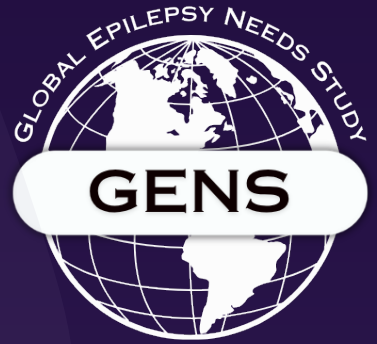


Global Epilepsy Needs Study



Policy Advocacy Report

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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 110 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 (WHO)'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 (ILAE), 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 programs 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 (PWE). 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 are targeted at 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 Leaders (GELs) program and driving meaningful engagement with our Lived Experience Project. We partner with ILAE to deliver international and regional congresses where speakers with lived experience are ensuring healthcare professionals (HCPs) are trained to address their real needs.

No single organization 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.



Francesca Sofia
DR FRANCESCA SOFIA
President, IBE

Structure of the Report

The Global Epilepsy Needs Study explored the priority needs of PWE across 10 domains of life [1]. This report has been developed by analyzing 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.

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 5 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. They were developed with input from IBE's Community Council, which brings together PWE and those who care for them from around the world to share lived-experience perspectives and advise on IBE's ongoing initiatives. Input was also provided by IBE's Regional Committees, representing national epilepsy organizations worldwide.

The recommendations are aligned with the targets of the WHO IGAP [2] and are 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 the quality of life for PWE 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 IBE launched GENS [1] to address a longstanding and critical gap in epilepsy research: the limited understanding of the psychosocial and everyday needs of PWE.

While epilepsy advocacy has advanced globally - evidenced by the unanimous adoption of WHO's 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-centered 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 selected needs emerged across 5 of the 10 life domains (refer to pages 8-9): Healthcare and Wellbeing, Safety and Survival, Knowledge and Advice, Community and Household, and Mental Health and Wellbeing. These findings highlight 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 PWE, 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 PWE and their families, presented on the next page.



5,296 people across 15 countries shared their lived experiences

5 major themes identified through GENS

	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 programs, and/or ensure epilepsy is integrated in national plans on neurology, rare disease, Non Communicable Diseases (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.

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.

4 

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.).

5 

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

9 

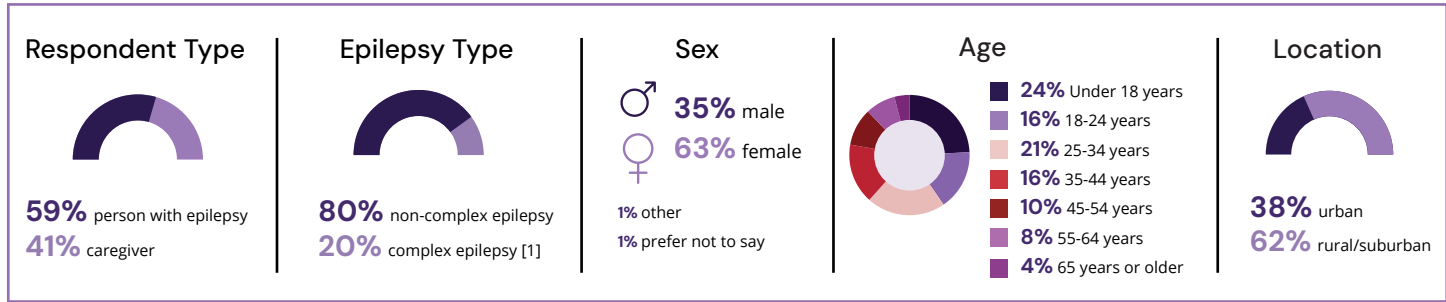
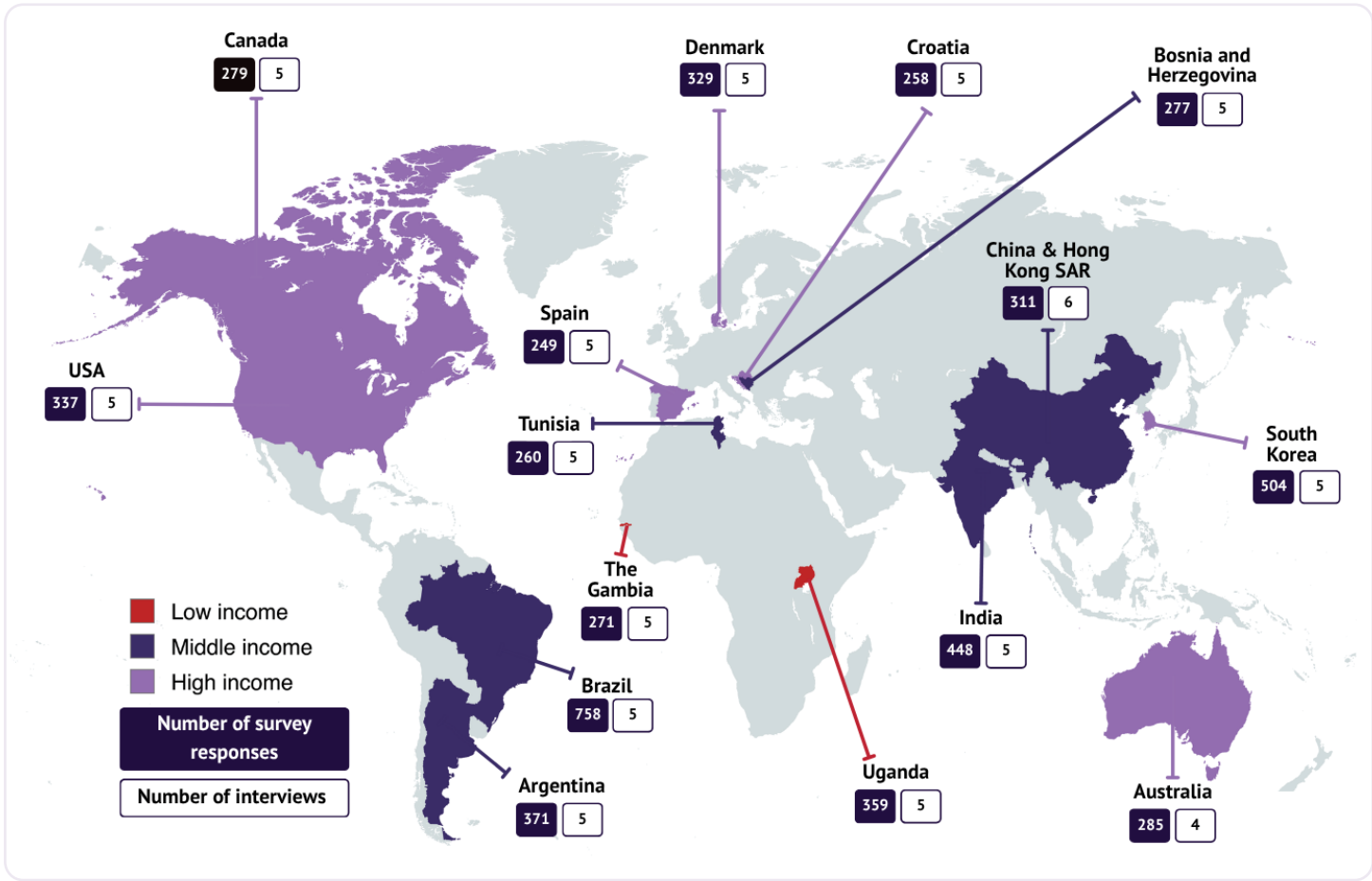
Advance urban planning and design of the built environment to enhance safety, accessibility, and inclusion.

