTINA**

Policy Recommendations

Policy-makers should take coordinated action to promote the inclusion of people with epilepsy in employment through the following measures:

1. **Strengthen legal and policy frameworks** to prohibit discrimination and ensure equal access to employment, in line with international human rights standards, including the UN Convention on the Rights of Persons with Disabilities.
2. **Mandate reasonable accommodations across workplace settings** to support full participation, including flexible approaches that address health, cognitive, and environmental needs, and offer grants or incentives to support employers.
3. **Establish minimum standards for safe and supportive workplaces,** including seizure first-aid preparedness and risk reduction measures.
4. **Integrate epilepsy into national labour and health policies,** promoting coordinated, cross-sectoral approaches to support inclusion across the life course.
5. **Ensure access to effective accountability and redress mechanisms** to address discrimination and exclusion in employment.
6. **Promote economic inclusion through social protection and inclusive workforce strategies,** particularly for individuals facing barriers to sustained participation.

Best Practice Examples

Fundación Ivo Josue
PARAGUAY
Emprendedores Púrpura (Purple Entrepreneurs)

RATIONALE & APPROACH	Caregivers of people living with refractory epilepsy frequently experience financial instability due to loss of employment and difficulties generating income to fund treatment. To address this, the project trained 20 participants, selected through a free call for applications for adult caregivers of PWE, either running a subsistence business or planning to start one in the short term. Between March and June 2025, participants attended weekly face-to-face training sessions covering digital sales, branding, social media management, customer service, business models, leadership, stock management, and basic finance. In partnership with Fundación Paraguaya, the project also implemented the ‘Poverty Stoplight’ methodology to identify areas of multidimensional poverty requiring support, with participants focusing on savings, household budgeting, and diversified income, while simultaneously developing business plans and professional branding for their businesses.
OUTCOMES & IMPACT	Of the 20 participants enrolled, 10 completed the program and improved their skills in savings, household budgeting, and diversified income. Some participants also worked on additional indicators including public sector advocacy and community participation. Ten participants launched businesses using smartphones provided as seed capital, created professional social media profiles, and are now generating income from home.

Epilepsy Foundation
UNITED STATES OF AMERICA
Course: Successful Strategies for Navigating the Workplace as A Person with Epilepsy or As an Employer

RATIONALE & APPROACH	People with epilepsy continue to face barriers in employment, including stigma, discrimination, lack of workplace understanding, and uncertainty around disclosure and reasonable accommodations. To address this, the Epilepsy Foundation developed an accessible online course to provide practical resources, information, and strategies for navigating the workplace as a person with epilepsy or as an employer.
OUTCOMES & IMPACT	The certified course includes three online modules covering the reasonable accommodation process, disclosure during the pre- and post-offer hiring phases, qualification standards related to safe performance, and return-to-work issues. With no prerequisites, the course is accessible to anyone seeking to better understand employment rights, workplace inclusion, and strategies for supporting people living with epilepsy in the workplace.

Transport & Driving

This domain explored the transport and mobility needs of people with epilepsy

It focused on accessible and affordable travel options, safety and preparedness on public transport, training for transport staff, and reducing barriers - such as driving restrictions - that limit independence and access.

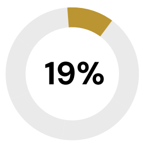
> *"I found it very limiting when I first was acquired by epilepsy that I lost my driver's license immediately. So after 60 years on the road, suddenly you're walking and immediately cuts down your range of where you can go. What is the part that you don't like about it? And for me, that was the biggest down. Down issue was the fact I lost my driver's license last Monday. Lost my independence, my mobility and again after 60 years of driving at will anywhere kind of saying it really hit me like a hammer blow."*
>
> **CANADA**

> *"Unfortunately, there aren't many conveniences available regarding transportation. While some buses have ramps, they aren't present in all buses or at all stops. Additionally, marked parking spaces exist but are often disrespected by others."*
>
> **BOSNIA & HERZEGOVINA**

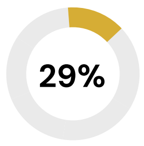
> *"To facilitate our transportation, whether it was to attend her medical appointments or to take her out for a walk, we tried to buy a car for this purpose because our transportation is tiring and exhausting, given that I cannot carry her and wait for a long time on the side of the road until I find a bus or a taxi."*
>
> **TUNISIA**

Transport & Driving

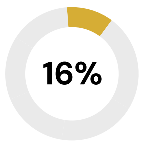
Below are self-reported findings on the availability of transport options for people with epilepsy:



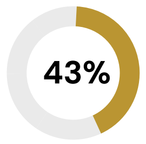
Specialised transport services (i.e., specifically for people with more transport needs or people with epilepsy)



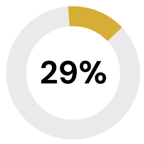
Public transport with general adjustments (e.g., special measures for people with disabilities or epilepsy, free public transport)



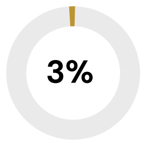
Private services with trained drivers (e.g., where drivers are trained in seizure first-aid)



Only standard public transport options without any adjustments (i.e., no special safety measures for people with disabilities or epilepsy)



I don't know



Other

Top 5 Most Frequently Selected Needs

There is a need for more support and plans in case people have a seizure on public transport — **49%**

Public transport workers need training to support people with epilepsy (e.g., spotting seizures, giving first aid, etc.) — **48%**

There needs to be safe travel options that people with epilepsy can afford — **40%**

I would like public transport to be easier for me to access (e.g., through special fares, lifts, ramps etc.) — **33%**

Driving restrictions on people with epilepsy in my country limit my independence — **30%**

Key Survey Insights

1. Location

Respondents living in **rural areas** were more likely than those living in **suburban** or **urban areas** to report the need for:

- support to travel to work and earn a living
  33% vs. 27% vs. 25%

2. Disability

Respondents who view **epilepsy as a disability** compared to **those who do not**, were more likely to report the need for:

- public transport to be easier access (e.g., through special fares, lifts, ramps etc.)
  39% vs. 28%

Overall, people with epilepsy selected fewer needs than caregivers, but were more likely to report that driving restrictions limit their independence (PWE: 34% vs. Caregivers: 24%).

Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING EVERYDAY LIFE	
Barriers to everyday roles and recreation	Limited freedom of travel.
THEME 3: CHALLENGES IN NAVIGATING INACCESSIBLE SYSTEMS	
Health related mobility challenges	Driving restrictions due to diagnosis, physical strain of travelling, and safety concerns when using public transport.
Transport accessibility and infrastructure gaps	Bureaucratic hurdles in accessing transport support, cost barriers to transport services, and inadequate accessible transportation infrastructure.
THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES	
Burden of caregiving	Gaps in social support systems.

Community Lived Experience Reflections

> *"For over ten years, my wife has been responsible for driving, which makes me feel apologetic. Driving and operating large machinery can be tied to a sense of masculinity, and losing that can create feelings of loss. Additionally, since I have not disclosed my condition, I must avoid situations where driving is required at work, which creates a sense of guilt."*
>
> KYOHEI, **JAPAN**

> *"My family and I were afraid of the moment when I would have to travel alone on public transportation and might have a seizure without receiving the support I needed. For that reason, I only learned to use public transportation when I was 17, but I always felt insecure and fearful of what could happen if I had a seizure. I was always aware that, because of my condition, I would not be able to drive, so it was only after epilepsy surgery that I began driving a vehicle at the age of 28. It would have been very useful and reassuring for me and my family if public transportation services had been adapted for people with health conditions requiring special care, if drivers had basic first aid training for seizures, and if people in general were capable of helping someone when needed."*
>
> CAROLINA, **COLOMBIA**

Policy Recommendations

Policy-makers should take coordinated action to improve safety, accessibility, and inclusion in transport systems for people with epilepsy through the following measures:

1. **Mandate seizure first-aid training for transport personnel and establish standardized emergency protocols,** ensuring drivers, station staff and security personnel can recognise seizures and provide immediate, appropriate response in vehicles and transport hubs.
2. **Strengthen public transport safety and accessibility standards,** including physical accessibility measures and clear passenger information systems, to ensure inclusive and safe use of transport services for people with neurological conditions such as epilepsy.
3. **Integrate brain health and seizure safety into transport planning and operations,** embedding risk reduction considerations into transport safety management and broader urban infrastructure design.
4. **Ensure transport affordability and equitable access through social protection measures,** including subsidies or concessions for people with epilepsy where needed to support mobility and participation.
5. **Modernize driving laws using evidence-based, person-centred approaches,** replacing blanket restrictions with clinical assessments that support autonomy when seizures are appropriately controlled.

Best Practice Examples

FundHemi
ARGENTINA

Epilepsy Travel by Bus & Train

RATIONALE & APPROACH	The primary goal of the campaign was to educate the general public and transport workers on safe seizure response using simple and accessible messaging. Delivered through video across public transportation in Rosario, the initiative provided a step-by-step seizure response guide while addressing stigma, myths, and misinformation about epilepsy. The project was developed in collaboration with local authorities, patient organisations, the Municipal Mobility Authority, Transport Secretariat, and City Council, and was supported by GENS data.
OUTCOMES & IMPACT	Over the four-month implementation period, the campaign reached more than 450,000 public transport users, representing a large proportion of the city's population. The initiative increased awareness of seizure first aid and epilepsy across Rosario.

Indian Epilepsy Association
INDIA

Revision of Driving Licence Regulations for Persons with Epilepsy

RATIONALE & APPROACH	In India, under the Motor Vehicles Act of 1939, individuals with epilepsy are disqualified from obtaining a driving license if they have experienced even a single seizure. This project was undertaken to revise these blanket restrictions and align regulations with current medical evidence and international best practices that permit driving after defined seizure-free periods while maintaining road safety. A dedicated task force led sustained advocacy efforts with policymakers, transport authorities, health ministry officials, neurologists, regulatory bodies, and patient representatives to develop and submit evidence-based medical recommendations.
OUTCOMES & IMPACT	Advocacy efforts began in October 2024, with an expert committee finalising revisions to the medical certification process in 2025. Ongoing follow-up for final approval and implementation continues. The revised framework enables individuals with well-controlled epilepsy to obtain private driving licenses under defined medical criteria, improving independence while maintaining safety.

Community & Household

This domain explored the social inclusion needs and rights of people with epilepsy.

It focused on feeling welcomed and supported in the community, safe participation in social and family life, confidence in disclosing epilepsy, protection of rights, and access to legal protections and support if treated unfairly.

> *"I had a boyfriend when I was about 21 or 22 and his mother was bothered by my epilepsy and we broke up."*
>
> **CROATIA**

> *"They dare not make friends or fall in love like normal people, always worrying that others will despise them once they know about their condition. They end up isolating themselves day by day, becoming more and more introverted and less confident."*
>
> **CHINA**

> *"Some years ago I came across of a support group and the support group provide assistance to all kinds of patients not only epilepsy but any other condition, but that did not last long and their procedures are so tedious we could not proceed with that. I also came to find out that that support group is helping themselves more than the patient."*
>
> **THE GAMBIA**

Community & Household

Top 5 Most Frequently Selected Needs

Need	%
My country needs to protect the rights of people with epilepsy	53%
Social events need to avoid epilepsy triggers and make sure people who can give seizure first-aid are available	43%
I need better legal support when being unfairly treated or harmed because of my epilepsy	37%
I would like to feel welcomed when connecting with others in my community	32%
I need advice on how, who and when to confidently tell others about my epilepsy	30%

Key Survey Insights

1. Location

Respondents living in rural areas were more likely than those living in suburban or urban areas to report the need for:

- their country to protect the rights of people with epilepsy
  59% vs. 54% vs. 50%

2. Disability

Respondents who view epilepsy as a disability compared to those who do no were more likely to report the need for:

