

## RESEARCH ARTICLE

# Precision medicine in epilepsy: Clinicians' perspectives from an international qualitative study

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## Abstract

**Objective:** Precision medicine (PM) is gaining increasing importance in the treatment of rare genetic epilepsies. However, its availability and implementation in clinical practice remain limited. This study explores the barriers and facilitators influencing the implementation of PM for people with epilepsy (PWE).

**Methods:** Semistructured interviews were conducted with clinicians involved in epilepsy care for PWE across various global regions. Participants were purposefully selected based on geographical distribution and World Bank income classification. Framework analysis was used to identify key themes.

**Results:** Sixteen clinicians from six different continents were interviewed. Five key themes emerged. The implementation of PM depends on (1) the personal perspective and experience of health care providers; (2) the attitude of PWE and their caregivers toward PM, and their interaction with clinicians; (3) continuous education of health care providers, formation of expert teams, and generation of robust evidence on PM; (4) multilevel collaboration including patient advocacy groups; and (5) a clear, consistent organizational approach and the development and implementation of standardized guidelines.

**Significance:** Clinicians consider PM as transformative for the care for PWE and expect it to redefine standard practice in the near future. Insufficient knowledge is the primary barrier to PM implementation, irrespective of socioeconomic context, highlighting the need for its integration into basic medical training and residency

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programs. To address inequities, integrated care pathways and standardized guidelines for genetic testing and PM, and the establishment of local PM-focused expert teams are essential to support clinicians in making informed PM decisions.

#### KEYWORDS

clinicians' opinions, framework analysis, genetic epilepsies, implementation barriers, implementation facilitators, organization of epilepsy care

## 1 | INTRODUCTION

Until recently, the choice of antiseizure medication (ASM) for genetic epilepsies was mainly based on seizure types and epilepsy syndrome diagnosis. Today, precision medicine (PM), referring to the personalization of medical care taking into account also genetic and molecular understanding, has become increasingly important in epilepsy management.<sup>1</sup> For certain genetic epilepsies, PM has been successfully applied. For example, sodium channel blockers are used in *SCN2A*-related early infantile developmental and epileptic encephalopathy, and the ketogenic diet is effective for glucose transporter 1 deficiency syndrome.<sup>2,3</sup> Despite these advances, a genetic diagnosis does not ensure that PM will be available for every individual. Many genetic epilepsies still lack a tailored PM approach, and even when such therapies are available, they often remain inaccessible in clinical practice.<sup>4</sup> Several frameworks have been proposed to conceptualize PM in epilepsy, classifying different forms of PM based on how effectively they target underlying pathophysiological mechanisms, including genetic defects.<sup>5,6</sup> Lack of consensus on which therapies qualify as PM contributes to the difference in reported availability of PM, alongside the differences in population in which they were studied.<sup>4</sup> Quantitative studies conducted at tertiary epilepsy centers in high-income countries have identified various barriers to the implementation of PM.<sup>4,7-9</sup> Despite these studies, significant uncertainty remains regarding the feasibility of PM in broader clinical practice. Because the majority of people with epilepsy (PWE) receive care outside tertiary centers, it is essential to explore the perspectives and experiences of epileptologists from diverse global and clinical settings. Through this qualitative study, we aim to gain a deeper understanding of clinician's views on PM implementation, as well as insights into existing concepts and challenges. Our goal is to enhance knowledge on PM and its practical application worldwide, ultimately recommending tailored interventions to improve its implementation.

#### Key points

- Clinicians consider PM to be transformative for the care of people with epilepsy.
- Insufficient knowledge is the primary barrier to PM implementation.
- PM needs to be incorporated into basic medical training and residency programs.
- Integrated care pathways and standardized guidelines for genetic testing and PM are needed to ensure equity.
- The establishment of local PM-focused expert teams are essential to support clinicians in making informed PM decisions.

## 2 | MATERIALS AND METHODS

### 2.1 | Study design

We performed a qualitative study, using semistructured interviews with clinicians involved in epilepsy care for children or young adults. The study was designed and conducted through a collaboration between the multidisciplinary teams of Antwerp University Hospital/University of Antwerp and the Danish Epilepsy Center, Filadelfia.

### 2.2 | Recruitment

Participants were recruited through the professional networks of the researchers. We used purposeful sampling, applying the following criteria: participant's country/World Health Organization region, World Bank income classification of their country, and their work setting (categorized as university hospital or specialized epilepsy center vs. nonuniversity or nonspecialized epilepsy center). World region and World Bank income classification were defined according to the

World Bank website.<sup>10</sup> Participants fulfilled the following inclusion criteria: clinicians (with medical degree) who are actively involved in and experienced with clinical care for children and young adults with epilepsy, with a sufficient knowledge of the English, French, or Dutch language.

### 2.3 | Data collection

We conducted semistructured interviews between November 2023 and March 2024. All interviews were performed online by one of the researchers (M.D.W.) using Microsoft Teams (version 1.600.26474). Transcripts were automatically created using Microsoft Teams and manually reviewed for transcription errors. A semistructured interview guide ([Supplementary Material](#)), based on a literature review and expert input from the research team, was used. The interview guide was refined iteratively during data collection and analysis. Additionally, participants were asked to provide brief details about their current role in the field ([Table 1](#)).

### 2.4 | Ethics

This study was approved by the institutional review board at the Danish Epilepsy Center (EMN-2023-10904). This study was conducted according to the principles of the Declaration of Helsinki, amended at the 64th General Assembly (Fortaleza, Brazil, October 2013) and in accordance with the European Union General Data Protection Regulation. All participants provided informed consent.

