UK Rare Epilepsies Together

Solutions to Enhance Access to Appropriate Care for Individuals with Rare and Complex Epilepsies in the UK

A Multistakeholder Discussion

September 2025

The project concept was initiated by UCB. UKRET and UCB collaborated early in the process to define the overarching research topics. UCB funded the targeted literature review, roundtable meetings and the development of this report.

Table of Contents

Executive Summary

Individuals with rare and complex epilepsies and their families face many challenges in accessing appropriate care in the United Kingdom (UK). Greater attention to these issues is required in medical practice and social care to raise awareness and develop solutions aimed at improving access to high-quality care. UK Rare Epilepsies Together (UKRET), a network of patient support groups and charities, aimed to characterise current challenges in accessing high-quality care and identify associated solutions, through engagement with a variety of stakeholders involved in the care and management of individuals with rare and complex epilepsies in the UK.

A targeted literature review (TLR) was first conducted to gain an initial understanding of the documented challenges surrounding access to care for individuals with rare and complex epilepsies. Within the TLR, 26 materials were prioritised for extraction, with only one material specific to individuals with rare epilepsies within the UK, highlighting a substantial gap in the current evidence around the challenges faced by individuals and their families in the UK.

The TLR was augmented by a 'challenges' roundtable which gathered deeper insights around these challenges from a group of individuals with lived experiences, both personal and from their respective communities. Key challenges regarding diagnosis, treatment and co-ordination of care, including delayed diagnosis, limited availability of effective treatment, poor co-ordination of care and lack of support during the paediatric-to-adult transition were included. Participants specifically emphasised the importance of being heard by healthcare professionals (HCPs) and the need for improved support systems for individuals and families.

Finally, the findings from the 'challenges' roundtable informed the discussions of a 'solutions' roundtable which sought to determine solutions to the identified challenges. The roundtable discussions generated a variety of actionable solutions that would improve access to high-quality care for individuals with rare and complex epilepsies and their families within the UK. These discussions culminated in the identification of three groups of key stakeholders: HCPs, patient advocacy groups (PAGs) and individuals with rare and complex epilepsies and their families, who could action solutions belonging to themes outlined below.

Solutions: Overarching Themes

1. To increase effective collaboration between HCPs.
2. To streamline and optimise existing care pathways.
3. To increase education and engagement for HCPs.
4. To increase education and engagement for individuals with rare and complex epilepsies and their families.
5. To improve paediatric-to-adult care transitional support.

Stakeholders can use this report to spark discussions and implement key actionable solutions to drive change in order to improve the quality of care provided in the UK.

Meeting Participants

Key

‘Challenges’ Roundtable Meeting Organisers and Attendees

‘Solutions’ Roundtable Meeting Organisers and Attendees

‘Challenges’ and ‘Solutions’ Roundtable Meeting Organisers and Attendees

Meeting Chairs

- **Issy Newell**, UK Head of Rare Diseases, Costello Medical
- **Keval Haria**, Consultant, Rare Diseases, Costello Medical

Meeting Faciliators

- **Chloe Zentai**, Senior Analyst, Rare Diseases and Medical Affairs, Costello Medical
- **Emma Dutton**, Analyst, Rare Diseases, Costello Medical

Attendees

- **Alice Salisbury, PAG**
  Trustee, MedCan Family Foundation
- **Alison Fuller, PAG**
  Director for Health Improvement and Influencing, Epilepsy Action
- **Allison Watson, PAG, representative and parent of a child with rare epilepsy**
  Founder, UKRET; Co-Founder and Chief Executive Officer (CEO), Ring20 Research and Support
- **Alyson Koopman, PAG**
  Trustee Member and Chairperson, GRI-UK
- **Carol-Anne Partridge, PAG**
  Co-Founder and Chairperson, CDKL5 UK
- **Galia Wilson, PAG**
  Chair of Trustees, Dravet Syndrome UK
- **James Pauling, Paediatric HCP**
  Wirral University Teaching Hospital
- **Jessica Clatworthy, PAG**
  Co-Founder, CRELD1 Warriors
- **Kathryn Knowles, PAG**
  Co-Founder, CHD2 UK
- **Lara Carr, PAG**
  Research Manager, Young Epilepsy
- **Lindsay Randall, PAG, parent of two children with rare epilepsies**
  Founder and CEO, SLC6A1 Connect UK-AQ
- **Lisa Clayton, Adult HCP**
  Senior Clinical Research Fellow, University College London (UCL); Locum Consultant Neurologist, National Hospital for Neurology and Neurosurgery and Chalfont Epilepsy Centre
- **Lisa O'Brien, Paediatric and Adult HCP**
  Head of Health and Wellbeing Epilepsy Specialist Nurse (ESN), The Meath Epilepsy Charity; Hope for Epilepsy
- **Nick Meade, Policy**
  Chief Executive, Genetic Alliance UK
- **Pooja Takhar, PAG**
  Joint Chief Executive, Tuberous Sclerosis Association
- **Roger Winterbottom, PAG**
  Co-Founder, CHD2 UK
- **Sarah Tittensor, Adult HCP**
  ESN, West Midlands
- **Sarah Wynn, PAG**
  CEO, Unique
- **Shanika Samarasekera, Adult HCP**
  Consultant Neurologist, The Harborne Hospital
- **Sheela Upadhyaya, Policy**
  Life Sciences Consultant Specialising in Rare Diseases, OpenFlex Limited
- **Suresh Pujar, Paediatric HCP**
  Consultant Paediatric Neurologist, Great Ormond Street Hospital for Children; Honorary Lecturer, UCL