10 

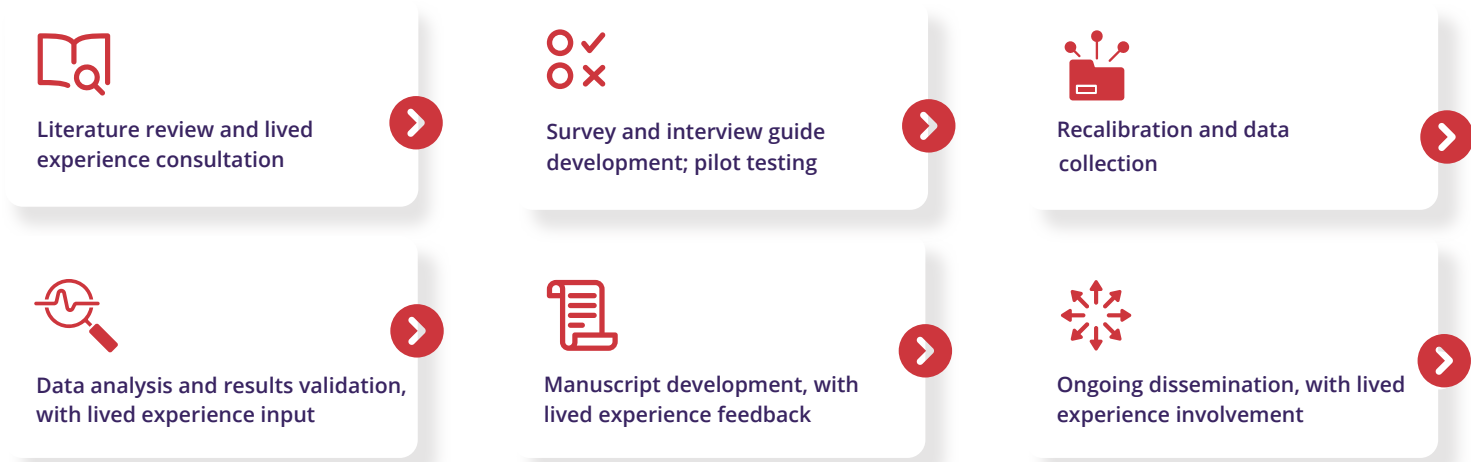
Support evidence generation through intersectoral research funding, support for innovative research and development (R&D), and the creation of national registries, epidemiological data, socio-economic analyses, etc. to inform political prioritization and action.