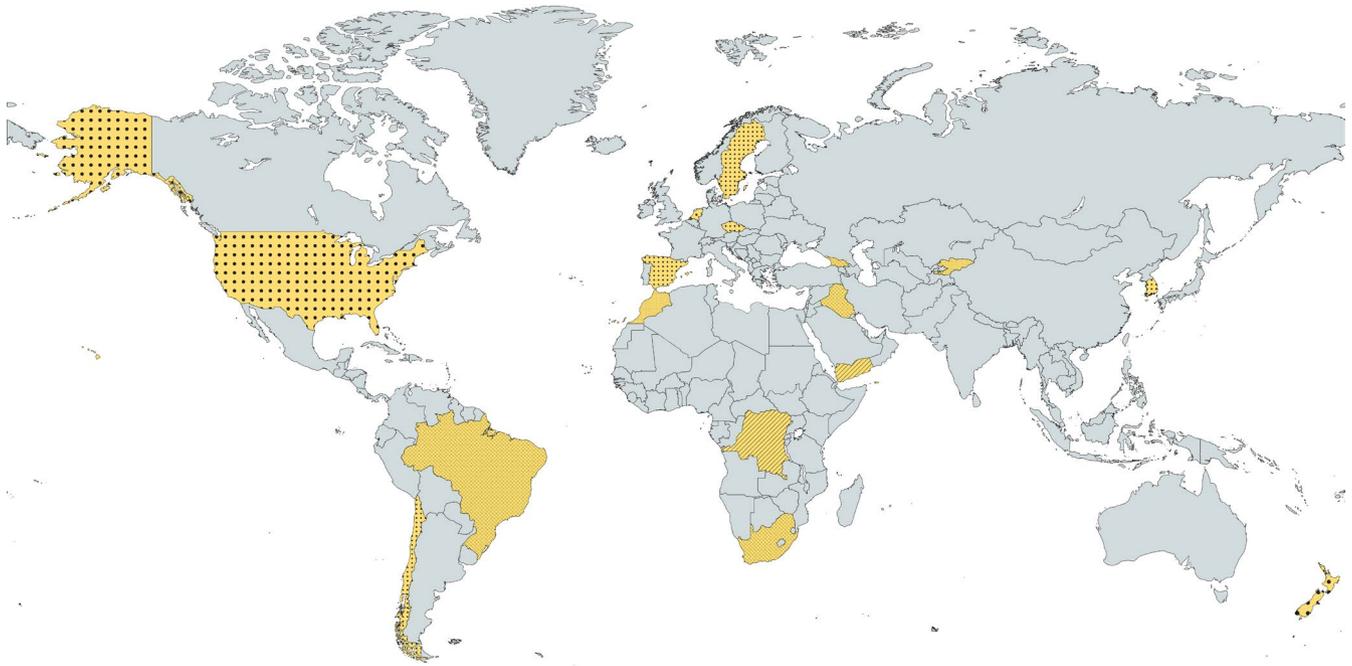
### 2.5 | Analysis and reporting

Framework analysis (FA), as developed by Ritchie and Spencer<sup>11</sup> and adjusted for multidisciplinary health care research by Gale et al.<sup>12</sup>, was used to identify relevant themes. FA included the following steps: data transcription, familiarization, coding/indexing, developing a working analytical framework, applying the analytical framework to the data, charting data into the framework matrix, and interpreting the results. A.J. and M.D.W. coded the transcripts and developed and applied the framework to the data, with the support and input of the research team during regular meetings. The framework was repeatedly discussed, until the final version, presented in [Figure 2](#), was established. All quotes were anonymized to prevent identification of

**TABLE 1** Overview of experience of participants and the clinical setting they are working in.

Participant	Years of experience in epilepsy care	Type of practice
P1	18	General child neurology center
P2	23	Specialized epilepsy center
P3	7	Specialized epilepsy center
P4	30	General child neurology center
P5	10	General child neurology center
P6	10	University center
P7	13	University center
P8	27	University center
P9	12	University center
P10	25	University center
P11	10	Specialized epilepsy center
P12	25	General child neurology center
P13	17	General child neurology center
P14	25	University center
P15	10	University center
P16	20	General child neurology center

participants or countries of practice. If necessary, quotes were rewritten in formal English, without altering the original meaning. Participants were randomly assigned pseudonyms. Findings were reported using the Standard for Reporting Qualitative Research recommendations. M.D.W. was a child neurologist and epileptologist in training with no prior personal or professional relationship with the participants. A.J. was trained as a research nurse and had extensive clinical experience with PWE. Both M.D.W. and A.J. were trained in qualitative research and received guidance from experienced qualitative researchers (A.C., A.C.J.). M.D.W. and A.J. were constantly aware of their role, using a reflexive journal and engaging in frequent discussions with the research team. The use of two coders was intended to ensure conceptualization of the framework rather than to achieve coding agreement. Their different professional backgrounds helped minimize the influence of preexisting personal opinions about the subject.



**FIGURE 1** World map representing countries of practice of participants. Patterns represent World Bank income: Dots: high income; crosshatch: high-middle income; diagonal stripes: lower middle income; plain: low income. From left to right, from top to bottom: United States of America, Brazil, Chile, Spain, Morocco, the Netherlands, Sweden, Czech Republic, Democratic Republic of Congo, South Africa, Georgia, Iraq, Yemen, Kyrgyzstan, Republic of Korea, and New Zealand.

### 3 | RESULTS

Sixteen participants from six different continents were interviewed. The 16 countries of clinical practice of these participants were the United States of America, Brazil, Chile, Spain, Morocco, the Netherlands, Sweden, Czech Republic, Democratic Republic of Congo, South Africa, Georgia, Iraq, Yemen, Kyrgyzstan, Republic of Korea, and New Zealand. World region, World Bank income, center of clinical practice, and experience levels of the participants are listed in [Table 1](#) and [Figure 1](#). We identified five key themes influencing the implementation of PM and subdivided them into different subthemes ([Figure 2](#)). The first theme addressed the individual clinician's role in the implementation of PM, whereas the second explored the role of the interaction between clinicians, PWE, and caregivers. The third focused on the need to improve knowledge of genetic testing, epilepsy care, and PM. The fourth theme discussed the collaborative efforts necessary for the implementation of PM, whereas the fifth emphasized the need for health care system restructuring to ensure its success. In the following paragraphs, we will discuss these themes in detail, supported by participant quotes.