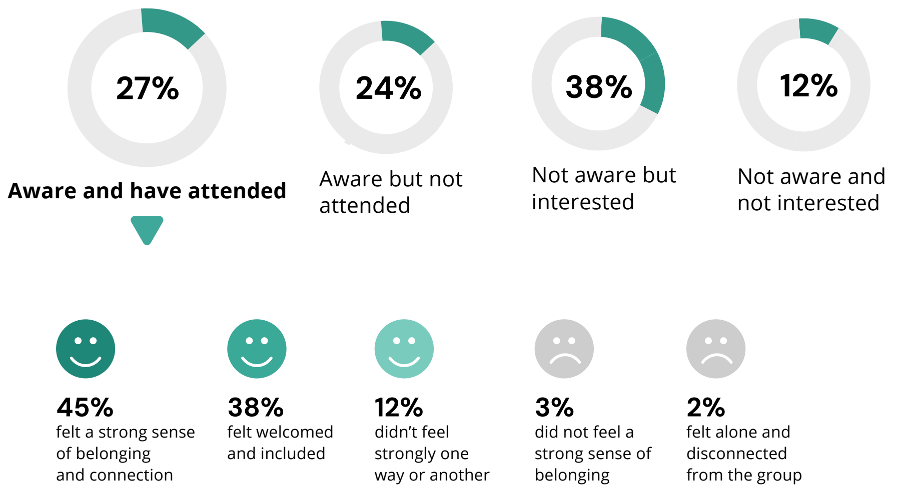
- feeling well enough to help with household chores
  29% vs. 21%

3. Income

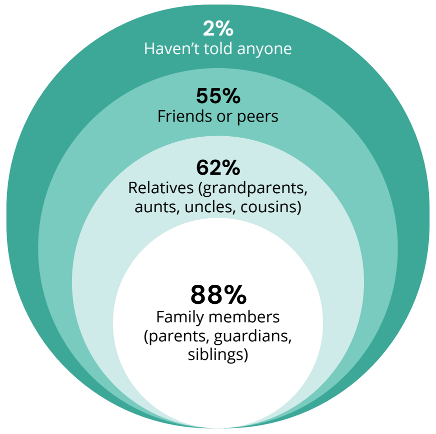
Respondents from low-income countries were more likely than those from middle-income and high-income countries to report the need for:

- feeling more included in the workplace and be able to build relationships
  77% vs. 60% vs. 39%

Awareness of epilepsy support groups:



Epilepsy disclosure:



Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING EVERYDAY LIFE	
Barriers to everyday roles and recreation	Barriers to recreational activities and constraints on household chores.
THEME 2: LIVING WITH RISK, SOCIAL EXCLUSION, AND MISUNDERSTANDING	
Intimacy and romantic relationships	Strains and shifts in existing relationships, and romantic rejection and barriers to future partnerships.
Barriers to personal growth and development	Loss of autonomy and daily independence, erosion of social participation, and gaps in inclusion and support systems.
THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES	
Burden of caregiving	Gaps in social support systems, and strain on family relationships and wellbeing (caregiver need)

Community Lived Experience Reflections

> *“My parents, possibly due to their rural background, strongly feared stigma and raised me to hide my condition. This contributed significantly to stigma formation. I hope for the development of social events where patients, families, healthcare providers, and caregivers can come together as a unified community.”*
>
> KYOHEI, **JAPAN**

> *“In my particular case, since I was a shy and somewhat insecure person, I related better to a few people who made me feel calm and safe, rather than getting involved with larger groups...Fortunately, I never felt discrimination in my educational environment, but I personally felt very nervous whenever I sensed a seizure coming, because I was embarrassed that people would notice. For anyone, the sense of belonging to a group is very important, but for someone with a medical condition it is even more relevant, since it is more difficult for them to fit into society.”*
>
> CAROLINA, **COLOMBIA**

Policy Recommendations

The policy recommendations for this domain mirror the cross-cutting recommendations found on pages 8-9. Policymakers must work to make everyday life safer, fairer, and more inclusive for people with epilepsy by ensuring meaningful engagement of people with lived experience in policy-making, increasing epilepsy awareness, promoting and protecting human rights, and working to:

1. **Promote inclusive policies** that enable independent living and community participation while ensuring tailored supports are available for those who require additional assistance.
2. **Strengthen access to social protection systems,** including disability benefits, carers’ allowances, social housing, and formal home care supports, to ensure adequate income security and independent living for people with epilepsy (and their caregivers), where needed.
3. **Remove discriminatory barriers** in financial and insurance systems to ensure people with epilepsy can equitably access financial products including mortgages, life insurance, and other essential services, where appropriate.
4. **Reduce geographical inequities** in access to epilepsy care and support by addressing regional disparities (“postcode lottery”) through standardised service provision, resource allocation, and national service planning.

Best Practice Examples

Kenya Association for the Welfare of Epilepsy (KAWE)

KENYA

The Curse of Epilepsy Stigma – Stigma Benches

RATIONALE & APPROACH

This project was undertaken to address stigma surrounding epilepsy in Kenya. The project created safe open spaces where participants could share personal experiences and challenges related to epilepsy and identify local solutions to locally identified issues. The sessions explored cultural myths, misconceptions, and stigma related to epilepsy in the community, alongside discussions on action planning and seizure first aid demonstrations. A Stigma Toolkit training session also covered the impact of stigma on families, traditional beliefs, psychosocial support, contact-based interventions, and multisectoral approaches.

OUTCOMES & IMPACT

Over one year, the project helped communities better understand how epilepsy is often perceived as a curse linked to witchcraft or possession, supporting improved awareness and education around epilepsy.

Tanzania Epilepsy Association

TANZANIA

Speaking Up, Standing Strong: Epilepsy Rights Project

RATIONALE & APPROACH

Despite existing legal and policy frameworks in Tanzania, persons with epilepsy and care-givers face stigma & discrimination - gender-based violence (GBV)- due to low legal literacy and self-advocacy skills. This means many are unable to access protections, government support, or effectively challenge injustice. To address this, the project conducted a four-day hybrid Training of Trainers workshop bringing together persons with epilepsy, caregivers, government officials, health practitioners, human rights organisations, and community advocates to strengthen legal literacy, self-advocacy, and GBV prevention skills. Through structured sessions on disability rights laws, Section 37A of the Local Government Finance Act (CAP 290), community mobilisation, and survivor-centred GBV response, participants were equipped with practical tools and training manuals to replicate learning at the grassroots level.

OUTCOMES & IMPACT

Over one year, the project established a certified cohort of 45 community trainers and initiated local-level trainings in Tanga, Dar es Salaam, and coastal regions. It strengthened grassroots advocacy, increased access to legal aid and government support mechanisms, and created a sustainable, community-led protection network.

