








## SPECIAL REPORT

# A call for ethical, equitable, and effective artificial intelligence to improve care for all people with epilepsy: A roadmap. A report by the ILAE Global Advocacy Council and Big Data Commission

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## Abstract

The artificial intelligence (AI) revolution is upon us. It will inevitably form a central component of epilepsy workflows and patient advocacy. Therefore, it behooves us as health care providers to ride the crest of this wave and guide its direction for the benefit of all people with epilepsy. Emerging AI-based solutions include decision support tools, automated interpretation of electroencephalography (EEG) and brain imaging, and wearable devices that detect seizures and improve patient safety. Pipelines, including decentralized approaches and federated learning, are now being built that will democratize access and facilitate the next generation of AI tools for the global epilepsy community. Despite this, enduring issues remain incompletely addressed. For example, AI requires high volumes of data, leading to concerns about ethical ownership, stewardship, and privacy. Few AI-based tools have progressed from derivation to validation stages, and only rare exceptions undergo real-world evaluation. Inadvertent harmful algorithmic and decision allocation biases also continue to represent major risks to the global epilepsy population. Additional barriers include geographical disparities in computing resources, proprietary ownership of electronic health records, EEG, and brain-imaging platforms, and greenhouse gas emissions related to the demanding power requirements of AI. Therefore, to fully avail ourselves of the benefits of AI, we assert that ethical, equitable, and effective AI for epilepsy requires collaboration from the entirety of the global epilepsy community. Fundamental to this is early and deliberate engagement of people from low- and middle-income

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countries to ensure that AI-based solutions do not exacerbate existing global disparities. Ultimately, we advocate for “decision intelligence” approaches to the development of AI-based epilepsy solutions, which involves early engagement of all interest-holders to ensure that the correct questions are addressed and the right technical approaches are deployed to maximize value for the global epilepsy community.

#### KEYWORDS

AI ethics, computational intelligence, data science, deep learning, Intersectoral Global Action Plan, machine intelligence, machine learning, synthetic intelligence

## 1 | ARTIFICIAL INTELLIGENCE (AI)

### 1.1 | What is it?

The artificial intelligence (AI) revolution is now here, and it will transform medicine. Despite being firmly established in our collective consciousness, a universally accepted definition of AI remains elusive.<sup>1</sup> However, at an overarching level it is considered an evolving field of computer science that aims to create algorithms that can perform tasks that typically require human intelligence.<sup>2</sup>

The World Health Organization (WHO) has now published a formal statement outlining six principles guiding ethical development and use of AI for health,<sup>3</sup> whereas the Bletchley Park declaration and formal EU regulations now exist that call for action and address risks of frontier AI to ensure that inclusive, ethical, trustworthy, and safe AI is consistently created and disseminated.<sup>4,5</sup> The International League Against Epilepsy's Global Advocacy Council's AI Task Force and Big Data Commission agree to such measures and acknowledge that generation of safe AI is paramount. It is incumbent upon us to proactively advocate for such measures, given that AI will continue to evolve at an unrelenting rate, and its routine use for epilepsy care is likely inevitable. The purpose of this statement is to succinctly review AI progress in the field of epilepsy, to identify risks and barriers to its use, and to provide a call to action for the generation of ethical, equitable, and effective AI that benefits all people with epilepsy equally across the globe. Within the context of this article, we use AI to refer to narrow AI, constituting approaches such as machine learning, natural language processing, artificial neural networks, deep learning, and generative models, that attempt to optimally use extant data and information to solve management and advocacy problems in epilepsy.

#### Key points

- Artificial intelligence (AI) is reshaping epilepsy care through decision support tools, automated diagnostics, and wearables.
- Privacy and governance, diverse data, bias awareness, human oversight, and transparency are critical for ethical and equitable AI.
- For optimal uptake, AI should be used as a tool that complements human-centered care and clinical judgment.
- AI can reduce care gaps in low-resource areas via tailored tools, capacity building, and affordable, culturally sensitive deployment.
- Decision intelligence approaches emphasizing content, context, and solutions domains are needed for ethical, effective, and equitable AI.

## 2 | THE CURRENT STATE OF AI IN EPILEPSY

### 2.1 | Decision support tools

Data-driven tools are used increasingly to support diagnosis, management, and prognostication in epilepsy (Table 1). Early models focused on clinical data for surgery planning, with particular emphasis on post-operative seizure outcomes,<sup>6,7</sup> but now incorporate multimodal data (electroencephalography [EEG], magnetic resonance imaging [MRI]) to additionally predict cognitive and mood outcomes with moderate-high accuracy (c-statistics: .68–.81).<sup>8–10</sup> Real-world deployment remains limited due to suboptimal accuracy, data limitations, and computing demands,<sup>8</sup> although more accessible data inputs like scalp EEG<sup>11</sup> are helping to bridge this gap. For now, the adoption of these machine learning (ML) surgical models has been restricted to

**TABLE 1** Artificial intelligence applications in epilepsy.

Theme	AI application	Goals and benefits	Current limitations
Decision support tools	Nomograms, ML algorithms, neural networks, deep learning, LLMs	Improves/facilitate decision-making through accurate outcome prediction (medication response, surgical outcomes, comorbidities)	Limited by need for high-dimensional, resource intensive data (clinical, scalp and intracranial EEG, MRI, genetics) and deployment into proprietary software
Seizure detection	ML algorithms, neural networks, deep learning	Accurate seizure detection for quantifying epilepsy burden and facilitating video and video-EEG interpretation	Real-world data quality, interoperability, computational demands, and resource requirements
Lesion detection	ML algorithms, neural networks, deep learning, LLMs	Identifies subtle abnormalities whose detection could improve surgical outcomes and disease prognostication	Real-world data quality, interoperability, computational demands. and resource requirements
Wearables	ML algorithms, neural networks, deep learning	Supports safety, seizure logging, and pre-emptive action, especially at home	False alarm rates, accuracy and validation for specific seizure types, generalizability across settings

Abbreviations: AI, artificial intelligence; EEG, electroencephalography; LLM, large language model; ML, machine learning; MRI, magnetic resonance imaging.

academic medical institutions, where they have been used to assist with surgical decision-making during multidisciplinary surgical conferences.