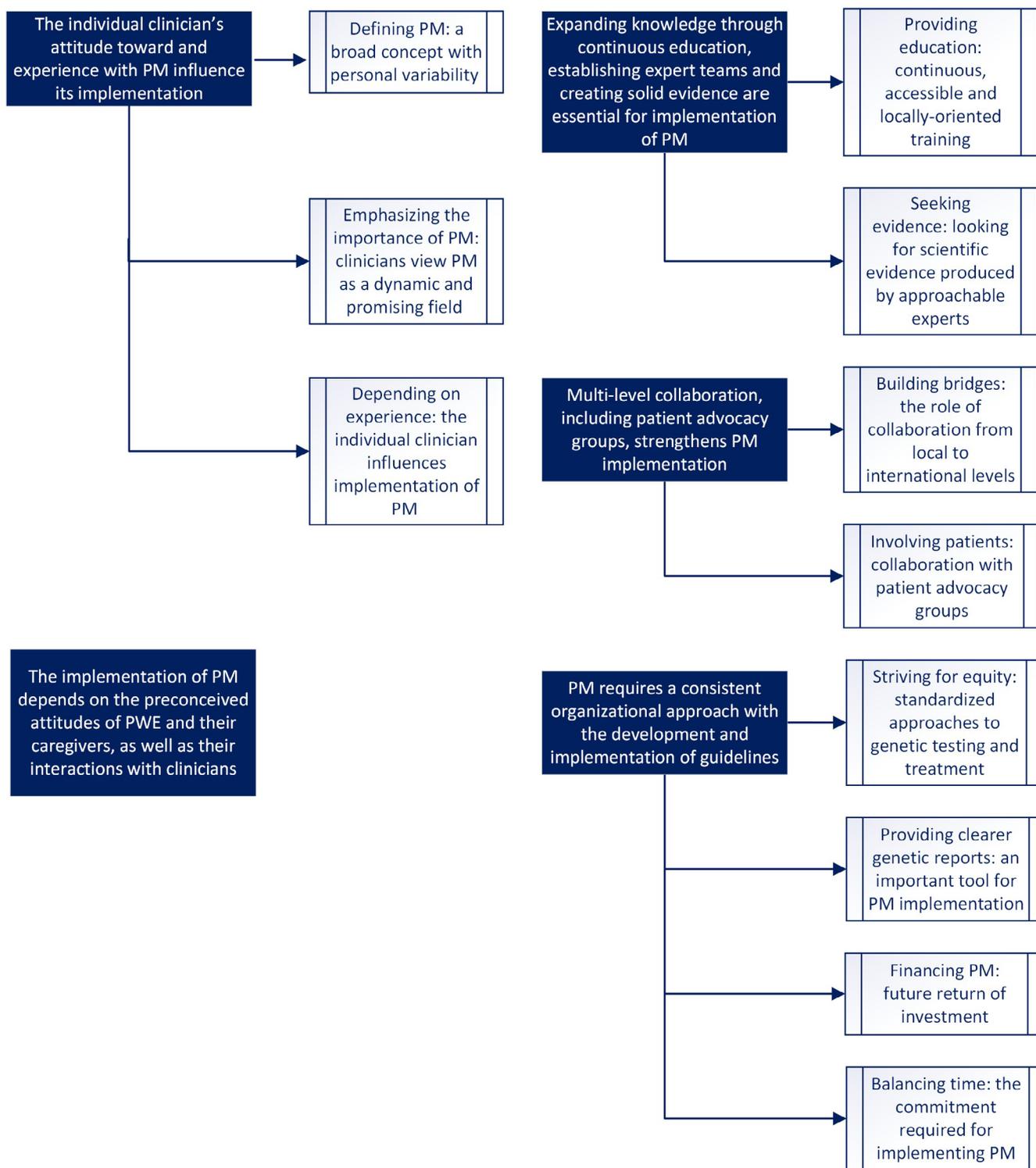
#### 3.1 | The individual clinician's attitude toward and experience with PM influence its implementation

##### 3.1.1 | Defining PM: A broad concept with personal variability

Participants demonstrated significant variation in their definitions of PM, frequently describing it as “broad” or as encompassing “more than one thing.” Although only some participants were familiar with the frameworks outlined in the literature, nearly all described a similar continuum within PM. Although they used different terms to explain their perspectives, they consistently conveyed that PM involves personalized treatment strategies, with varying degrees of targeting the underlying mechanisms ([Figure 3](#)).

I don't think that PM is one thing. (P15)

PM is every specific treatment strategy for a specific etiology, even when we don't know the molecular background. (P11)