Overview of GENS

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

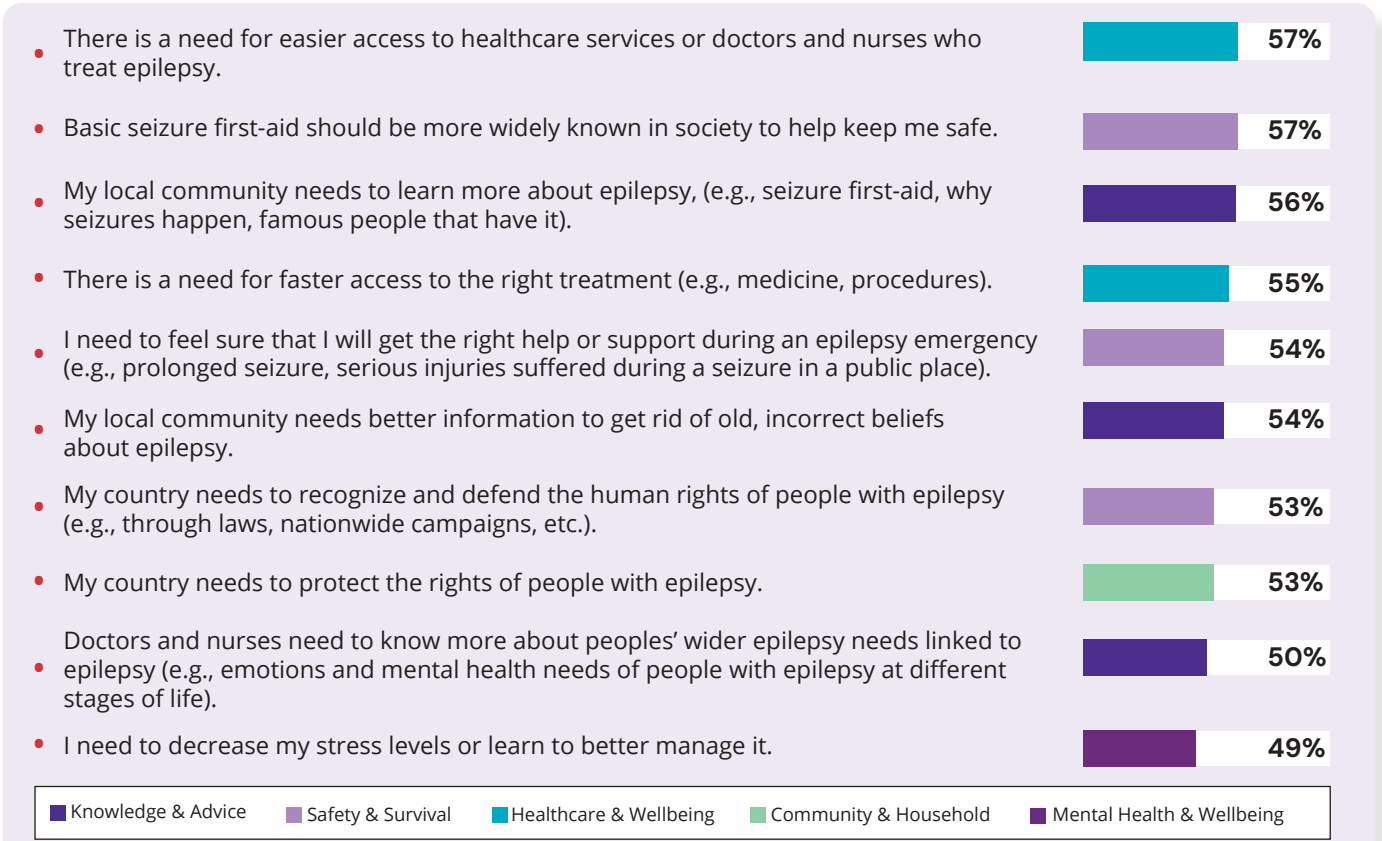


Research Tools & Processes



Survey & Interview Results

The top 10 most frequently selected needs across 8 domains are presented below. For 2 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 2 domains were therefore analyzed separately.



Analysis of the interview data identified sub-themes, which were merged with the survey findings and used to generate 5 overarching themes that reflect the core needs of PWE across all geographic and demographic settings (refer to page 7). The figures below illustrate how the 10 GENS life domains map onto these themes.



Global Burden of Epilepsy

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

51.7_m

people living with epilepsy.

80%

live in low and middle income countries.

0.5%

of the global disease burden.

14.4_m

DALYs (disability adjusted life years) linked to idiopathic epilepsy.

5th

leading neurological cause of DALYs.

125_k

epilepsy-related deaths each year.

3x

higher risk of premature death.

75%

treatment gap in low-income countries.

70%

could become seizure free.

25%

cases potentially preventable.

~50 %

prevalence of other physical or mental conditions.

\$100_b

estimated global economic burden.