Mental Health & Wellbeing

This domain explored the mental health and emotional wellbeing needs of people with epilepsy.

It focused on access to affordable, epilepsy specific mental health care, better coordination between epilepsy and mental health services, support for cognitive challenges, and tools to manage emotions, stress, isolation, and overall self-care.

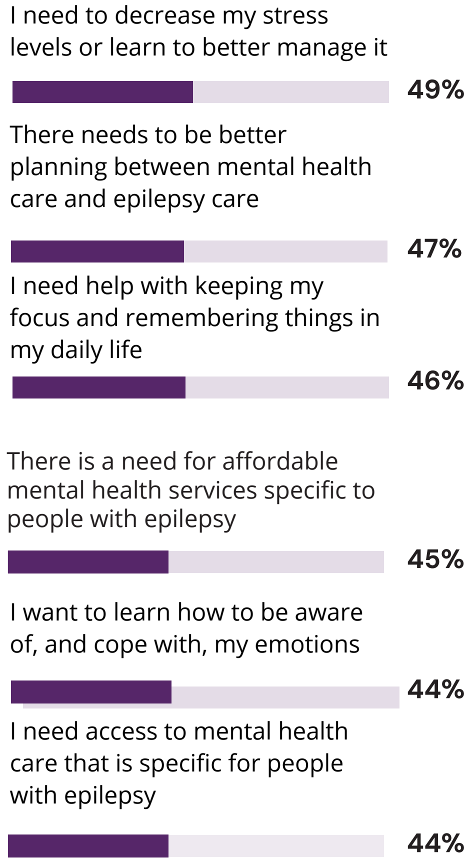
> *"I was not referred for a psychiatrist by my neurologist despite the fact that I had shown symptoms of depression but it was my family who supported me and who demanded that I see a psychiatrist but late in life, I had already ruined my married life."*
>
> **TUNISIA**

> *"Reducing stress would help me the most. For example, when I don't have many school obligations, I feel much better. Homework, studying, and other tasks create significant stress, and stress, as psychologists often say, acts as a "silent killer" that negatively impacts mental and overall health. There should be ways for people with epilepsy to better manage stress, as it greatly affects their condition and quality of life."*
>
> **BOSNIA AND HERZEGOVINA**

> *"Psychologically speaking what causes me the most problems is memory. I have to go, I will start going to a psychologist, to work on memory… have reached a point where it's a problem because they tell me things and I don't remember them. The important things, yes I can remember them, but the details, the small things, every day things like they told me to go get milk and I brought bread."*
>
> **SPAIN**

Mental Health & Wellbeing

Top 5 Most Frequently Selected Needs



I need to decrease my stress levels or learn to better manage it — 49%

There needs to be better planning between mental health care and epilepsy care — 47%

I need help with keeping my focus and remembering things in my daily life — 46%

There is a need for affordable mental health services specific to people with epilepsy — 45%

I want to learn how to be aware of, and cope with, my emotions — 44%

I need access to mental health care that is specific for people with epilepsy — 44%

Key Survey Insights

1. Sex

Female respondents were more likely than **male** to report the need for:

- access to mental health care that is specific to people with epilepsy
  47% vs. 40%
- better planning between mental health care and epilepsy care
  51% vs. 42%
- affordable mental health services specific to people with epilepsy
  48% vs. 41%
- support to learn how to be aware of, and cope with, their emotions
  48% vs. 39%
- support to cope with feelings of isolation and loneliness
  39% vs. 34%
- support to reduce stress levels or better manage stress
  53% vs. 44%

2. Minority

Respondents from who identified as belonging to a minority group compared to those who did not were more likely to report the need for:

- access to mental health care that is specific to people with epilepsy
  51% vs. 42%
- Better planning between mental health care and epilepsy care
  56% vs. 45%
- help with keeping focus and remembering things in daily life
  53% vs. 44%
- affordable mental health services specific to people with epilepsy
  52% vs. 43%
- support to learn how to be aware of, and cope with, their emotions
  50% vs. 42%
- support to cope with feelings of isolation and loneliness
  44% vs. 35%
- support to reduce stress levels or better manage stress
  54% vs. 48%
- learning about mindfulness and other self-care practices
  14% vs. 11%

Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING EVERYDAY LIFE

Emotional uncertainty and psychological strain	Emotional distress beyond seizures, emotional impact of stigma, and living with the unpredictability of seizures.

THEME 3: CHALLENGES IN NAVIGATING INACCESSIBLE SYSTEMS

Barriers to mental health support	Barriers to accessing support and coping strategies, and stress and environmental triggers.

THEME 4: CONSEQUENCES OF INACCESSIBLE OR INADEQUATE INFORMATION

Knowledge gaps in everyday and future planning	Feelings of fear and worry arising from knowledge gaps.

THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES

Cognitive, developmental, and emotional needs	Cognitive, developmental and extreme care needs, emotional and behavioural challenges, gaps in specialist medical support, and the need for psychosocial and emotional support.

Community Lived Experience Reflections

> *“From my experience, the emotional impact of epilepsy is profound and often invisible. There is a high prevalence of emotional difficulties and mental health conditions associated with epilepsy, which are often under-recognised and not adequately addressed in an integrated way. This reality affects not only the individual, but the entire family, creating a sustained emotional burden shaped by uncertainty, fear, and the need for constant adaptation. Yet mental health remains a secondary aspect in many care models, despite its direct impact on quality of life. This is why this domain is critical: epilepsy cannot be properly addressed without fully integrating the emotional and psychological dimension into care.”*
>
> KYOHEI, **JAPAN**

> *“The Mental Health & Wellbeing domain is very important to me because, for a long time, I did not even realise that mental health could be connected to epilepsy. It was never discussed in any of my consultations. While living alone during college, taking anti-epileptic medication (including one with anxiety and depression as known side effects), and navigating stigma in daily life, I experienced a significant emotional toll without understanding why. I did not initially link these changes to epilepsy or its treatment. It took time for me to recognise that this might be related to my condition. When I raised it with a neurologist, it was initially dismissed after basic checks, and I was told I did not have anxiety. I eventually had to advocate for myself, seek out information independently, access mental health support, and consult another neurologist who later adjusted my medication.”*
>
> AMEENA, **PAKISTAN**