Targeting the wider group of medically treated epilepsy, ML has been explored as a means of enabling prediction of drug response.<sup>12</sup> A recent study analyzing 7507 medical records from 1000 pediatric epilepsy patients developed a computational clinical decision-supporting system that leverages three multi-channel convolutional neural network (CNN) models tailored to three anti-seizure drugs (vigabatrin, prednisolone, and clobazam). Each CNN model predicts whether a respective drug is effective on a given patient or not. The CNN models showed area under the receiver-operating characteristic curves of .90, .80, and .92, respectively, in 10-fold cross-validation.<sup>13</sup> Another tool, EpiPick, is an online application designed to assist health care providers in diagnosing/classifying seizures and choosing an appropriate medication to use in monotherapy in people whose seizures start at 10 years of age or older.<sup>14</sup> None of these models have undergone regulatory approvals for integration into clinical care.

Finally, some pilot studies are exploring ML models to better manage comorbidity risk. One example is a pilot study designed to predict risk of incident depression based on clinical variables, first available EEG, and brain MRI in adults with epilepsy.<sup>15</sup>

## 2.2 | Automated EEG analysis

Despite being a cornerstone of epilepsy diagnosis, EEG interpretation in clinical practice faces two major

limitations, both of which can be effectively addressed through AI-based automated EEG analysis. For standard EEG studies performed in ambulatory patients, many countries with limited medical resources lack adequately trained physicians to provide reliable interpretations.<sup>16,17</sup> A shortage of such expertise is also evident in certain high-income countries. For long-term in-hospital EEG monitoring, the large volume of data generated results in a substantial workload for physicians, which should be reduced to enhance efficiency. Addressing this challenge is also a prerequisite for expanding long-term EEG monitoring to the patient's home environment.<sup>18,19</sup> Recent advances in AI-based EEG analysis have begun to address these challenges. A notable example is SCORE-AI, which employs a CNN to classify standard EEG recordings as normal or into specific abnormality categories with human-level accuracy.<sup>20</sup> This support tool has received approval from both the U.S. Food and Drug Administration (FDA) and the European Union's Conformité Européenne (CE), and is now integrated into proprietary software systems for routine clinical use. Another recently approved system, BrainWatch, enables point-of-care AI-based detection of status epilepticus. In addition, several commercial software platforms originally developed for spike and seizure detection, particularly for long-term recordings, have now incorporated AI to enhance their performance. Examples include Persyst and Encevis, which are now being used in certain epilepsy/seizure monitoring units.<sup>21</sup> These tools are accelerating the development of home-based long-term video-EEG monitoring, improving accessibility and reducing costs.<sup>22</sup>

AI has also shown promising potential in seizure prediction and forecasting<sup>23,24</sup> based on EEG, as well as in the automated interpretation of intracerebral EEG, including the detection of high-frequency oscillations.<sup>25</sup> Although most of these applications remain under development, one forecasting system, Minder—based on long-term intracerebral EEG recordings obtained via implanted electrodes—was recently approved by the FDA.<sup>26</sup>

### 2.3 | Automated lesion detection

Epileptogenic brain lesions, particularly focal cortical dysplasia (FCDs), may remain undetected on MRI. This could be because of the limited experience of interpreting physicians, that the lesions are too small or exhibit signal changes that are too subtle to be recognized by the human eye, or due to lower field strength MRI scanners, which are frequently donated to low- and middle-income countries (LMICs).<sup>27,28</sup> Furthermore, in LMICs, there is an absence of specialized epilepsy-imaging protocols, and a shortage of trained neuroradiologists.<sup>28</sup> These factors all significantly reduce the likelihood of successful surgical treatment. Several AI-based software tools, including MELD (Multi-Centre Epilepsy Lesion Detection), MAP-18 (Morphometric Analysis Program, version 2018), and DeepFCD, have demonstrated the ability to detect such “MRI-invisible” lesions with reported sensitivities ranging from 69% to 85% on internal test sets.<sup>27,29–32</sup> False-positive attribution, as exemplified by specificities of 56%–90% for FCD and positive predictive values of 67%–76% for tools like MELD graph, requires ongoing refinement.<sup>31</sup> Although none of these tools have yet received regulatory certification, many epilepsy surgery centers have already begun to incorporate them into clinical practice.

Beyond lesion detection, AI-enhanced MRI acquisition and reconstruction workflows are now used in modern commercial MRI systems, delivering higher-quality images in shorter scan times. These advances have paved the way for low-field and even portable MRI scanners, potentially reducing the diagnostic gap in LMICs by increasing accessibility to advanced neuroimaging.

### 2.4 | Wearable and video-based seizure detection

Various devices—including wearables worn on the wrist or upper arm, as well as video-based systems—are able to detect generalized convulsive seizures (GCSs) and enable timely caregiver intervention, which can be

life-saving.<sup>33–36</sup> As with EEG analysis software, some commercially available solutions, such as Embrace by Empatica, were initially developed before the advent of AI but have since integrated ML algorithms to improve performance.<sup>37,38</sup> More recently developed AI-native solutions include EpiWatch,<sup>39</sup> which has received FDA approval, and EpiSave.<sup>40</sup> Both of these systems employ a novel framework in which AI-based algorithms operate on off-the-shelf smartwatches (Apple Watch for EpiWatch and Android-based smartwatches for EpiSave) offering scalable, consumer-grade platforms for GCS detection.<sup>39,40</sup> An AI-powered, video-based system for detecting motor seizures, Nelli,<sup>41</sup> has also been certified in Europe, along with a wearable headband EEG device, EpiHunter, designed specifically for the detection of absence seizures.<sup>42</sup>

Taken together, a growing number of FDA-cleared or CE-marked AI-based solutions for the detection of EEG abnormalities and seizures have now entered clinical practice, creating opportunities for more accurate and efficient care for people with epilepsy.