Global Advocacy for Epilepsy

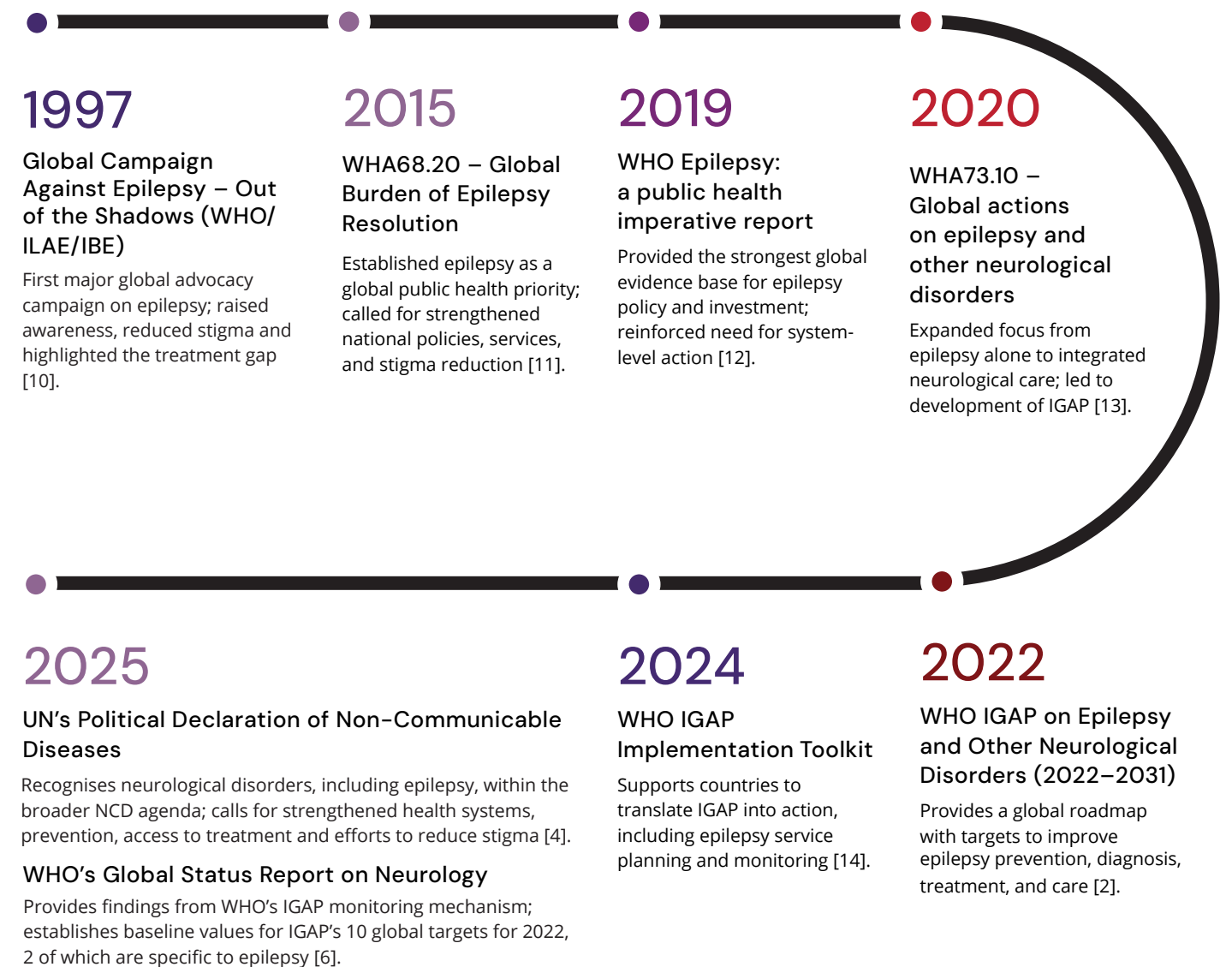
In recent decades, epilepsy has gained long-overdue recognition in global policy frameworks. The adoption of the WHO's 10-year Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) in 2022 marked a major milestone for global advocacy [2].

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

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.





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."

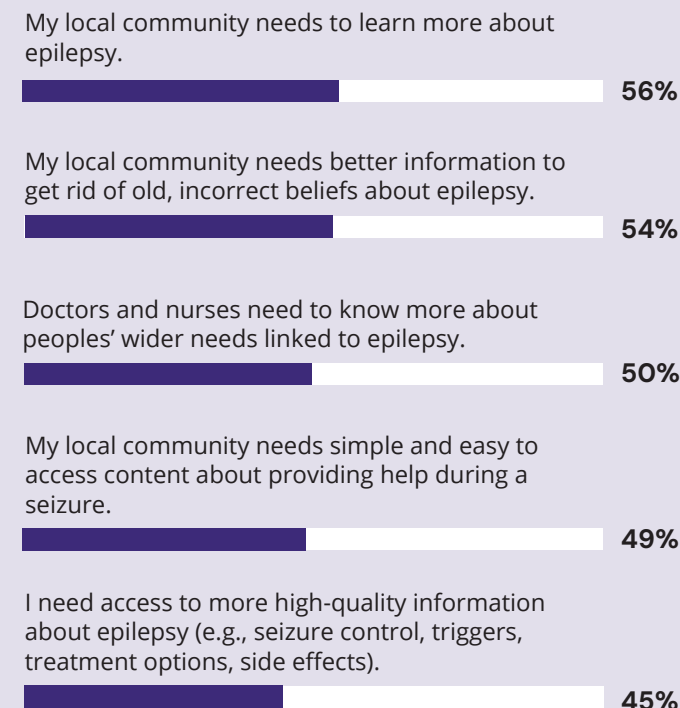
INDIA

"But now some videos on the Internet show that when seeing an epilepsy patient having a seizure, people put a towel or glove in the patient's mouth and pinch the philtrum. This incorrect knowledge is misleading the public."