> *“Stress is one of my seizure triggers so these findings are very important to me. I also know it is the most common seizure trigger for people with epilepsy so it’s very important that this information is being discussed.”*
>
> JESSICA, **USA**

Policy Recommendations

Policy-makers should strengthen mental health and wellbeing for people with epilepsy through integrated, rights based and cross-sectoral policy action:

1. **Integrate epilepsy into national mental health and NCD policies,** ensuring coordinated planning across conditions and addressing epilepsy alongside related psychosocial and cognitive impacts within a unified health strategy.
2. **Develop and implement national guidelines and integrated care pathways for epilepsy and mental health,** including clear referral systems across levels of care. In low- and middle-income countries, the WHO mhGAP Intervention Guide should be used to equip primary care providers with skills to identify and manage co-occurring mental, neurological and substance use conditions, supported by multidisciplinary collaboration between services.
3. **Strengthen national policies for cognitive and psychosocial well-being,** including the recognition of cognitive and behavioural comorbidities as a key public health priority and their inclusion in national epilepsy (or neurology) strategies.
4. **Ensure financial protection within Universal Health Coverage (UHC)** by including both epilepsy-related care and mental health support within benefits packages, and reducing out-of-pocket costs through targeted protection mechanisms.
5. **Enhance social protection frameworks to support wellbeing,** ensuring that benefits reflect the full costs associated with long-term neurological and mental health conditions, including indirect costs.

Best Practice Examples

Angelini Pharma & University of Oxford
UNITED KINGDOM

Brain Health Innovation Summit & subsequent publication

RATIONALE & APPROACH	This project was undertaken to advance the understanding of the relationship between epilepsy and psychiatric comorbidities. The Brain Health Innovation Summit brought together leading experts, researchers, clinicians, and advocates to discuss challenges and best practices around the identification and assessment of psychiatric comorbidities in patients with epilepsy, integrated-care models that address both epilepsy and psychiatric needs, and identify key areas for future research and knowledge gaps in the field. It took place from 7-9 October, 2024 in Rome, Italy.
OUTCOMES & IMPACT	This led to a publication in the British Journal of Psychiatry entitled *Epilepsy and mental health disorders: current challenges and potential solutions*. The publication has established new consensus standards for integrating psychiatric care into neurological practice, emphasizing that mental health screening should be a ‘standard of care’ for all epilepsy patients, and served as a primary source for the Headway 2025 Mental Health Index, influencing EU-level policy discussions regarding the economic and social benefits of treating epilepsy comorbidities.

Epilepsy Foundation India
INDIA

Mindful Seizure Management: Yoga & Wellness Initiative

RATIONALE & APPROACH	This project was undertaken to address anxiety, stress, mood disturbances, and cognitive concerns, which remain under-addressed and can worsen seizure frequency, reduce treatment adherence, and significantly affect quality of life. The project provided an affordable, structured, and evidence-informed yoga-based intervention aimed at improving emotional wellbeing, reducing stress related seizure triggers, and integrating mental health support into comprehensive epilepsy management. The program emphasised breathing regulation, gentle postures, relaxation training, and mindfulness techniques tailored for individuals with epilepsy. It involved patients, caregivers, neurologists, EEG technicians, and rehabilitation professionals over one year.
OUTCOMES & IMPACT	Participants reported reduced stress, improved emotional regulation, better sleep quality, and enhanced confidence in managing their condition.

Sexual & Reproductive Health

This domain explored the sexual and reproductive health needs of people with epilepsy.

It focused on access to specialised care and information about the effects of epilepsy and its treatment on sexual health and parenthood, support in managing stigma in intimate relationships, and expert guidance to make informed decisions about becoming a parent.

> *“I thought if I passed epilepsy on to my child, I would be very guilty, so I thought I’d rather not have children.”*
>
> **SOUTH KOREA**

> *“If a pregnant woman has an epileptic seizure, can she lose her fetus or not? Does the medication have repercussions on fertility, especially on the fetus? Does the medication stop during pregnancy or not? All these questions were like a movie running in my head and I could not find an answer to them and could not ask them in front of anyone.”*
>
> **TUNISIA**

> *“The sexuality of such people is a complete taboo. Some of us parents talk about it, others don’t. I don’t know what will happen when she hits puberty, whether she will be immature or want to have a boyfriend. It’s not discussed at all. So far, I’ve found out a little about contraceptives, our association can’t finance rehabilitation educators specializing in sexuality. For example, if [name of daughter] takes progesterone, there are no side effects from her medications”*
>
> **CROATIA**

Sexual & Reproductive Health

Top 5 Most Frequently Selected Needs

There needs to be simple information for people with epilepsy who want to become parents (e.g., risks from epilepsy medicines) **36%**

I need advice on the effect of epilepsy medicine on my sexual health and plans to become a parent 29% **29%**

I want to learn how to manage stigma, linked to epilepsy, in intimate relationships **27%**

I need access to doctors and nurses specialized in sexual health and reproduction and epilepsy **26%**

I would like expert help to make the best choice about becoming a parent **25%**

Key Survey Insights

46% of respondents in this domain did not report any needs, and there were no statistically significant findings for this domain. Factors that may have contributed to this include: cultural taboo surrounding the topic and use of survey assistants, who captured survey responses orally, in some countries.

A **gendered lens** of the data:

Male	**51%**	reported at least one need
Female	**56%**	reported at least one need
Other	**53%**	reported at least one need

A **lifespan lens** of the data:

0–11 years	**31%**	reported at least one need
12–17 years	**46%**	reported at least one need
18–44 years	**69%**	reported at least one need
45+ years	**37%**	reported at least one need

0–11 years and 12–17 years → Survey filled in by caregivers of behalf of children with epilepsy

18–44 years → Among these, 46% reported a need for 'simple information for those who want to become parents'.

Reproductive age (15–49 years) [15]

Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING EVERYDAY LIFE

Parenthood, planning and uncertainty	Concerns around having children, and gaps in knowledge and support on sexual and reproductive health.

THEME 2: LIVING WITH RISK, SOCIAL EXCLUSION, AND MISUNDERSTANDING

Intimacy and romantic relationships	Sexual anxiety and loss of intimacy.