## 3 | TOWARDS REALIZING THE TRANSFORMATIVE POTENTIAL OF AI IN EPILEPSY

### 3.1 | Epilepsy pipelines to facilitate future AI tools

#### 3.1.1 | Data linkage and input features

Outcome prediction tasks are typically better achieved by integrating multi-modal data. Epilepsy benefits from a plethora of data collected during routine care, including electrophysiological, imaging, genetic testing, and post-surgical tissue testing. However, the process of AI model development needs to account for the depth and size of what is captured within each data type. For example, EEG recordings can last for days in the context of pre-surgical evaluations, and almost innumerable AI input features can be derived through post-processing. The same richness and complexity apply for structural and functional MRI data. Platforms for multi-modal data integration and efficient feature selection become critical. Such work remains compelling, as preliminary evidence suggests AI applied to combined EEG–functional MRI (fMRI) has potential for predicting progression from a first seizure to epilepsy. This was accomplished through the combined value of extracting complex features including phase-lag index and synchronization likelihood in specific EEG frequency bands and fractional amplitude of low frequency fluctuation on fMRI.<sup>43</sup>

### 3.1.2 | Federated analytic approaches

Federated analytic approaches for regional, national, and international collaborations are essential, since they account for the regulatory complexities that typically slow down data sharing. In particular, decentralized federated learning (DFL) is hailed as a major breakthrough.<sup>44,45</sup> Its network architecture allows clients to communicate directly without a central server, thereby permitting collaborative users to train models without sharing private data. This technology is relatively nascent in the field of epilepsy, and exemplars would be highly valuable to support its use.

### 3.2 | Validation, decision analyses, and real-world evaluation of AI tools

Using these steps, we can begin to generate internally valid AI-models for epilepsy. However, efforts to demonstrate external validity and generalizability are frequently lacking (Table 2). Few derivation studies progress to formal external validation, a critical step, since a model's accuracy typically declines when evaluated in completely independent populations, especially when the process is performed by completely autonomous authors.<sup>46</sup> The extent to which all algorithms must generalize is debatable, and this step may not be necessary if the model is intended solely for site-specific deployment.<sup>47</sup> Here, it may be sufficient that the model is both internally valid and continually learns from novel, locally derived data, ensuring it remains accurate and responsive to changes in the region's clinical milieu.

Similarly, a dearth of algorithms proceed to formal decision curve analyses (which quantify the clinical “net benefit” of a prediction model<sup>48</sup>) and randomized-controlled trials (RCTs) or pragmatic trials (which is integral given not all meet primary outcomes in unbiased trials<sup>49</sup>). As of early 2024,<sup>50</sup> a scoping review revealed that only one epilepsy AI algorithm has undergone formal evaluation in an RCT<sup>51</sup> (a model that uses natural language processing to promote early identification of candidates for resective epilepsy surgery<sup>52</sup>). We re-ran the search strategy in PubMed

up to and including October 31, 2025, using additional key words to restrict the results to seizures and epilepsy, and confirmed that no additional RCTs reports were published after completion of this systematic review. However, our search did yield a protocol published in 2025, proposing to perform an RCT using an AI model to personalize anti-seizure medication (ASM) choice in newly diagnosed epilepsy.<sup>53</sup> Examples are available from other medical fields where AI can counterintuitively impede care, generating inefficiencies and suboptimal outcomes if its real-world performance is not comprehensively assessed in advance of deployment.<sup>54,55</sup>

### 3.3 | Moving toward population-level benefits in epilepsy: electronic learning health systems

A major promise of AI lies in its potential to propel advances in learning health systems (LHSs). Electronic LHSs aim to improve health by learning from the care that is being provided,<sup>56</sup> often referred to as “real-world” evidence. With the exponential increase in electronic health record (EHR) systems, there is an opportunity to harness artificial intelligence to propel advances in learning health systems (LHSs). The availability of large EHR systems can facilitate AI-based analyses of delivered health care, which can be fed back to improve future health outcomes through decision support tools and comparative effectiveness research. For instance, AI can be used to identify epilepsy surgery candidates early in the course of their disease, plausibly improving outcomes.<sup>57</sup> The Epilepsy Learning Health System (ELHS) in the United States was created in 2018<sup>58</sup> to improve epilepsy care at the point of care using a system level approach. Natural language processing can enhance the functionality and capability of the ELHS by efficiently extracting data and for research and analytic consumption. Many of the advances most useful for LHSs are related to the use of AI-based analytics, which permit cost-effective solutions for scaling sophisticated LHS platforms that cover disease prevention, treatment, and management at population and individual levels.<sup>59</sup>

**TABLE 2** Steps in artificial intelligence model validation and evaluation.

Step	Description/goal	Common issues/barriers
Internal validation	Assess accuracy on development data	Overfitting, lack of generalizability
External validation	Test on independent populations	Performance decline
Decision curve analysis	Quantify clinical net benefit	Lack of data, primarily intended for binary outcomes, lack of familiarity among clinicians and researchers
Real-world trials	Randomized/pragmatic evaluation	Resource intensive, commercial and proprietary concerns if product fails