CHINA

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 control) **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 organizations.
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 standardized and consistently applied guidance across key sectors of society (e.g. education, law enforcement, first responders, community services) and promotion of seizure emergency response protocols.
- 3. Require healthcare services to adopt a holistic, person-centered 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 organizations** to act as credible and accessible information providers.

Good Practice Examples



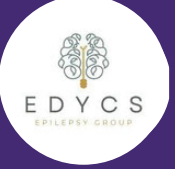
‘My Journey with Epilepsy’ Podcast
Fundación Epilepsia y Juventud (Epilepsy and Youth Foundation), Chile

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.



Educational Comic Book: ‘Savane Bien’, Mauritius
EDYCS Epilepsy Group

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 or death, ensuring safety in public spaces, travel, and emergencies, promoting seizure first-aid awareness, protecting 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'."

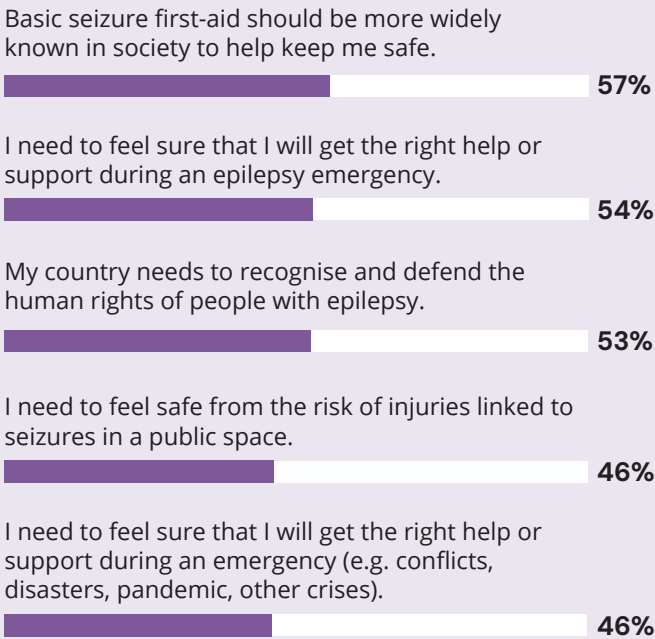
DENMARK

"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



Key Survey Insights

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 recognize 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%

1. Sex

Female respondents 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 recognize and defend the human rights of people with epilepsy (e.g., through laws, nationwide 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 standardized and consistently applied guidance across key sectors of society (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. **Integrate epilepsy into emergency preparedness and humanitarian response plans**, maintaining continuity of care during crises; and ensuring rapid-response systems to assess needs and restore services during disruptions.
- 6. **Ensure continuity of access to essential medicines during emergencies**, through resilient supply chains, monitoring systems and contingency planning.
- 7. **Leverage digital health solutions**, to improve and maintain access to care and specialist support in crisis, remote or under-served settings.

Good Practice Examples



Integrating Rapid and Early Seizure Termination (REST) and Seizure-Safe School Policies
EpiStop, Czech Republic

RATIONALE & APPROACH

The absence of nationally standardized 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.



Disaster Response Manual
Japan Epilepsy Association, Japan

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 systematize 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 specialized services, personalized 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 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 viewed **epilepsy as a disability** compared to those who **did 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.

Good Practice Examples



Train the Trainer Project
Kiserem Epilepsy Foundation, Kenya

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.



Free Epilepsy Consultation Dial-in
Japan Epilepsy Association, Japan

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

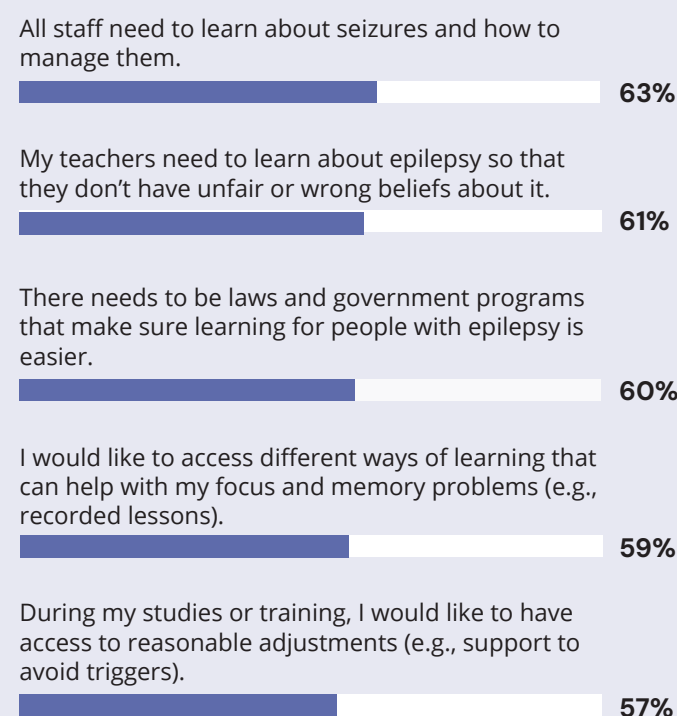
Learning & Education



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, 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 educators.
- 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 education settings.