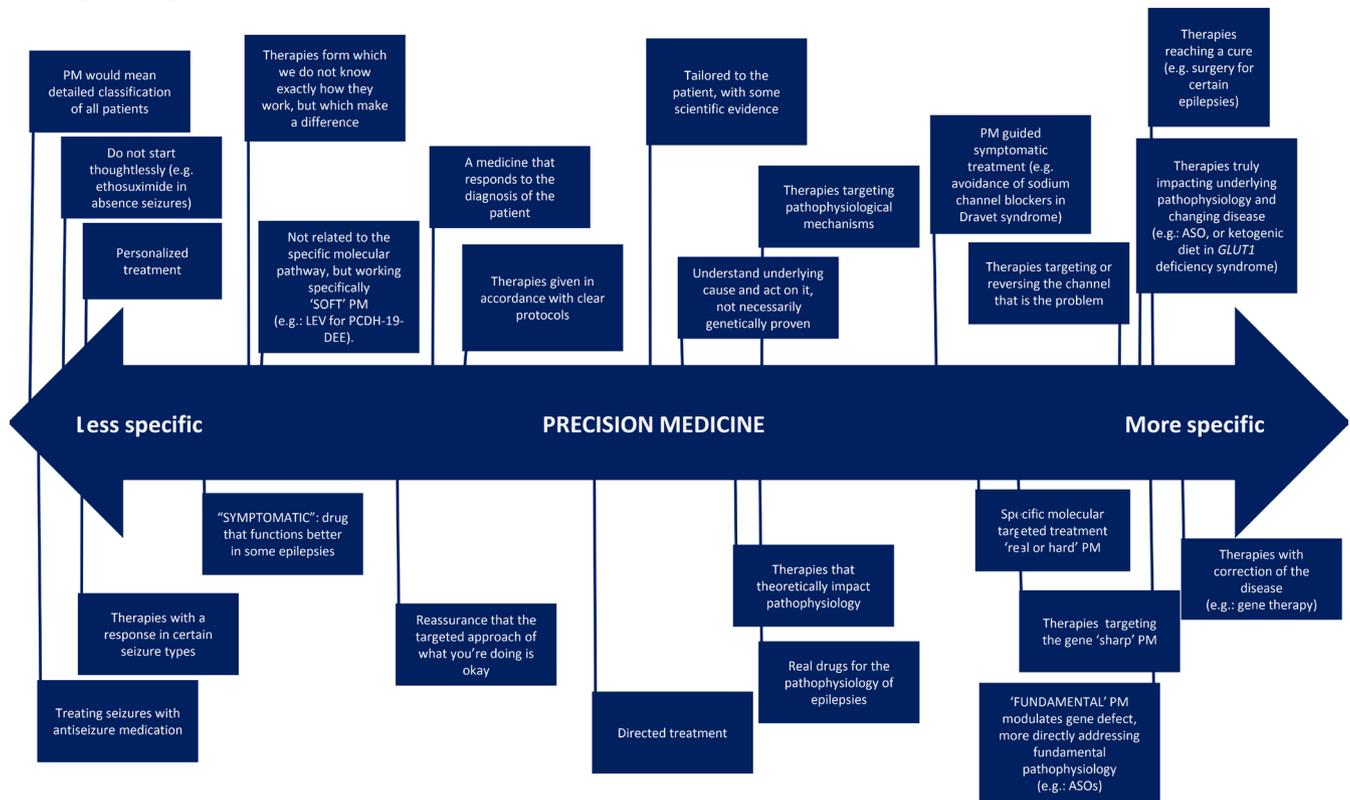


**FIGURE 2** Schematic overview of the framework created. PM, precision medicine; PWE, people with epilepsy.

### 3.1.2 | Emphasizing the importance of PM: Clinicians view PM as a dynamic and promising field

Participants considered PM a complex and rapidly evolving field, with continuously changing evidence and practices.

Participants highlighted the growth and future potential of PM to significantly improve the quality of life for PWE. They stressed the importance of staying informed and recognizing even small advancements as meaningful progress. Even if they did not have the resources to provide PM themselves, they encouraged their patients to seek PM opportunities elsewhere.



**FIGURE 3** Participants' personal definitions of precision medicine (PM) ranged from less to more specific. ASO, antisense oligonucleotide; LEV, levetiracetam; PCDH-19-DEE, *PCDH19*-related developmental and epileptic encephalopathy.

PM is a complex knowledge which could be used to manage the patient.

(P4)

I think future belongs to PM, that is my answer.

(P4)

PM is important and it is useful.

(P6)

### 3.1.3 | Depending on experience: The individual clinician's expertise influences implementation of PM

Participants represented diverse backgrounds, encompassing geographical, theoretical, and experiential differences that shape their approach to PM. Some participants were actively involved in PM-related research, education, advocacy on policy matters, and daily management of rare diseases, positioning them as key advocates for PM in the care for PWE. Other participants were well aware of their limited experience in the field and readily sought guidance from experts when it came to implementing PM strategies. Overall,

participants highlighted that diagnostic and treatment options may differ between clinicians, which could influence care provided to PWE.

We only have one or two patients with a specific genetic diagnosis. So, it's really hard [...] and we have to rely on advice.

(P12)

## 3.2 | The implementation of PM depends on the preconceived attitudes of PWE and their caregivers as well as their interactions with clinicians

The willingness of PWE and their caregivers to engage with PM emerged as a critical factor in its implementation. Participants described a range of attitudes from PWE and caregivers toward adopting PM, with starting a new treatment often evoking concerns and anxieties that may lead to resistance. Factors such as age, disease acceptance, and current life circumstances were mentioned as specifically influencing readiness to explore novel therapeutic approaches. Disease severity influenced the readiness for PM, with greater severity leading to increased openness to

its use. At the same time, participants reported that PWE and their caregivers demonstrated a strong willingness to consider PM, often going as far as seeking genetic testing abroad, funding it privately, and traveling both domestically and internationally for potential PM options.

Some parents do not want to try anything anymore. They just don't want to because they are afraid.

(P14)

Participants stressed the importance of aligning expectations about PM among clinicians, PWE, and caregivers. They noted that preconceived expectations about treatment effects and quality of life required clear communication, time, and evidence to align effectively.

I actually have to spend most of my time talking with families, reducing expectations of these new therapies, even if they're not here [available] yet.

(P15)

If you can provide them with decent evidence, they'll be right on to a certain PM.

(P8)

### 3.3 | Expanding knowledge through continuous education, establishing expert teams, and generating solid evidence are essential for implementation of PM

#### 3.3.1 | Providing education: Continuous, accessible, and locally oriented training

Participants expressed the need for education on various aspects of PM for PWE, including epilepsy in general, rare diseases, genetic testing, and PM itself. Participants provided examples of existing educational resources but emphasized the need for a more continuous and easily accessible training. Furthermore, they emphasized the need to tailor educational initiatives to regional circumstances and differences. Participants often acknowledged their own gaps in training and expressed concern about a knowledge gap among collaborators and policymakers.

I think education should be approached systematically. Every clinician should know at least some aspects of PM.

(P4)

#### 3.3.2 | Seeking evidence: Looking for scientific evidence produced by approachable experts

Participants acknowledged that PM is still in its early stages; long-term outcomes are lacking, diseases can be ultrarare, and often PWE diagnosed with a rare genetic epilepsy have not even reached adulthood. Participants expressed the need for robust evidence to make informed treatment decisions. They are very specific about the types of information they seek, which include (1) information about pathophysiological mechanisms, ideally supported by *in vitro* or *in vivo* models; (2) information on therapeutic efficacy measured across a range of outcomes such as seizures, cognition, alertness, reduction of ASM, quality of life, and autonomy; (3) information on potential therapeutic biomarkers, including electroencephalography; and (4) information on safety profiles or side effects of PM approaches.

Participants searched for the highest level of evidence in literature, webinars, and specialized websites. They prioritized reproducibility over large sample sizes and recognized the lack of randomized controlled trials in rare disorders, which motivated them to also rely on case reports. Notably, they placed significant value on literature authored by experienced professionals, particularly those with whom they have established professional relationships and who can provide specific, practical guidance.

I would want those really big studies that tried different medicines. But I know that's impossible right now. So I don't even look for it [...]

(P12)

Usually, I ask those persons I can easily reach out to by just calling them.

(P5)

### 3.4 | Multilevel collaboration, including patient advocacy groups, strengthens implementation of PM

#### 3.4.1 | Building bridges: The role of collaboration from local to international levels

Participants frequently emphasized the importance of collaboration with health care workers across multiple levels. Personal collaboration involved easily accessible advice from/brainstorming with colleagues whom they could personally reach out to. Local collaboration included

multidisciplinary meetings or clinics within the hospital (network). National collaboration involved formal partnerships, for example, national child neurology organization or epilepsy workgroups. International collaboration encompassed both formal organizations, for example, EpiCARE or NETRE,<sup>13</sup> and informal partnerships, such as sending patients abroad for genetic testing. Participants who had access to formal collaborations recognized their pivotal role in the successful implementation of PM. Those lacking formal collaborations expressed a need to establish such formal partnerships.