### 3.4 | Multimodal data and the digital brain twin

The natural culmination of current data and AI advances in epilepsy is the integration of multiple disparate data sources, including, but not limited to, clinical, imaging, neurophysiology, genetics, wearables, and pathology, into large representative real-world repositories. Such constructs can be leveraged to yield “self-adaptive digital twins”—a high-dimensional “living” (incorporating new information as it is acquired) representation of anything from an individual person to a health system that can be harnessed for modeling and simulation-based predictive insights.<sup>60</sup> Workflows have been proposed for establishing personalized brain twins that integrate scalp and stereotactic EEG with structural MRI data that can be used to estimate individual epileptogenic zones in advance of epilepsy surgery through a combination of direct stimulation and modeling of simulated data.<sup>61,62</sup> Given the self-evident potential for such an approach, concerted global efforts to integrate conventional and emerging biometric data with the aim of creating a dynamic multimodal representation of a person with epilepsy, whilst adhering to ethical and equity standards, are warranted to explore the role of self-adaptive digital brain twins for advancing precision personalized and public health interventions<sup>60</sup> in epilepsy.

## 4 | ANTICIPATING RISK AND HARMFUL BIAS: A PROACTIVE APPROACH

### 4.1 | Data acquisition, storage, confidentiality, and ownership

Biomedical data acquisition often involves sensitive patient information, including EHR-derived information (e.g., prescriptions of ASMs), and real-time physiological monitoring (e.g., EEG data), which requires strict protocols to ensure confidentiality and ethical use. Data collection must follow standardized procedures for informed consent, ensuring that people with epilepsy are fully aware of how their data will be used, shared, and protected. To mitigate confidentiality risks, encryption techniques are required and sensitive identifiers, such as personal details, should be anonymized prior to sharing. In addition, data-sharing agreements should be clear and secure, defining the specific purpose and duration of data use to reinforce patient privacy.

Data ownership in AI applications for epilepsy is another critical issue. People with epilepsy, health care providers, and researchers all have a stake in the ownership and ethical stewardship of these data. Data ownership

laws vary widely, which complicates the cross-institutional and international use of biomedical data for AI. This is particularly problematic in the era of large models such as large language models (LLMs), which are trained on massive amounts of information that are subsequently abstracted, stored internally, and then used for various tasks. Adopting best practices, such as standardized data governance frameworks, can help ensure that ownership and access are both transparent and ethically managed. Proactively signaling how data can be used, and what parts of the data cannot be used for training AI models can also potentially address such challenges.

### 4.2 | Harmful algorithmic and data bias

As AI systems continue to be adopted in epilepsy care, we must be vigilant about potential harmful biases that can be built inadvertently into algorithms and datasets (Table 3). Models are only as good as the data on which they are trained. If the data are not representative of diverse patient populations, the resulting algorithms may perform poorly or make harmfully biased predictions for underrepresented groups.

For example, if an AI system for seizure detection is trained primarily on EEG data from younger adults, it may have reduced accuracy when applied to older adults with late-onset epilepsy. Similarly, training data sourced mainly from academic medical centers may not generalize well to community hospital settings. Developers must intentionally curate diverse, representative datasets and test their models across different patient subgroups to mitigate these risks.

There is also a risk of AI systems perpetuating or amplifying existing harmful societal biases and health disparities.<sup>63</sup> For instance, if an algorithm for predicting ASM response is trained on historical prescribing data, it may recommend suboptimal treatments for minority patients who have been commonly under-treated.<sup>64</sup> Careful analysis of training data and model outputs, applied in the context of locally available diagnostic and treatment paradigms, is needed to identify and correct for such biases.

### 4.3 | Harmful decision allocation bias

As AI tools become more sophisticated, there is a risk that human clinicians may over-rely on algorithmic recommendations and abdicate their clinical judgment. This “automation bias” could lead to harmful outcomes if the AI model makes an error or fails to account for important contextual factors.

**TABLE 3** Classification scheme for inadvertent harmful bias that can lead to inaccuracy and inequities through AI-delivered care.

Domain	Bias	Issue	Sources and consequences
Data bias	Selection bias	Training data lacks diversity across age, sex, racial, or socioeconomic groups	Non-random missing data or data disproportionately come from a specific region or health system
	Documentation bias	Health records reflect provider biases in symptom interpretation or treatment choices	Provider cognitive biases and difficult to capture data (e.g., social determinants of health) will lead to important missing data
	Historical data bias	Reliance on outdated datasets that do not accurately capture conventional care	May perpetuate inequities in certain groups that were historically undertreated
	Measurement/labeling bias	Systematic errors in how data are collected or measured	Imprecise or inconsistent interpretation of diagnostic studies due to variations in skill and training may lead to erroneous values in the dataset
Algorithmic bias	Diagnostic disparity bias	Performance gaps emerge across patient subgroups for critical predictions	Can result from race/ethnicity correction factors in risk calculators leading to performance inconsistency across minority groups
	Coding proxy bias	Using administrative or billing codes as health need proxies	An algorithm could misclassify an underrepresented group as “healthier” if they systematically underuse the health system
	Whole cohort performance bias	Overreliance on whole cohort performance metrics	The model is well tuned for common patient groups but underperforms for minority classes
	Bias due to lack of external validity or real-world performance evaluations	Models may be well fitted to the source data but fail to generalize to external populations	The model will underperform when deployed on unseen data from a disparate population
Decision bias	Decision allocation bias	The model is internally and externally accurate but leads to systematic discrimination	A model may suggest that people with epilepsy are at high risk of seizure recurrence, so employers choose not to hire them when accommodations could have been made to ensure safety
	Resource misallocation bias	Targeting high-risk groups can create new disparities in preventative care	Using an algorithm that prioritizes invasive, higher-risk treatments for patients predicted to have more severe disease may disproportionately recommend their use in minority groups who historically may have had worse outcomes due to suboptimal care rather than intrinsically more severe disease
	Prevention paradox	Targeting high-risk groups creates new disparities in preventive care access	Using an algorithm to prioritize screening for high-risk groups could lead to diminished care for “borderline” groups
	End-user bias	Health care providers use AI recommendations for only a subset of patients	Complex interfaces and burden of use for more complicated patients may lead clinicians to ignore AI advice for people with more severe disease to minimize disruptions to workflow
Publication bias	Geographical publication bias	Overrepresentation of priorities and needs from specific regions	Models developed in high resource areas may not be relevant for low- and middle-income countries
	False positive publication bias	The majority of published models only report “positive” findings	Lack of published negative results provides an incomplete perspective of the utility of AI and may perpetuate use of biased models

Abbreviation: AI, artificial intelligence.