Good Practice Examples



Reasonable Accommodations
Epilepsy Ireland, Ireland

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 policy-makers 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.



Salud cerebral y epilepsia (Brain Health and Epilepsy Program)
FundHemi, Argentina

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 the 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

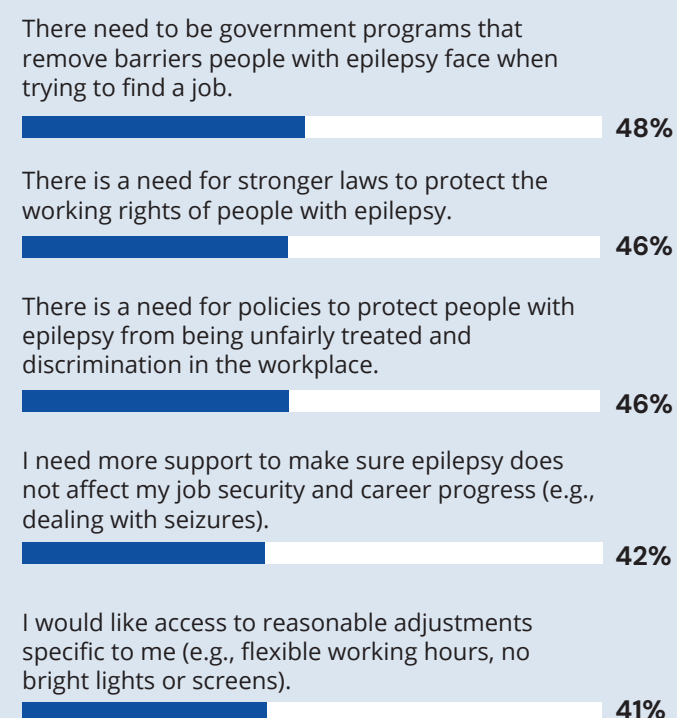


Through survey routing, only those currently working or seeking employment selected needs in this domain, which was:

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 **did 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 and 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.

Good Practice Examples



Emprendedores Púrpura (Purple Entrepreneurs)
Fundación Ivo Josue, Paraguay

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.



Course: Successful Strategies for Navigating the Workplace as A Person with Epilepsy or As an Employer
Epilepsy Foundation, United States of America

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

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%

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

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

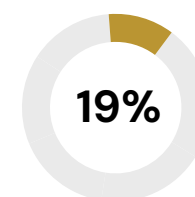
Respondents who view **epilepsy as a disability** compared to those who **do not**, were more likely to report the need for:

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

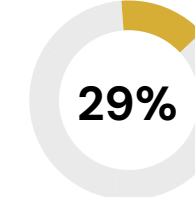


Overall, PWE selected fewer needs than caregivers, but were more likely to report that driving restrictions limit their independence.

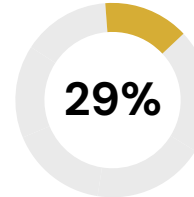
Below are self-reported findings on the availability of transport options for people with epilepsy:



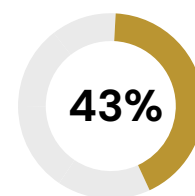
Specialized transport services
(e.g. specifically for people with more transport needs or people with epilepsy.)



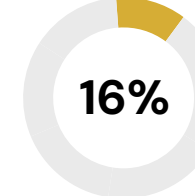
Public transport with general adjustments
(e.g., special measures for people with disabilities or epilepsy, free public transport)



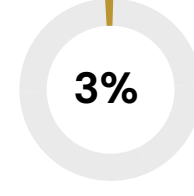
I don't know



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



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



Other

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 accesibility 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.”

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-centered approaches**, replacing blanket restrictions with clinical assessments that support autonomy when seizures are appropriately controlled.

Good Practice Examples



Epilepsy Travel by Bus & Train
FundHemi, Argentina

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.