We have a meeting, every month, and then we discuss these cases with the clinical geneticists, clinicians, and laboratory.

(P9)

I guess the ILAE has to take the leadership on that [international collaboration and research about PM].

(P11)

### 3.4.2 | Involving patients: Collaboration with patient advocacy groups

Participants strongly advocated for increased involvement of patient advocacy groups, emphasizing the need to establish new groups for rare diseases that currently lack representation. Participants thought the advocacy groups are crucial in driving change at both the individual PWE and policy level, particularly in lobbying for the implementation of PM.

Establish workable and powerful patient organizations in each country, that's also the way to implement PM more openly and more sustainably.

(P4)

## 3.5 | PM requires a consistent organizational approach with the development and implementation of guidelines

### 3.5.1 | Striving for equity: Standardized approaches to genetic testing and treatment

Participants highlighted the practical challenges of PM, often linked to the organization of health care within a specific country. These challenges included the lack of genetic testing facilities, limited availability of specific drugs or treatments, and shortage of specialized clinicians. They

emphasized that successful implementation of PM requires comprehensive infrastructural improvements.

We have no laboratory to carry out genetic analysis.

(P3)

Participants also expressed concerns about disparities in health care within their countries. Access to genetic testing and PM depended more on how the health care system is organized than on the country's economic status and was influenced by factors such as receiving care in cities or remote areas and in private or governmental hospitals, and on health care insurance status.

There is incredible inequity in terms of who gets genetic testing and who doesn't.

(P8)

All participants shared similar concerns about equity and transparency in treating rare genetic epilepsies. They advocated for broader access to genetic testing and PM treatments, and considered the development of guidelines on genetic testing and treatment crucial to influence policymakers on availability and reimbursement of PM. To ensure equal care, participants proposed creating frameworks for PM, which included systematic referral processes and establishment of local multidisciplinary care teams.

There is not a clear pathway to refer patients to the reference hospital.

(P11)

We put in a guideline that says: all children that [...] get genetic testing. And so, the pediatricians will know that [...] So it'll equal [...]. I think guidelines really help guide education, guidelines help fix equity.

(P8)

I think is critical to moving us from disconnected and varied approaches to both research and clinical care to a more cohesive [...] system for implementation of rare diseases.

(P15)

### 3.5.2 | Providing clearer genetic reports: An important tool for PM implementation

Participants viewed the genetic report as essential for PM implementation. They stressed the importance of relevant and

concise information, noting issues with the incorrect use of the American College of Medical Genetics and Genomics classification and insufficient references to the literature, especially for variants of unknown significance. Clear genetic reports were particularly critical in settings with limited collaboration between neurologists, geneticists, and laboratories. Participants had different opinions about including treatment implications in the report. Many participants perceived this to be valuable but they believed the responsibility for treatment ultimately rests with the clinician, not with the lab.

If there is a problem with any reports, it's not that there's not enough information. It's probably that there's too much information for people who don't have high level expertise to sift through.

(P8)

They try to make very clear reports for the usual neurologists, that are not very involved in genetics. So sometimes they don't mention important variants, so I have to contact them.

(P11)

### 3.5.3 | Financing PM: Future return of investment

Participants acknowledged that implementing PM introduces financial challenges, including the need for investments in research, drug development, genetic testing, and multidisciplinary team organization. However, participants stressed that these investments could lead to long-term cost savings by improving outcomes. In this regard, participants stressed that patient advocacy groups have a great potential to push policy changes.

I think the government should be prepared, not only for the diagnosis [of rare diseases], but also for [implementing] treatments to change the outcome [of the disease]. The costs will be much lower when we do something now, because it will maybe work preventive.

(P1)

### 3.5.4 | Balancing time: The commitment required for implementing PM

Participants agreed that the implementation of PM is more time-consuming than standard care, requiring a

personalized approach for each patient, and additional administrative work, including reimbursement, ethical approval, or other paperwork. Participants recognized that this time investment reflects the infancy of the field, and the effort required to integrate PM into clinical practice. Despite these challenges, participants were willing to dedicate the necessary time for its advancement.

It's just that rare diseases are rare diseases. It takes a lot of work for each rare disease.

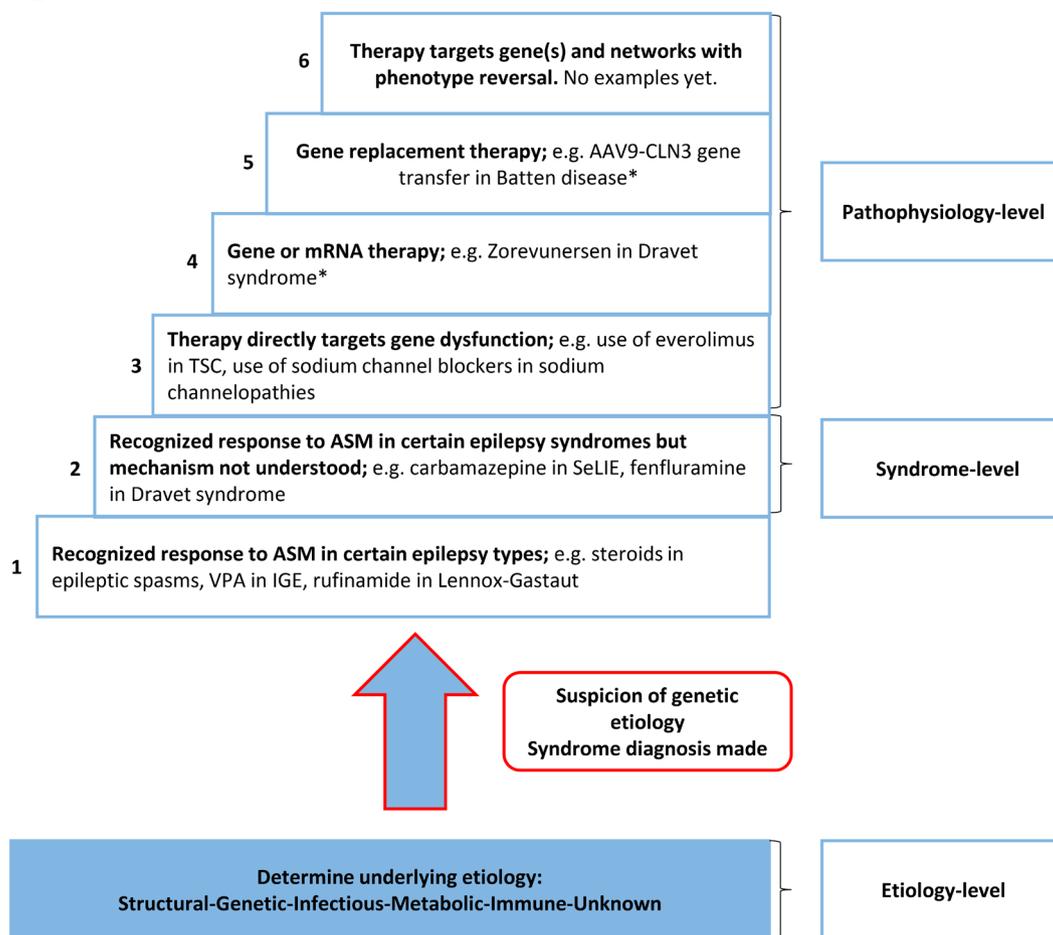
(P8)