As an example, an AI system may recommend continuing an ASM as prescribed based solely on seizure frequency, without considering quality of life impacts of which the human clinician is more aware. Alternatively, a seizure prediction algorithm may generate frequent false alarms (false positives) that lead care teams to become desensitized and potentially miss true seizure events (true positives). Epilepsy models, even if completely accurate, could still result in harmful bias if decisions are made without proper context. Accurate and reliable models of seizure recurrence could be exploited to deny people with epilepsy gainful employment, when mitigation strategies could have instead been instituted to optimize safety and reduce liability.<sup>63</sup>

AI systems should be designed and leveraged as decision support tools that look to augment rather than replace clinical expertise. Clinicians need proper training on the strengths and limitations of AI tools, and user interfaces should be designed to facilitate critical evaluation of AI outputs. Maintaining human oversight and the ability to override AI recommendations is necessary.

#### 4.4 | Disinformation and hallucinations of generative AI models

Generative AI models, including LLMs, have shown promise for information retrieval and clinical decision support. These models are, however, prone to generating plausible sounding but incorrect information, a phenomenon referred to as “hallucinations.” In a clinical context, hallucinations could lead to disinformation—misinforming clinicians about diagnostics, treatment options, or prognostic outcomes. Such risks necessitate robust validation protocols, ensuring that AI outputs are always cross-referenced with verified sources or datasets before being applied in clinical decision-making. Parameters can be adjusted to ensure that models operating in health care settings do so under a deterministic manner, thus prioritizing greater consistency reliability and reproducibility over diversity of outputs.<sup>65</sup> In addition, ongoing model refinement and limiting scope to specialized, high-quality labeled data, for example, from existing clinical cohorts or registries, can potentially reduce the incidence of hallucinations.

To counteract disinformation, it is essential to implement “human-in-the-loop” oversight.<sup>66</sup> Clinicians should be advised to critically assess AI-generated outputs and identify those deviating from accurate clinical guidelines. One potential mitigation strategy is the development of confidence scoring systems within AI models, which flag outputs that diverge from established

medical knowledge or contain speculative language.<sup>66</sup> Such systems would allow clinicians to quickly identify outputs requiring further validation, thereby reducing the risk of disseminating inaccurate information within epilepsy care.

#### 4.5 | Interpretability and opaque AI models

Many advanced AI techniques like deep learning produce opaque models the decision-making processes of which are difficult to interpret. This lack of transparency and explainability poses challenges for clinical adoption, regulatory approval, and patient trust.

In epilepsy care, where treatment decisions can have profound impacts on patients' lives, it is important for clinicians to understand the rationale behind AI recommendations. In addition, patients have a right to explanations for decisions affecting their care. Techniques for improving AI interpretability, such as attention maps for imaging models or rule extraction for clinical decision support systems, should be further developed and implemented.

Simpler and more interpretable AI models may be preferable, even if they sacrifice some predictive performance. The goal should be to strike a balance between leveraging the power of AI and maintaining transparency and accountability in medical decision-making.

### 5 | BARRIERS AND FACILITATORS TO THE USE OF AI IN EPILEPSY

#### 5.1 | Infrastructure required to link, process, and analyze high-dimensional epilepsy-specific data

A high-performance computing environment is frequently a prerequisite for deriving AI solutions, especially those in epilepsy that depend on high-dimensional clinical, EEG, MRI, genomic, and pathology data. These typically entail clusters of processors (central, graphics, and tensor processing units), high-speed storage, advanced networking, and specialized software, thus allowing for parallel distributed processing to increase computational speed. Access to such clusters is frequently costly and resource intensive, which is problematic in LMICs. Hence, we must advocate for sustainable computing resources in LMICs. Similarly, wide dissemination of open-source solutions, such as MariaDB<sup>67</sup> and scikit learn (Python),<sup>68</sup>

and R packages and scripts,<sup>69</sup> will democratize AI programming globally.

## 5.2 | Proprietary ownership of EHR and neurodiagnostic software

Proprietary ownership of data in EHR and biosignal/imaging commercial platforms is an important rate-limiting factor of further development. Training AI models need large amounts of data, but access is often hindered or denied for reasons of proprietary ownership. Often this predicated on patient privacy issues, but proper de-identification protocols, federated data analyses, and proactive government and industry engagement offer potential solutions. Health care providers, researchers, and people with lived epilepsy experience should work collaboratively with private corporations to promote data exchange across independent health information systems. By increasing agency in how their data are used, people with epilepsy can ensure that advancements in AI meet their specific priorities. Similarly, strong government policies that encourage the use of common data models across electronic health data platforms and guide the use of commercially integrated cloud storage can enhance public-private partnerships, leading to efficient, cost-effective, and patient-driven AI solutions.<sup>70</sup>

## 5.3 | Climate change in the age of AI

As of 2019, the health care sector accounted for 4%–5% of global greenhouse gas emissions.<sup>71</sup> However, health care providers have been world leaders for instigating meaningful change and overall health system emissions (including supply chain and broader responsibilities) has declined by 22% since 1990.<sup>72</sup> We must ensure that AI-based advances are not accomplished at the expense of the progress we have made in mitigating the effects of health care interventions on climate change.