Revision of Driving Licence Regulations for Persons with Epilepsy
Indian Epilepsy Association, India

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



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 not**, were more likely to report the need for:

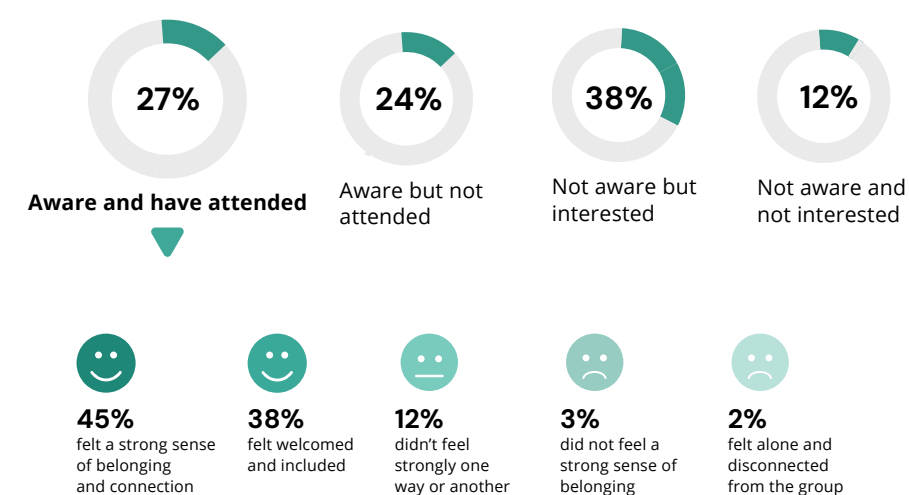
- feeling well enough to help with household chores
29% vs. 21%

3. Income

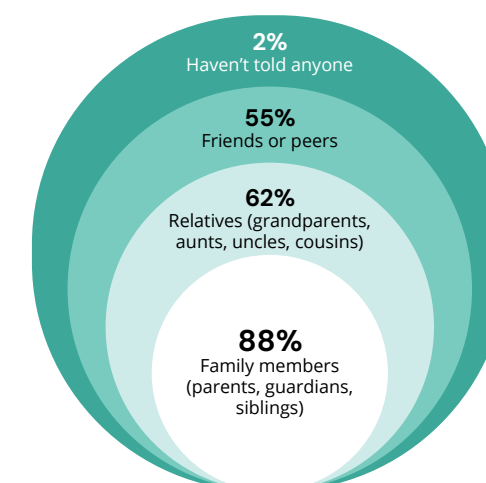
Respondents from **low-income** countries were more likely than those from **middle-income** and **high-income** countries to report the need for:

- 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 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 Page 8-9. Policy-makers 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 standardized service provision, resource allocation, and national service planning.

Good Practice Examples



The Curse of Epilepsy Stigma – Stigma Benches
Kenya Association for the Welfare of Epilepsy (KAWE), Kenya

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.



Speaking Up, Standing Strong: Epilepsy Rights Project
Tanzania Epilepsy Association, Tanzania

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 people 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."

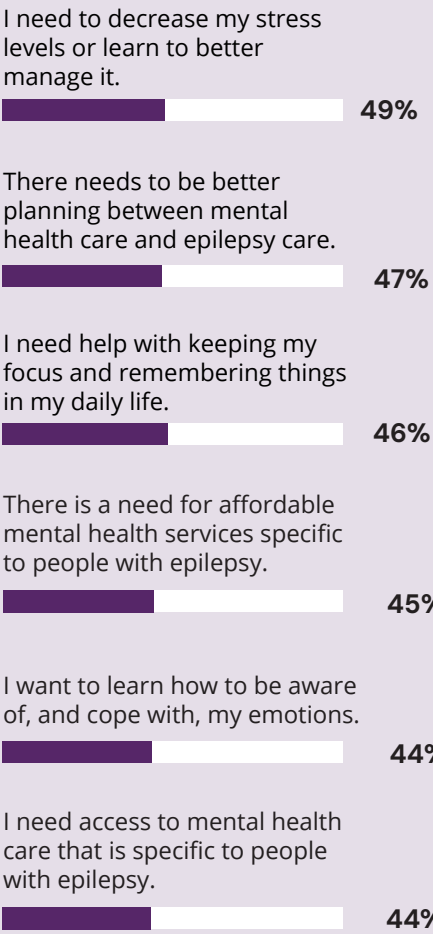
BOSNIA AND HERZEGOVINA

"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



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 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.”



“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.”



“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.”



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.

Good Practice Examples



Brain Health Innovation Summit & subsequent publication
Angelini Pharma & University of Oxford, United Kingdom

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 and 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."