Introduction

Rare and complex epilepsies are a heterogeneous group of conditions in children and adults in which seizures are refractory to treatment and/or surgery.[1,a] The European Reference Network for rare and complex epilepsies (EpiCARE) manages more than 160 rare forms of epilepsy, a number which is steadily increasing as new forms of genetic epilepsies are identified every year.[1] Together, rare and complex epilepsies affect approximately 5 in 10,000 people in Europe.[1]

These conditions are associated with numerous comorbidities, causing impacts on many aspects of health and daily living, including neurodevelopment, health-related quality of life (HRQoL), education, employment and life expectancy.[1] Compounding these impacts, UKRET has heard from children and adults with rare and complex epilepsies, and their families, that they face many challenges in accessing appropriate care in the UK. Therefore, greater attention on these issues in medical practice and social care is required to raise awareness, and is essential for developing solutions to improve access to high-quality care.

This report describes a project which characterised current challenges to generate solutions, through engagement with a variety of stakeholders involved in the care and management of individuals with rare and complex epilepsies in the UK. Initially, UKRET collaborated with PAG leaders or representatives, who portrayed their own lived experiences and those of individuals and families in their respective communities, to characterise key shared challenges and perceived gaps in care and support across individuals with rare and complex epilepsies in the UK.

Subsequently, a collaborative effort was undertaken to explore how to address the identified challenges, enhancing the quality of care and support available in the UK. This involved the generation of practical, actionable solutions and defined recommendations that could be established in the UK healthcare system, ultimately improving individuals’ outcomes and HRQoL.

This collaboration involved a diverse range of individuals including PAGs, HCPs, policymakers and a social care worker, all of whom had firsthand experience of the challenges, example solutions and/or policymaking.

Existing priorities for rare diseases across the UK have been reported in the rare disease action plans of England, Scotland, Northern Ireland and Wales.[2-5] Key priorities identified by the action plans include:

1. Faster diagnosis
2. Better co-ordination of care
3. Increased awareness of rare diseases among HCPs
4. Improved access to specialist care, treatment and drugs

UKRET aimed to understand how the challenges and solutions prioritised by the rare and complex epilepsy community aligned with current UK priorities, ensuring relevance and feasibility.

This report has been developed to inform stakeholders about the challenges faced by individuals with rare and complex epilepsies, to suggest solutions, which stakeholders[b] can action, and to spark discussions regarding driving change to improve the quality of care provided in the UK.

By working together as the UKRET network with other stakeholders, we can amplify our voice to drive change for the often-overlooked rare and complex epilepsy community, whose priority of needs differ from, but are no more or less important than, those with more controlled seizures.

[a]For the purposes of this report, rare and complex epilepsies are typically conditions where seizures are refractory to treatment, therapy, and/or surgery; these are often associated with many comorbidities, such as intellectual disability (ID) and behavioural disorders. Nevertheless, the challenges, solutions, and recommendations discussed in this report are not limited to these conditions alone and are likely applicable to a broader range of related conditions. [b]Stakeholders include HCPs, PAGs, individuals and their families, policymakers, industry, academics and UK professional boards.