## 4 | DISCUSSION

This study offers an in-depth analysis of the barriers and facilitators involved in implementing PM in epilepsy care, using a qualitative research approach. Based on interviews with 16 clinicians from six continents, we identified five key themes, ranging from the role of the individual clinician in applying PM to the need for a consistent organizational approach to PM implementation. A systematic review by Sheidley et al.<sup>14</sup> revealed that implementation of PM for PWE with a genetic diagnosis varied from 12% to 80%. Other studies have showed that implementation depends not only on the availability of a specific PM option (varying from 40% to 72%) but also on barriers such as uncertain functional effect of a genetic variant, degree of seizure control or acceptance of disease, limited access to certain therapies outside a research setting, and high costs.<sup>4,7,9</sup> Our study confirms the existence of these barriers while also proposing potential strategies to enhance implementation of PM across diverse clinical settings.

First, clinicians in this study emphasized the importance of PM and view it as integral to the future of epilepsy care, aligning with findings reported in the literature.<sup>15</sup> However, a lack of uniformity in how PM is defined presents a significant barrier (see [Figure 3](#)). Participants expressed varying interpretations of PM, shaped by their individual experiences and expertise in the field. This wide interpretation may hinder broader adoption, study, and evaluation of PM. To address this, we strongly encourage the use of clear definitions and frameworks when discussing PM, as this enables meaningful comparisons across studies and facilitates unified strategies for its implementation. [Figure 4](#) displays an integration of easy-to-use, already available frameworks. We call upon the International League Against Epilepsy to develop an internationally accepted and clinically applicable framework for PM in epilepsy.

Second, this study identifies the individual clinician as an important facilitator of PM implementation.



**FIGURE 4** Integrated frameworks for precision medicine in epilepsy, as adapted from Byrne et al.<sup>5</sup> (displayed on the left) and Balestrini et al.<sup>6</sup> (displayed on the right). The examples displayed are based on current literature and are subject to change in the future as new discoveries, technological advancements, and further research may lead to revisions or new interpretations. AAV9, adeno-associated virus 9; ASM, antiseizure medication; IGE, idiopathic generalized epilepsies; SeLIE, self-limited (familial) infantile epilepsy; TSC, tuberous sclerosis complex; VPA, valproic acid. \*Although not yet available in clinical practice, preliminary results from phase 1 and 2 studies were promising.<sup>16,17</sup>

Clinicians with expertise in PM not only enhance its integration into their own clinical practice but also play a key role in the education of their colleagues and collaborators. The successful implementation of PM also depends heavily on the clinicians' communication and relational skills. PWE and their caregivers may hold both positive and negative attitudes toward PM, necessitating transparent, honest, and empathetic communication. Clinicians must contextualize expectations and fears while demonstrating confidence in their expertise to provide credible information. These communication skills, already recognized as important in clinical epilepsy care,<sup>18</sup> require adaptation to PM's specific context. Inherent to PM are the ethical considerations clinicians must navigate when communicating potential PM options to PWE and their families. These include the high costs of some treatments, limited availability, and a lack of robust long-term evidence. Conversely, both families

and clinicians may experience a sense of having "nothing to lose," which can lower the threshold for pursuing treatments with limited empirical support. The emotional complexity surrounding such discussions underscores the value of a multidisciplinary approach, ideally incorporating psychological support.

Third, knowledge emerged as a critical facilitator for successful PM implementation. In this study, participants considered the current understanding of PM to be inadequate. They particularly highlighted a lack of expertise in interpreting genetic variants and the PM options these variants inform, which aligns with previous reports.<sup>19</sup> To address this gap, incorporating comprehensive genetic training in medical education and residency programs is essential. Continuous education is equally important in this rapidly evolving field, with locally organized training sessions complementing international online courses to address region-specific needs.

Generating robust scientific evidence is also a crucial step for advancing PM. Although clinicians recognize the methodological challenges, they feel more confident in considering PM options for PWE when supported by well-designed studies, with a clear risk/benefit analysis and outcomes that do not focus only on seizures. Recent developments are beginning to shift the real-world feasibility of PM in epilepsy. Disease-specific registries and natural history studies are increasingly being integrated into research and clinical trial design, enabling better stratification of patient populations and more robust outcome measures. A notable example is Dravet syndrome, where a combination of coordinated natural history studies, international patient registries, and strong community engagement has laid the groundwork for the first clinical trial of an RNA-based antisense oligonucleotide therapy targeting *SCN1A*.<sup>20–22</sup> This convergence of infrastructure and therapeutic innovation exemplifies how rapidly evolving tools and knowledge are transforming what is clinically actionable, and illustrates the growing translational momentum across the field of genetic epilepsies.<sup>23–25</sup> Additionally, clinicians rely heavily on their readily accessible personal networks for support throughout the treatment process, highlighting the value of establishing local expert groups.<sup>26</sup>

Fourth, collaboration was identified as another cornerstone of PM implementation.<sup>1</sup> Effective collaboration involves different geographical levels, and encompasses research, education, clinical care, and policymaking. Direct partnerships between the genetic laboratories, geneticists, and clinicians were seen as critical to improve genetic reporting, which participants frequently cited as inconsistent.<sup>27</sup> Because clinicians' ability to interpret genetic results is essential for implementing PM, a clear and standardized genetic report is necessary. Including PM options in genetic reports, although complex due to potential legal implications, could help less-experienced clinicians make informed decisions. International collaboration can also extend PM to PWE in countries lacking genetic testing or specific treatments. Additionally, patient advocacy groups play a pivotal role in bridging gaps between clinicians, patients, and policymakers, by advocating for equitable care pathways and drug availability.