Community Lived Experience Reflections

> *"Stigma regarding sexual health remains a major obstacle for our community. Many people still harbor false beliefs about whether women with epilepsy can have healthy pregnancies or if men face fertility issues. We believe that comprehensive education on these topics is non-negotiable. Our goal must be to replace these myths with clear, accessible information, ensuring that sexual health and the right to a family are recognized as essential parts of living well with epilepsy ."*
>
> IVANA, **ARGENTINA**

> *"Discussions around epilepsy and reproductive health often focus on women, which is extremely important - but it is equally important to acknowledge that men with epilepsy can also experience reproductive health challenges related to treatment and long-term medication use. In my own experience, ASMs impacted my testosterone levels and during family planning I chose to use donor sperm as a practical and positive alternative rather than viewing it as a limitation. Reproductive health conversations in epilepsy should be inclusive of both women and men ensuring that individuals and families are informed and supported to make decisions best suited to their circumstances."*
>
> VIINAY, **INDIA**

Policy Recommendations

The policy recommendations for this domain mirror the cross-cutting recommendations found on pages 8-9. Policymakers should implement the following measures:

1. **Remove discriminatory laws and policies that restrict human rights,** including outdated provisions affecting marriage, parenthood, and autonomy in reproductive decision-making.
2. **Ensure training for healthcare workers** to provide non-discriminatory, accessible, and informed counselling and care
3. **Integrate epilepsy** into sexual, reproductive, maternal, and child health policies and practices.
4. **Establish coordinated care pathways** linking neurology, primary care, and sexual and reproductive health services across the life course.
5. **Include clear referral systems for timely specialist input** in complex cases, such as pregnancy and preconception care

Best Practice Examples

Epilepsy Ireland
IRELAND

The EpiKNOW Project

RATIONALE & APPROACH	This project was undertaken to identify information gaps for women with epilepsy in the preconception to postpartum period. It was delivered between 2023-2025 in partnership with subject matter experts, researchers, HCPs, women with epilepsy, and their family members.
OUTCOMES & IMPACT	EpiKNOW developed resources to support conversations between women with epilepsy and their Primary Care, Epilepsy Specialist, and Maternity Care teams. The resources include checklists covering fertility, contraception, pregnancy sickness, preparing for birth, birth plans, managing seizures postpartum, and much more. The project also produced a quality-ranked table of online resources available to women with epilepsy.

Epilepsy Action
UNITED KINGDOM

The Maternity Toolkit

RATIONALE & APPROACH	This project was undertaken to address the increased risks faced by women with epilepsy during pregnancy, including maternal death, and elevated rates of complications such as stillbirth, premature birth, and mental health conditions. Between 2024–2026, Epilepsy Action worked with people with lived experience and healthcare professionals to identify barriers including limited professional knowledge, inconsistent resources, communication challenges, and variation in the adoption of national recommendations. The project co-produced a comprehensive pathway including a clinical guideline, benchmarking self-assessment, and audit tools.
OUTCOMES & IMPACT	The project developed resources to define and quantify best practice in maternity care for women with epilepsy and support providers to evaluate services and implement minimum care standards. All maternity care providers in the North West region of England completed the benchmarking tool, with national rollout now underway. The project also improved visibility of service quality and opportunities for improvement, and supported the creation of a new Epilepsy Specialist Midwife role in the North West region.

Achieving Life Goals

This domain explored the personal development and independent living needs of people with epilepsy.

It focused on building confidence, managing fear and anxiety about seizures, strengthening self-care and resilience, improving access to stable housing and reliable care, and developing skills to cope with stigma, and pursuing personal goals and ambitions.

> *"They dare not make friends or fall in love like normal people, always worrying that others will despise them once they know about their condition. They end up isolating themselves day by day, becoming more and more introverted and less confident."*
>
> CHINA

> *"I'm a little afraid of going somewhere alone...I really wanted to go to Japan in the winter, but now that I think about it, I'm a little scared...if I fall down on the street, can these people help me?... I don't think that's possible."*
>
> SOUTH KOREA

> *"My level of happiness has also significantly reduced because I don't interact in the community as much as I typically would if I didn't have epilepsy. For example, if I was to go for a function or event, I'd only stay there for two or three hours before leaving for home. I'd be worried that I'd need to get back home safely before I get a seizure. On leaving I'd be told of all these stories about all the fun that happened in my absence leaving me quite depressed at the whole experience. Epilepsy greatly limits my ability to interact comfortably within the community for fear of getting seizures... I am a bit sensitive or insecure because my earlier experiences and the condition..."*
>
> UGANDA

Achieving Life Goals

Top 5 Most Frequently Selected Needs

I need support to manage my fear and anxiety about seizures

44%

There is a need for programs and support to improve confidence and achieve personal goals and dreams

40%

I need reliable access to epilepsy care for my overall happiness and daily life to improve

38%

I feel I need more time and support than others to be able to reach my goals and ambitions

37%

I need to learn how to identify, handle and/or protect myself from stigma around epilepsy that exists in my country

36%

Key Survey Insights

1. Disability

Respondents who view epilepsy as a disability compared to those who do not were more likely to report the need for:

- reliable access to epilepsy care in order to improve their overall happiness and daily life

45% vs. 32%

2. Location

Respondents living in rural areas were more likely than those living in suburban or urban areas to report the need for:

- help managing fears and anxiety about seizures

46% vs. 43% vs. 43%

Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING EVERYDAY LIFE

Barriers to everyday roles and recreation	Limited freedom of travel, barriers to recreational activities, and constraints on household roles.

THEME 2: LIVING WITH RISK, SOCIAL EXCLUSION, AND MISUNDERSTANDING

Barriers to personal growth and development	Loss of autonomy and daily independence, missed opportunities for learning and career development, erosion of social participation, and gaps in inclusion and support systems.

THEME 5: COMPLEX EPILEPSY NEEDS DEMAND MORE THAN STANDARD APPROACHES

Burden of caregiving	Hopes, fears, and uncertainty about the future.