The computational infrastructure and servers; type and quantity of energy required for hardware, software, and back-up generators; and hardware turnover all contribute to AI's carbon footprint. If AI continues to evolve at its current rate, it is estimated that annual power consumption could reach 85–134 terawatt hours, or ~1% of global electricity use.<sup>73,74</sup> We therefore support existing calls for transparent reporting of AI energy consumption, responsible stewardship that entails the creation of only the most computationally efficient algorithms that do not attempt to exceed a priori accepted performance thresholds, promotion of efficient and secure

cloud-based platforms where appropriate, and ethically based carbon offsetting incorporated into hospital and grant budgets.<sup>73</sup>

## 5.4 | Engagement of the epilepsy community to facilitate AI solutions

Progress in AI should be guided by principles of ethics, equity, and effectiveness to ensure that the benefits reach all individuals living with epilepsy, irrespective of their socioeconomic, geographical, or demographic circumstances.<sup>75–77</sup> When developing AI solutions, we must prioritize patient rights, data privacy, and informed consent. AI-based projects should involve people with lived experience in all phases of the research and deployment process.<sup>78,79</sup> Study planning must encompass people with epilepsy across different ethnicities, socio-economic strata, and geographic regions to prevent biases, ensure fair outcomes, and produce local environmentally sustainable solutions.

Robust partnerships with communities, patient advocacy groups, health care professionals, and health organizations are critical for understanding the unique needs and challenges faced by people living with epilepsy. Tailoring AI tools to address these challenges ensures equitable care delivery.<sup>78,80–82</sup> The Intersectoral Global Action Plan (IGAP), a WHO initiative that aims to improve the care and quality of life of people with epilepsy and other neurological disorders, underscores the importance of the development of new diagnostics, treatments, technologies, and innovations, including AI-driven solutions. Governments and health care authorities will play a central role by establishing ethical and regulatory frameworks for AI integration, promoting community engagement and coordination among interest-holders, facilitating intersectoral partnerships to enhance resource sharing, and developing policies for equitable distribution of AI benefits, especially in LMICs. Incorporating AI within the IGAP roadmap strengthens its implementation, particularly in addressing disparities in epilepsy care and achieving United Nations Sustainable Development Goals (SDGs).<sup>4,83,84</sup>

## 6 | GLOBAL IMPACT OF AI

The transformative potential of AI in epilepsy care is perhaps particularly evident in its ability to address health care disparities in LMICs. By leveraging AI technologies, it is possible to improve epilepsy diagnosis, treatment, and management in resource-constrained settings. It is, however, vital to do this mindful of unique regional challenges and ethical concerns.

## 6.1 | Potential benefits in LMICs

The worldwide inequity in epilepsy care is vast. For example, there are between 1 and 3 neurologists per 10 000 000 people in Africa, compared to 1 neurologist for every 36 000 persons in the United States.<sup>85,86</sup> Given the challenges in sufficiently increasing the number of epilepsy specialists across LMICs, AI-based solutions represent a potentially more tractable means to reduce inequality. For example, AI-based diagnostic applications have demonstrated high accuracy in identifying convulsive epilepsy through culturally tailored questionnaires, enabling health care workers without specialist training to make accurate diagnoses. These tools have shown effectiveness across multiple African regions, reducing diagnostic delays and improving patient outcomes.<sup>87,88</sup> These models can also guide resource allocation, ensuring tools like EEG and MRI are used efficiently.<sup>76,87,89</sup> For example, applications have been developed to compensate for the inconsistent access to EEG expertise, especially in pediatric epilepsy, for detection and classification of epileptic seizures in Tunisia.<sup>90,91</sup> Simply providing an EEG machine or an MRI scanner is not helpful unless there is surrounding technological support to help report the results from such investigations.

## 6.2 | Unique issues and solutions for LMICs

Several challenges must be addressed to ensure equitable AI implementation in LMICs. One significant barrier is the digital divide, defined by disparities in access to internet and computational infrastructure. Targeted initiatives such as cloud-based analytics and federated learning frameworks are critical for enabling secure and efficient data sharing without compromising patient privacy.<sup>87,88</sup> These will have the knock-on effect of catalyzing curation of large datasets specific to LMIC regions leading to region-specific AI solutions. Edge and fog computing, which leverage local processors and nearby servers, only sending relevant information to a cloud, offer alternatives to centralized or cloud servers, thereby reducing latency and enabling real-time alerts. Such setups may improve speed, reliability, and patient data security in LMIC health care systems.

Cost is another critical factor. To ensure affordable access to AI-enabled epilepsy care, partnerships with governments, non-profits, and industry are necessary to subsidize deployment costs and eliminate proprietary barriers. As an example, Tunisia has adopted the creation of a research consortium—The Tunisian Consortium

of Artificial Intelligence for Advanced Medicine—as a means of convening all relevant parties for the goal of sustainable AI. Such collaborations can also promote open-source development, making AI tools more accessible.<sup>87</sup> Tools must also be culturally contextualized, and iterative patient-centered engagement is crucial. Taking a tool from one country and implementing it in another without paying careful attention to all necessary processes can be potentially harmful, especially in LMIC regions where reliance on such tools can increase rapidly.