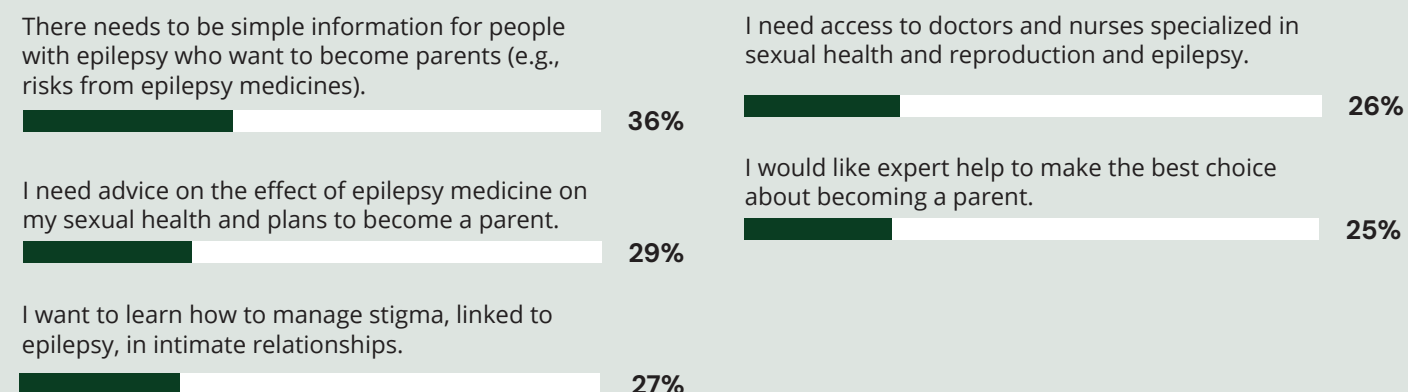
TUNISIA

"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



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:



51%
Male reported at least one need

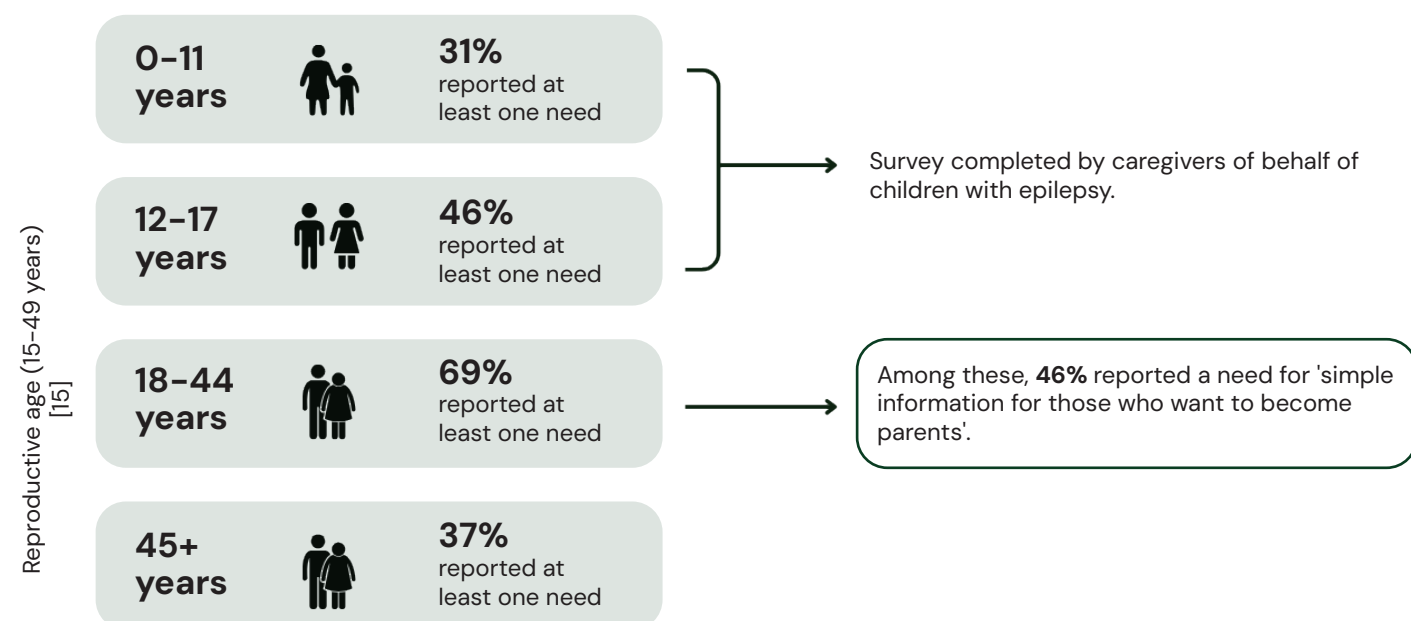


56%
Female reported at least one need



53%
Other reported at least one need

A lifespan lens of the data:



Interview Themes That Emerged

THEME 1: MANAGING UNCERTAINTY AND REDEFINING EVERYDAY LIFE	
Parenthood, planning & 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

<i>“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.”</i> IVANA, ARGENTINA 	<i>“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.”</i> VINAY, INDIA 
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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. 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.

Good Practice Examples

The EpiKNOW Project Epilepsy Ireland, Ireland	
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.
The Maternity Toolkit Epilepsy Action, United Kingdom	
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



Key Survey Insights

1. Disability

Respondents who viewed **epilepsy as a disability** compared to those who **did 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**, ensuring non-discrimination, and offering recourse mechanisms when human rights are violated.
2. **Develop and implement national epilepsy plans and programs**, 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 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 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 prioritization and action.

Good Practice Examples



Self Advocacy Toolkit
Epilepsy Action, United Kingdom

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.



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

This project has been initiated and equally funded by Jazz Pharmaceuticals and UCB Pharma Jazz Pharmaceuticals, UCB Pharma, E+A (Epilepsy+ Alliance – CREA Asbl) & International Bureau for Epilepsy

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

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

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