Community Lived Experience Reflections

> *"For me, epilepsy does not only affect health, but also how people envision their future. Fear of seizures, uncertainty, and external limitations can shape personal decisions, reducing expectations and influencing life goals. In many cases, people are not only managing a condition, but also rebuilding confidence and redefining what they believe is possible for themselves. This is why this domain is critical: the true impact of epilepsy is not only clinical, but lies in people's ability to live the life they choose."*
>
> ELVIRA, **SPAIN**

> *"My greatest fear is that my son will not be accepted for who he is—that he will not have the freedom to choose his own path, or that he will not find a place where he truly belongs. That there is not yet a society ready to protect him, embrace him, and support him. I have been living with this fear for 16 years. Epilepsy is not only about managing seizures; it is about whether a person will be able to build a life, to dream, to participate, and to be included without limitations imposed by stigma or lack of opportunity."*
>
> MARIA MARTA, **ARGENTINA**

Policy Recommendations

Achieving life goals requires coordinated action across all sectors. Our cross-cutting policy recommendations (see pages 8-9) are listed, again, below and must be implemented to ensure people with epilepsy can live their lives to the fullest:

1. **Strengthen human rights-based legal and policy frameworks,** to ensure non-discrimination, and offering recourse mechanisms when human rights are violated.
2. **Develop and implement national epilepsy plans and programmes,** and/or ensure epilepsy is integrated in national plans on neurology rare disease, NCDs, and all other relevant policies.
3. **Ensure meaningful involvement of people with lived experience of epilepsy**, in policy and program research and design, implementation and evaluation.
4. **Run nationwide epilepsy awareness campaigns** focused on stigma reduction and seizure safety; mandating mandating seizure first aid training for community gatekeepers (educators, employers, sports coaches, etc.).
5. **Support and resource national epilepsy and community-based organisations** to deliver services and support locally.
6. **Develop integrated, person-centred and cross-sectoral systems of care** across the life course; improving coordination between health, education, employment, transport, and social protection systems.
7. **Increase health workforce capacity in epilepsy care,** including integrated mental health and sexual and reproductive health care; leveraging innovation.
8. **Ensure continuous access to essential medicines and services,** particularly in times of conflict and crisis.
9. **Advance urban planning and design of the built environment,** to enhance safety, accessibility, and inclusion.
10. **Support evidence generation through intersectoral research funding,** support for innovative R&D, **and the creation of national registries, epidemiological data, socio-economic analyses, etc. to inform political prioritisation and action.**

Best Practice Examples

Epilepsy Action
UNITED KINGDOM

Self Advocacy Toolkit

RATIONALE & APPROACH

People living with epilepsy report a range of issues with their healthcare providers, such as poor communication, a lack of epilepsy knowledge, and key information not being shared. Epilepsy healthcare professionals have also stated that tangible resources would help them care for people affected by epilepsy more effectively. Between August 2025 - April 2026, Epilepsy Action partnered with self-advocacy charity Vital to create tools to empower PWE to advocate for their care more effectively, conducting focus groups with PWE, parents & caregivers, and surveying HCPs to identify themes needs for self-advocacy resources. A self-advocacy toolkit was created, containing tools on communication skills, preparing for appointments, topics to discuss with HCPs, discrimination, variations in treatment and care between devolved nations, and more.

OUTCOMES & IMPACT

Preliminary impact data show PWE developed self-advocacy skills and feel more in control of their condition & decisions, leading to reduced health inequalities. The project is also expected to support improvements in holistic support and quality of care.

Jazz Pharmaceuticals, UCB Pharma, E+A (Epilepsy+ Alliance – CREA Asbl) & International Bureau for Epilepsy

This project has been initiated and equally funded by Jazz Pharmaceuticals and UCB Pharma

Together for Lifelong Care – Championing Rights for Rare and COMPLEX Epilepsies

RATIONALE & APPROACH

Across Europe, many people living with rare and complex epilepsies face major challenges when transitioning from paediatric to adult care, often described as 'falling off a cliff' due to the loss of specialist expertise, multidisciplinary teams, and structured support. Led by the four partners, the project will develop and launch a Charter in 2026 defining the 'continuity of care rights' for people living with rare and complex epilepsies. The Charter is informed by research across 15 countries examining policies, care pathways, and best practice models, and guided by a 15-strong EU multidisciplinary Steering Committee with expertise in lived experience, healthcare, health economics, and health policy.

OUTCOMES & IMPACT

Following launch and national rollout by program 'Ambassadors', the Charter aims to help ensure that people living with rare and complex epilepsies receive the lifelong care they need and deserve. It could be used to start conversations with decision-makers, policymakers, and healthcare providers; highlight national gaps and challenges; and promote examples of good practice.

M-INT-EPL-2600015 Date of Prep May 2026.

Abbreviations and references

1. Baker GA, Bagga SK, Walsh D, Nolan C, Sharma S, Hooker C et al. The Global Epilepsy Needs Study (GENS): a mixed-methods, multi-country exploration of the unmet psychosocial and everyday needs of people with epilepsy. Epilepsia Open. 2025 Sep 12.
2. Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031. Geneva: World Health Organization; 2023 (https://www.who.int/publications/i/item/9789240076624). Licence: CC BY-NC-SA 3.0 IGO.
3. Sustainable Development Goals: 17 goals to transform our world. New York: United Nations; 2015 (https://sdgs.un.org/goals).
4. Political declaration of the fourth high-level meeting of the General Assembly on the prevention and control of non-communicable diseases. New York: United Nations; 2025 (https://docs.un.org/en/A/80/L.34).
5. Universal Declaration of Human Rights. New York: United Nations; 1948 (https://www.un.org/en/about-us/universal-declaration-of-human-rights).
6. Global status report on neurology. Geneva: World Health Organization; 2025 (https://www.who.int/publications/i/item/9789240116139). Licence: CC BY-NC-SA 3.0 IGO.
7. Improving the lives of people with epilepsy: a technical brief. Geneva: World Health Organization; 2022 (https://www.who.int/publications/i/item/9789240064072). Licence: CC BY-NC-SA 3.0 IGO.
8. Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, Engel Jr J, Forsgren L, French JA, Glynn M, Hesdorffer DC. ILAE official report: a practical clinical definition of epilepsy. Epilepsia. 2014 Apr;55(4):475-82.
9. Epilepsy. Geneva: World Health Organization; 2024 (https://www.who.int/news-room/fact-sheets/detail/epilepsy).
10. Global Campaign Against Epilepsy. International League Against Epilepsy (https://www.ilae.org/about-ilae/public-policy-and-advocacy/global-campaign-against-epilepsy).
11. World Health Assembly. Resolution WHA68.20: global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications. Geneva: World Health Organization; 2015 (https://www.ilae.org/files/dmfile/WHO-Epilepsy-2015.pdf).
12. Epilepsy: a public health imperative. Geneva: World Health Organization; 2019. (https://iris.who.int/handle/10665/325293). Licence: CC BY-NC-SA 3.0 IGO.
13. World Health Assembly. Resolution WHA73.10: global actions on epilepsy and other neurological disorders. Geneva: World Health Organization; 2020 (https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_R10-en.pdf).
14. Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit. Geneva: World Health Organization; 2024 (https://www.who.int/publications/i/item/9789240096356). Licence: CC BY-NC-SA 3.0 IGO.
15. Zeng G, Liu L, Wang Y, Yu J, Wang H, Li F. Global, regional, and national burden and trends of reproductive-aged male and female infertility from 1990–2021. Frontiers in Endocrinology. 2025 Sep 4;16:1506229.