Lastly, efficient implementation of PM requires systematic adaptation of health care infrastructure. Beyond improving access to genetic testing and certain therapies,<sup>28,29</sup> establishing multidisciplinary teams and centralized care pathways is essential. This process requires sufficient time, logistics, and investments to ensure multidisciplinary and integrated care for rare genetic epilepsies. Successful examples, such as for tuberous sclerosis complex, demonstrate the feasibility of such approaches.<sup>30</sup>

Ensuring equity necessitates the development of universal guidelines for genetic testing and PM that are adaptable to specific settings.<sup>26,28</sup> Importantly, these recommendations provide the evidence required by policymakers to recognize PM as a standard of care.

This study has several limitations. Although it includes diverse perspectives from clinicians across multiple continents, the representation of countries was limited, potentially overlooking regional nuances. Although we briefly discussed differences based on geography or socioeconomic status, the qualitative design of our study does not support a formal comparison between high- and low/middle-income countries or regions. Future research could expand on these findings by focusing on these regional differences. Nonetheless, purposeful sampling ensured the inclusion of a diverse group of experienced clinicians, representing both specialized and nonspecialized centers, as well as countries with varying income levels. Additionally, researchers' and participants' personal experiences may have influenced the results, which is an inherent aspect of qualitative research. However, this qualitative approach remains a significant strength, offering a deeper and richer exploration of the challenges and opportunities in PM implementation.

## 5 | CONCLUSIONS

In conclusion, clinicians consider PM a critical component of future epilepsy care and anticipate its transformation into standard-of-care in the near future. To achieve this, a uniform framework is essential to ensure consistency in collaboration and research. The lack of adequate training was identified as a major barrier to implementing PM, regardless of a country's socioeconomic status, emphasizing the urgent need to incorporate PM into medical education and continuous professional development. To address inequities, it is crucial to establish clear care pathways and guidelines for genetic testing and PM. Furthermore, establishing local PM expert teams will provide a formalized point of contact for clinicians from different backgrounds, guiding them in making informed PM decisions. In the future, the implementation of PM will be positively influenced by increasingly accurate disease data derived from natural history studies and disease-specific registries, as well as by the rapid advancement of gene therapy. As highlighted in this study, however, achieving an equitable implementation of PM will remain a challenge, as access to and participation in these advances will be strongly dependent on the various themes identified in our findings. Recommendations derived from this paper can be found in [Table 2](#). Beyond epilepsy care, our findings may

**TABLE 2** Recommendations to increase implementation of PM in rare genetic epilepsies.

Recommendations	Existing examples	Possible areas for improvement
<p>Epilepsy care in general should be personalized (targeted to the patient and their environment) and holistic (looking beyond seizures), and PM should not be used as an equivalent term to refer to this approach, as it needs to be considered standard-of-care. Frameworks of PM should differentiate between different levels of PM, as clinicians are intuitively referring to PM as a broad and complex concept. These levels should ideally be based on the underlying pathophysiological mechanism of a disease, ideally the genetic mechanisms. However, therapies with a reproducible and established clinical benefit, even in the absence of a clear pathophysiological basis, should also be included, as they remain valuable in clinical practice, especially for diseases where precise mechanisms are not yet fully understood.</p>	<ul style="list-style-type: none"> <li>• Framework by Byrne et al.<sup>5</sup></li> <li>• Framework by Balestrini et al.<sup>6</sup> (Figure 4).</li> </ul>	<ul style="list-style-type: none"> <li>• Promote the use of established frameworks in research to enable comparison between different studies.</li> <li>• Enhance clinicians' awareness and knowledge of these frameworks by integrating them into guidelines, similar to the epilepsy syndrome classification of the ILAE.<sup>31</sup></li> </ul>
<p>Both local and international epilepsy communities should prioritize education on genetic testing and PM. Training should be integrated in basic medical education and residency programs. Regular refresher courses should be easily accessible and affordable. Although international standardization is crucial, it is equally important to address and accommodate regional differences.</p>	<ul style="list-style-type: none"> <li>• European Pediatric Neurology Society: neurogenetics education is incorporated in recommendations for training programs and the European examination.<sup>32</sup></li> <li>• Young Epilepsy Section (ILAE endorsed) webinars on genetic testing in epilepsy.</li> <li>• NorEpiNet: understanding epilepsy genetics and PM course 2023.</li> </ul>	<ul style="list-style-type: none"> <li>• Organize local training to address regional challenges, such as reimbursement issues and lack of availability of genetic testing, while focusing on promoting uniformity within the region.</li> <li>• Organize "train the trainer" courses on genetic testing and PM in epilepsy, similar to the "Pediatric Epilepsy Training" from the British Paediatric Neurology Association.<sup>33</sup> As such, international experts can train local experts, who can further train their colleagues, with regard to their specific work setting.</li> </ul>
<p>The international research community is strongly encouraged to invest in disease-specific registries and natural history studies, developed in collaboration with patient advocacy groups. These efforts should incorporate relevant and measurable outcomes and be designed to ensure accessibility for researchers worldwide. Such registries may serve as historical control cohorts and provide validated outcome measures for use in future clinical trials.<sup>34</sup></p>	<ul style="list-style-type: none"> <li>• The RESIDRAS project, as an example of an international disease-specific registry, enables centers involved in the care of individuals with Dravet syndrome to contribute data.<sup>21</sup></li> <li>• Examples of national registers: tuberous sclerosis complex (<a href="https://www.tscalliance.org/research-strategy/natural-history-database/">https://www.tscalliance.org/research-strategy/natural-history-database/</a>); KCNQ2 (<a href="https://kcnq2.de/en/kcnq2-registry/">https://kcnq2.de/en/kcnq2-registry/</a>)</li> <li>• Published natural history studies on <i>STXBPI</i> or <i>SCN8A</i>.<sup>35,36</sup></li> </ul>	<ul style="list-style-type: none"> <li>• To ensure effective international collaboration, data sharing should be intuitive and time-efficient, while remaining fully compliant with international data protection regulations.</li> <li>• Ideally, these registries should be regularly updated to monitor long-term disease evolution.</li> <li>• Dissemination of data from such studies should be as wide as possible, in full consideration with any confidentiality, as suggested by the FDA.<sup>37</sup></li> </ul>