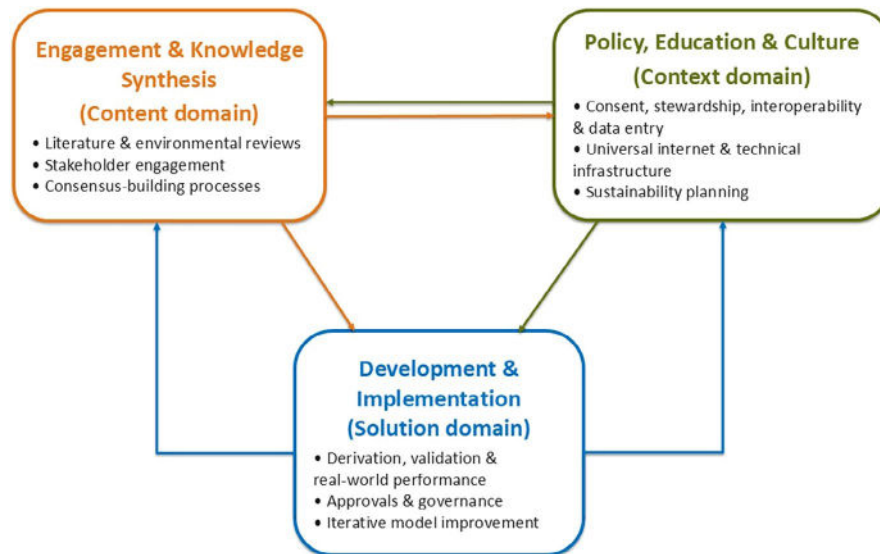
Educational initiatives are required to train health care providers on AI technology and best practices.<sup>92,93</sup> Current solutions include the creation of new technology departments and pre-graduate AI training courses in Tunisia. In addition, the creation of consortiums and research collaborations between health care providers and engineers can lead to mutually beneficial educational opportunities for the development and deployment of applications and tools to improve diagnosis and care. AI may also augment medical teaching opportunities, especially in LMICs, but it should not impede or discourage teaching opportunities that foster humanistic roles such as mentorship and communication.<sup>94</sup> Establishing minimal ethical, equity, practical, and performance standards is required prior to universal deployment of AI-based educational initiatives, such as for those designed for EEG instruction,<sup>95</sup> and can help advance the aim of equalizing training in high- and low-resource settings.

Achieving global equity in AI-driven epilepsy care will require sustained, collaborative efforts. Priorities include fostering international data-sharing initiatives, expanding training for health care workers in LMICs, and tailoring AI tools to specific cultural and clinical contexts. Integrating real-world data from diverse sources into dynamic, accessible clinical tools will be crucial for addressing these challenges.<sup>96</sup>

## 7 | A ROADMAP FORWARD

Development of AI that safeguards equal, effective, and ethical models for the global epilepsy community requires a measured and deliberate approach. We propose that three distinct but complementary domains, namely “content,” “context,” and “solutions,” are required to achieve this aim (Figure 1).

We advocate for the use of “decision intelligence” at all stages, but especially as applied to the content domain, which comprises engagement and knowledge synthesis.<sup>97</sup> Decision intelligence is a practical discipline that advances decision-making by explicitly understanding and engineering how decisions are made and how outcomes are



**FIGURE 1** To ensure that artificial intelligence (AI) benefits all people with epilepsy globally, a strategic roadmap grounded in equity, ethics, and effectiveness is essential. This framework spans three interdependent domains: Content, which emphasizes interest-holder engagement and decision intelligence; context, which addresses policies, education, infrastructure, and cultural readiness; and solutions, which encompass the development, evaluation, and implementation of trustworthy AI tools. The content and context domains mutually inform each other, which feeds into the solution domain. The resultant AI tool derived from the solution domain will iterate back to the content and context domains, thus comprising an enduring, cyclical framework for building AI that is scientifically sound, socially acceptable, and clinically meaningful.

evaluated, managed, and improved via feedback. This naturally entails early and enduring involvement of interest-holders at all stages of development, including planning stages, who address pertinent issues (Table 4). Crucial to this stage are comprehensive environmental and literature reviews and an engagement process that involves people with epilepsy, health care providers, researchers, information technology professionals, industry, and institutional/governmental representation. Early involvement of people with epilepsy is particularly critical. Evidence exists that the general public desires AI that (i) provides risk indications but not necessarily a diagnosis, (ii) autonomy as to whether to follow AI recommendations, (iii) improved transparency regarding source data and AI model function and interpretability, (iv) proper AI supervision by health care providers, and (v) AI that is used primarily as a reference or decision tool that is complementary and not prescriptive to clinical care.<sup>98</sup> Concurrent early interactions with health care providers who can synthesize domain knowledge will allow developers to generate tools that are actually needed all while avoiding solutions that improve care at the expense of increased administrative and technological burden. These forms of engagement should entail a mixture of surveys, focus groups, and consensus-based recommendations. Surveys and focus groups are integral for defining specific views and perspectives and can inform thematic analyses on what AI solutions are possible and desired. Consensus-based approaches, such as the

Delphi technique, the nominal group technique, and the RAND corporation/University of California Los Angeles appropriateness methods, will build on this foundational knowledge by consolidating broad community agreement on how to achieve the desired priorities. These methods of engagement must be iterative, given that goals will inevitably change with time.