Abbreviations

ASM: Anti-seizure Medication
DALYs: Disability Adjusted Life Years
EEG: Electroencephalogram
EU: European Union
GBV: Gender based Violence
GENS: Global Epilepsy Needs Study
GP: General practitioner
GT: Global Targets
HCP: Healthcare Professionals
IBE: International Bureau for Epilepsy
IGAP: Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders
ILAE: International League Against Epilepsy
KAP: Knowledge, attitudes, and practice
mhGAP: Mental Health Gap Action Programme
NCD: Non-communicable Disease
PWE: People with Epilepsy
R&D: Research & Development
REST: Rapid Early Seizure Termination
SO: Strategic Objectives
SUDEP: Sudden Unexpected Death in Epilepsy
UHC: Universal Health Coverage
UN: United Nations
WHA: World Health Assembly
WHO: World Health Organisation

Acknowledgements

GENS Policy Advocacy Editorial Board
This report would not have been possible without without the dedication and generosity of all those who contributed to its development. With sincere gratitude, we acknowledge following:
Ameena Aimen, Pakistan; Maria Marta Bertone, Argentina; Jessie Buckle, UK; Elisa Dibra, Albania; Ivana Garcia, Argentina, Ivana Gugić, Croatia; Fred Kiserem, Kenya; Carolina López, Colombia; Matisse McCullough, Australia; Bindu Menon, India; Pooja Mehta Nandi, India; Lecio Figueira Pinto, Spain; Kyohei Sawamura, Japan; Swastika Shrestha, Nepal

GENS Policy Advocacy Report Content & Design
Thank you to Shivani Sharma, Research & Insights Manager; and Niamh O'Neill, Communications Officer for your tireless work in preparing the content of this report.

We also acknowledge the IBE Community Council, IBE staff team and IBE chapters whose additions, feedback and reflections helped shape the GENS project and this report.

We extend our gratitude to the wider global epilepsy community for sharing their experiences and perspectives through the GENS study. Your voices continue to drive progress towards a better future for people with epilepsy worldwide.

Thank you to Elena Montes Casado for supporting report design.

During the preparation of this work, the author(s) used ChatGPT (V.5) to improve grammar and sentence clarity, and NotebookLM (Google) to assist in the summarization of policy literature. The author(s) reviewed, edited and verified all AI-generated suggestions and bear full responsibility for the final interpretation and presentation of the findings.

We also acknowledge the original GENS authors and collaborators, whose work laid the foundation for this report. Gus A. Baker, UK; Sandeep Kumar Bagga, UK; Donna Walsh, UK; Claire Nolan, UK; Shivani Sharma, UK; Charlotte Hooker, UK; Pepa Gonzalez Parrao, UK; Francesca Sofia, Italy; J. Helen Cross, UK; Ma. Marta Bertone, Argentina; Ivana García, Argentina; Adam Jallow Janneh, The Gambia; Alison Kukla, USA; Elvira Vacas Montero, Spain; Ding Ding, China; Latica Friedrich, Croatia; Lecio Figueira Pinto, Spain; Gagandeep Singh, India; Chahnez Charfi Triki, Tunisia; Leya Raj, Canada; Allan Reese, UK.

Naziya Anzari, India; Alicia Bogacz, Uruguay; Martin Brodie, Scotland, UK; Heather Brooks, Canada; Nicole Coulthard, Australia; Laura Dickson, Canada; Laura Maria de Figueiredo Ferreira Guilhoto, Brazil; Anchor Hung, Hong Kong SAR, China; John Nute Jabang, The Gambia; Boram Lee, Republic of Korea; Kheng-Seang Lim, Malaysia; Rebecca Lisle, UK; Anita Mago, Uganda; Sharon Mbugua, Kenya; Bindu Menon, India; Sarah Nekesa, Uganda; Youssouf Noormamode, Mauritius; Per Olesen, Denmark; Kris Pierce, Australia; Dzenana Rustempasic, Bosnia and Herzegovina; Jitendra K. Sahu, India; Ana Sruk, Croatia; Christa Studzinski, Canada; Nirmal Surya, India; Maria Alice Susemihl, Brazil; Laura Weidner, USA; Samuel Wiebe, Canada; Andrea Wilkinson, USA; Leonie Wollscheid, Germany; Ada Wong, Hong Kong SAR, China; Bernadette Zappa, Australia.

The following pharmaceutical companies have provided financial support to the development of Phase 1 of the Global Epilepsy Needs Study, through grants to the International Bureau for Epilepsy: Angelini Pharma, Jazz Pharmaceuticals, Takeda Pharmaceuticals, and UCB. These companies have had no editorial influence on this research article. Funds were used to contract the research consultancy (MediPaCe), cover project management fees (for IBE and its Chapters), reimburse contributors, support translation and dissemination costs, and offset other miscellaneous expenses.

For further information please contact:
info@ibe-epilepsy.org

GLOBAL EPILEPSY NEEDS STUDY
GENS

IBE
International Bureau
for Epilepsy