TABLE 2 (Continued)

Recommendations	Existing examples	Possible areas for improvement
The international research community should publish outcomes of PM trials, including both positive and negative results. As randomized controlled trials are difficult to conduct in rare genetic epilepsies, investing in well-designed n-of-1 trials presents a viable alternative.	<ul style="list-style-type: none"> <li>• Use of 4-aminopyridine in <i>KCNA2</i> gain of function-related epilepsy, as an example of a well-documented case series of PM.<sup>38</sup></li> <li>• Use of quinidine in <i>KCNT1</i>-related epilepsy as an example of the importance of reporting negative outcomes from previously promising PM trials.<sup>39</sup></li> <li>• Recommendations for n-of-1 trials in rare diseases.<sup>40</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Publish negative results, as this is essential to provide an objective perspective on novel therapies.<sup>41</sup></li> <li>• Reports should provide a risk–benefit discussion and include outcomes beyond seizures. Ideally, they contain practical recommendations to guide implementation.</li> </ul>
Develop structured guidelines and pathways for genetic testing, for referral of PWE to expert teams, and for implementation of PM to ensure equity and encourage policymakers to prioritize investments in these areas.	<ul style="list-style-type: none"> <li>• Recommendations for genetic testing in epilepsy, as published by the Genetics Commission of the ILAE.<sup>26</sup></li> <li>• Referral algorithm for genetic testing in unexplained epilepsy in the United States.<sup>42</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Address local differences by tailoring international guidelines to national or regional contexts; e.g., implement simple genetic testing protocols in Africa that focus on well-recognized epilepsy genes.<sup>43</sup></li> </ul>
Form local expert groups specializing in genetic epilepsies and PM to provide clinicians with accessible support considering PM options.	<ul style="list-style-type: none"> <li>• NETRE.<sup>13</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Establish regional or local expert groups, preferably coordinated by local (child) neurology or epilepsy organizations, to advise clinicians in providing PM. These groups can facilitate collaboration with international experts of NETRE<sup>13</sup>, EpiCARE, ILAE or other international organizations.</li> </ul>
Organize centralized, multidisciplinary clinics for rare genetic epilepsies, enabling integrated care in partnership with local clinicians.	<ul style="list-style-type: none"> <li>• Multidisciplinary clinics for tuberous sclerosis complex and Dravet syndrome, as available across Europe and the United States, following the recommendations outlined in the literature.<sup>30,44</sup></li> <li>• International networks such as EpiCARE can assist local teams in delivering optimal care, conducting research, and securing funding.</li> </ul>	<ul style="list-style-type: none"> <li>• Develop multidisciplinary clinics to provide PM in rare genetic epilepsies, with a focus on evidence-based application of PM.</li> </ul>
Strengthen collaboration between genetic laboratories and clinicians to ensure accurate interpretation of genetic results and appropriate treatment adjustments. The genetic report should be concise, standardized, and aligned with ACMG guidelines. <sup>45</sup> Ideally, genetic laboratories should support clinicians in interpreting genetic reports.	<ul style="list-style-type: none"> <li>• Multidisciplinary teams discussing genetic results of PWE referred to their center.<sup>4,7</sup></li> <li>• EpiCARE case discussions offer the possibility to present (unsolved) genetic cases to international experts.</li> </ul>	<ul style="list-style-type: none"> <li>• Establish local multidisciplinary teams, consisting of (child) neurologists, geneticist, genetic counselors, and laboratory technicians, to interpret genetic results and provide assistance to the clinicians.</li> <li>• Ensure genetic counseling and advice are readily available at any center specializing in genetic epilepsy.</li> <li>• Invest in the training of genetic counselors in the field of epilepsy.</li> <li>• Highlighting PM options when reporting a genetic diagnosis can help clinicians to guide treatment, in accordance with local jurisdiction and ethics.</li> </ul>

Abbreviations: ACMG, American College of Medical Genetics and Genomics; EpiCARE, European Reference Network for Rare and Complex Epilepsies; FDA, US Food and Drug Administration; ILAE, International League Against Epilepsy; NETRE, Network for Therapy in Rare Epilepsies; NorEpiNet, Nordic Network for Precision Medicine in Epilepsy; PM, precision medicine; PWE, people with epilepsy.

have broader implications for other fields of medicine where PM is emerging, such as neuromuscular disorders. Addressing similar barriers, such as clinician training,

interdisciplinary collaboration, and standardized care pathways, could facilitate the integration of PM across various specialties.

**AUTHOR CONTRIBUTIONS**

*Conceptualization:* All authors. *Conducting interviews:* Matthias De Wachter. *Data curation, coding, and framework:* Matthias De Wachter and Anne Juul. *Writing—original draft:* Matthias De Wachter and Anne Juul. *Writing—review and editing:* All authors.

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**CONFLICT OF INTEREST STATEMENT**

None of the authors has any conflict of interest to disclose. 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.

**DATA AVAILABILITY STATEMENT**

The full study protocol, as well as local research ethics committees' approval and the information leaflet for the participants, is available at <https://cloud.uza.be/index.php/s/0kkd4kDiHcKVIxh>. To ensure transparency in the methodology used in this paper, the initial codebook and subsequent frameworks are available upon request. All these data will be accessible immediately following publication until 5 years thereafter, for anyone who wishes to access the data. For participant confidentiality reasons, neither transcripts nor audio files will be made available.

**ETHICS STATEMENT**

This study was approved by the institutional review board at the Danish Epilepsy Center (EMN-2023-10904). This study was conducted according to the principles of the Declaration of Helsinki, amended at the 64th General Assembly (Fortaleza, Brazil, October 2013) and in accordance with the European Union General Data Protection Regulation. All participants provided informed consent. Findings were reported using the Standard for Reporting Qualitative Research recommendations.

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### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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