The context domain, comprising policy, education, and culture, is parallel to and heavily interconnected with the content stage (Figure 1). Government and institutional policies are needed to address major data issues, including consent for use, stewardship, quality, misuse, and underuse. Creating organizational regulations and educational programs that guide the tenets of individual consent, stewardship, and mandate comprehensive and reliable data entry are necessary to ensure that models are derived from accurate and representative information. Legislation is required that not only directs privacy-conserving data safety, but also requires interoperability protocols<sup>99</sup> to safeguard secure and rapid exchange of health information both for model development and use at points of care. The latter point is particularly pertinent given that non-use of accessible and high-quality health data arguably contributes equally to harm as misuse and is comparatively underappreciated.<sup>100</sup> Such legislation should also mandate efforts to promote representative data and require concerted efforts to reduce unintended harmful bias as a means of building public trust. Policies

Theme	Key questions/considerations
Relevance and Necessity	<ul style="list-style-type: none"> <li>Is the AI solution necessary and will it change practice? Or will it create more burden?</li> </ul>
Data Availability and Quality	<ul style="list-style-type: none"> <li>Are all required data readily available both at the point of development and deployment?</li> <li>Can the known and unknown biases in the dataset be adequately addressed and mitigated?</li> </ul>
Interpretability and Trust	<ul style="list-style-type: none"> <li>What degree of interpretability of the AI model is required?</li> </ul>
Regulatory and Institutional Fit	<ul style="list-style-type: none"> <li>What are the institutional, administrative, and regulatory requirements for the proposed solution to be deployed within its intended context?</li> </ul>
Communication and Usability	<ul style="list-style-type: none"> <li>How is the AI output going to be conveyed to health care workers and people with epilepsy?</li> <li>Can this solution be readily implemented into clinical workflows?</li> </ul>
Infrastructure and Resources	<ul style="list-style-type: none"> <li>Are sufficient computer resources available?</li> </ul>
Equity, Ethics, and Global Impact	<ul style="list-style-type: none"> <li>Will it inadvertently create local or global inequities?</li> </ul>
Scalability and Sustainability	<ul style="list-style-type: none"> <li>Is the solution scalable and sustainable? If so, what are the costs and do organizations (private, public, or a hybrid) exist that will support the solution?</li> </ul>
Industry and Commercialization	<ul style="list-style-type: none"> <li>Will industry (for profit) engagement promote speed and efficiency of AI development, testing, and deployment and, if commercialized, can revenue be reinvested in research and development and advocacy efforts to directly assist people with epilepsy?</li> </ul>

Abbreviation: AI, artificial intelligence.

are required that mandate universal internet access<sup>101</sup> and guide the development of environmentally sustainable, high-performance computing decentralized environments as a means of facilitating implementation of equitable, ethical, and effective AI tools. Blueprints must be made a priori that guide long-term viability, including a clear and cogent outline of which parties will be responsible for governing and financially sustaining and supporting the AI solution. Central to this will be specifying whether the product will be commercialized, non-profit, or a hybrid venture.

By necessity, achieving these prerequisite milestones must entail early and enduring collaborations between professional organizations (e.g., the International League Against Epilepsy and its constituent chapters), layperson organizations (e.g., the International Bureau for Epilepsy), universities, research institutions, global epilepsy research collaboratives, and industry and commercial partners. Concomitant with this, training programs are urgently needed to equip people with epilepsy and health care providers with the obligatory knowledge, literacy, and tools necessary to provide the required foundations to contribute meaningfully to the content and context domains, and

to engender a sense of trust and confidence in AI solutions. Ultimately, success in the content domain depends on successful engagement with the content domain and vice versa—the epilepsy community is essential to inform and advocate for AI policies that benefit people living with the disease, and the extant policies, culture, and technological infrastructure guide decision intelligence efforts to identify solutions currently tractable in the existing milieu.

The content and context domains directly inform the AI solution. Once the candidate problem is determined, and the potential solution identified, efforts can be made to derive a tool by following a logical “end-to-end” progression from “bench to bedside,” as outlined by the SALIENT-AI framework.<sup>102</sup> Successful completion of this process is predicated on transparency and adherence to best practices. Where possible, derivation and validation steps should conform to guidelines and reporting standards<sup>103,104</sup> such as PROBAST<sup>105</sup>/PROBAST-AI,<sup>106</sup> TRIPOD<sup>107</sup>/TRIPOD-AI,<sup>106</sup> and DECIDE-AI.<sup>108</sup> Once internal and external validity and early clinical evaluations are established, efforts must be made to perform decision curve analyses and subject models to rigorous RCTs and

**TABLE 4** Examples of core issues that should be addressed by a representative panel of interest-holders as a means of instituting decision intelligence informed engineering and deployment of AI in epilepsy.

health economics analyses to establish real-world performance according to current and evolving guidelines and reporting standards.<sup>104</sup> For clinical trials involving AI, protocols and publications should conform to SPIRIT-AI and CONSORT-AI consensus guidelines respectively,<sup>109</sup> whereas CHEERS-AI<sup>110</sup> addresses health economics analyses of AI-based solutions. These studies and trials should not only evaluate accuracy and health savings, but also explore decision analyses of net benefit,<sup>48</sup> risks of clinician burnout,<sup>111</sup> and evidence of inadvertent harmful bias, and ensure local and/or global equitable care. Once these goals are achieved, approvals must be sought from regulatory bodies, as AI-based solutions are increasingly considered “software as a medical device” (SaMD).<sup>112,113</sup> Approved AI solutions must recursively receive regular health data to ensure that they remain flexible and accurate in response to evolving local care environments. Finally, implementation and knowledge translation should be undertaken only after careful and systematic preparation. Recommendations exist on how to accelerate the adoption of sustainable AI tools.<sup>114</sup> Succinctly, these involve developing education plans to promote AI literacy, conducting local needs assessments and environmental scans, developing engagement and awareness campaigns, creating certificate-based user interventions, conducting mixed-methods studies piloting the tool, and creation of best practice guidelines to maximize value in the new local context.<sup>114</sup> Successfully implemented AI solutions will then naturally feed back to the context and content domains as new problems emerge, and novel insights are realized.

We call for such road maps to be instituted promptly. If implemented and executed according to broad scientific and ethical standards, we strongly believe in the ability of AI to revolutionize epilepsy care for the betterment of all people across the globe. However, the risks are not trivial. We must therefore act expeditiously and emphatically, since the creation of equitable and effective AI is something we simply cannot afford to get wrong.

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#### DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

#### ETHICS STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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