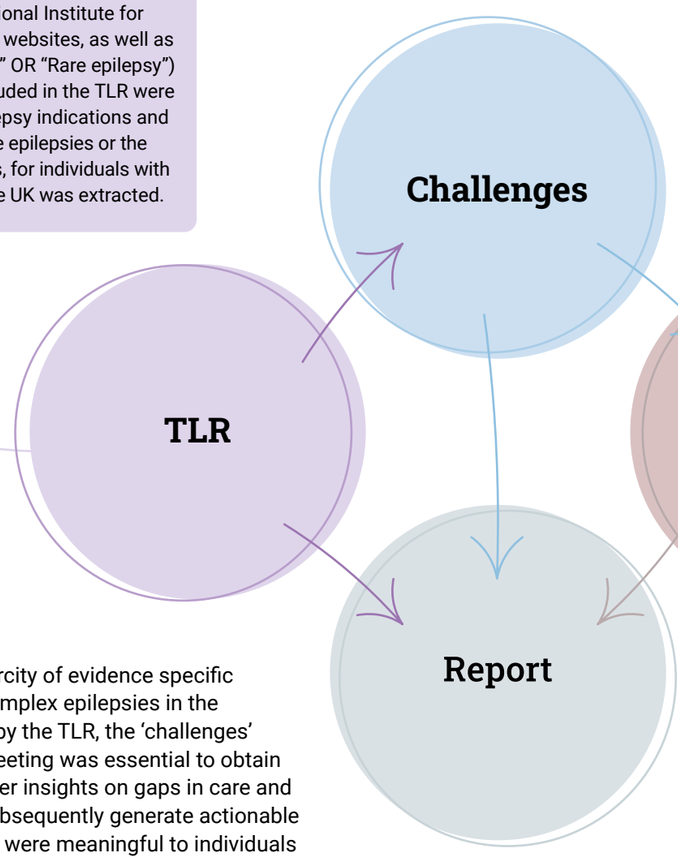
Methods

Figure 1. Methodology overview

Targeted Literature Review (TLR)

Aim: To understand the current landscape and explore ongoing discussions related to the topic of access to high-quality care for individuals with rare and complex epilepsies in the UK, and wider epilepsy indications and geographies.

Targeted searches were performed on PubMed, Google, Google Scholar, the National Institute for Health and Care Excellence (NICE) and the Scottish Medicine Consortium (SMC) websites, as well as websites of epilepsy charities and PAGs. Search terms included ("Rare epilepsies" OR "Rare epilepsy") or Rare epilepsy* combined with terms for topics of interest. Materials to be included in the TLR were specific to rare epilepsies and the UK, as well as materials relevant to wider epilepsy indications and other geographies. Of the identified, relevant materials, those that pertained to rare epilepsies or the UK were prioritised for extraction. Evidence on recurring and prominent challenges, for individuals with rare and complex epilepsies and their families, in accessing appropriate care in the UK was extracted.



'Challenges' Roundtable Meeting

Date of meeting: 27th September 2024

Aim: To gather insights from a group of individuals with lived experiences of rare and complex epilepsies, and those who act as PAG representatives, in order to identify key challenges and perceived gaps in care and support provided in the UK.

Insights identified by the TLR were used as a basis to inform discussion topics and develop the agenda for the 'challenges' roundtable meeting. This meeting brought together representatives from PAGs, including people caring for an individual with a rare or complex epilepsy, to discuss and characterise challenges at an in-person half-day meeting.

An **infographic leave piece** was developed to summarise the challenges identified during the roundtable. These findings were validated by meeting attendees and wider UKRET members who were unable to attend the original 'challenges' roundtable meeting.

TLR Findings

Of the 47 identified publications, 26 materials were prioritised for extraction of which 12 were specific to rare epilepsies, 13 specific to the UK and solely one publication was specific to both the UK and rare epilepsies (Gordon 2020).[6] These numbers highlight a significant gap in the evidence around the challenges faced by individuals with rare and complex epilepsies and their families in the UK.

The identified challenges were categorised into three themes: diagnosis, treatment and co-ordination of care. Challenges included delayed referrals, misdiagnoses, inadequate access to treatments and specialist care alongside a lack of holistic care, which are issues present in both common and rare epilepsies. However, these issues are likely exacerbated in rare and complex epilepsies due to the refractory nature of seizures, complexity of these conditions and the limited specialist knowledge and resources.

Given the scarcity of evidence specific to rare and complex epilepsies in the UK identified by the TLR, the 'challenges' roundtable meeting was essential to obtain specific, deeper insights on gaps in care and support, to subsequently generate actionable solutions that were meaningful to individuals and their families in the UK, and compatible with UK health and social care systems. As portrayed in **Figure 1**, these findings informed the agenda for the 'challenges' roundtable meeting.

Prioritised materials from the TLR for extraction: Gordon 2020,[6] Rare Epilepsies 2016,[7] Camfield 2016,[8] Miller 2020,[9] Baumgartner 2021,[10] LoPresti 2024a,[11] LoPresti 2024b,[12] Solaz 2024,[13] Soto 2024,[14] Balestrini 2021,[15] Nabbout 2017,[16] RightCare 2020,[17] London Epilepsy Standards 2018,[18] National Health Service (NHS) England 2024,[19] Rare Epilepsy Syndromes 2020,[20] Hoffman 2022,[21] Cross 2024,[22] SIGN 2018,[23] NICE 2023,[24] NICE 2022,[25] Epilepsy Service Provision 2024,[26] NHS 2024,[27] Epilepsy12 2024,[28] Young Epilepsy 2021,[29] Epilepsy Society 2022.[30]

'Solutions' Roundtable Meeting

Date of meeting: 12th March 2025

Aim: To develop actionable solutions to the identified challenges faced by individuals with rare and complex epilepsies and their families in the UK when accessing appropriate care.

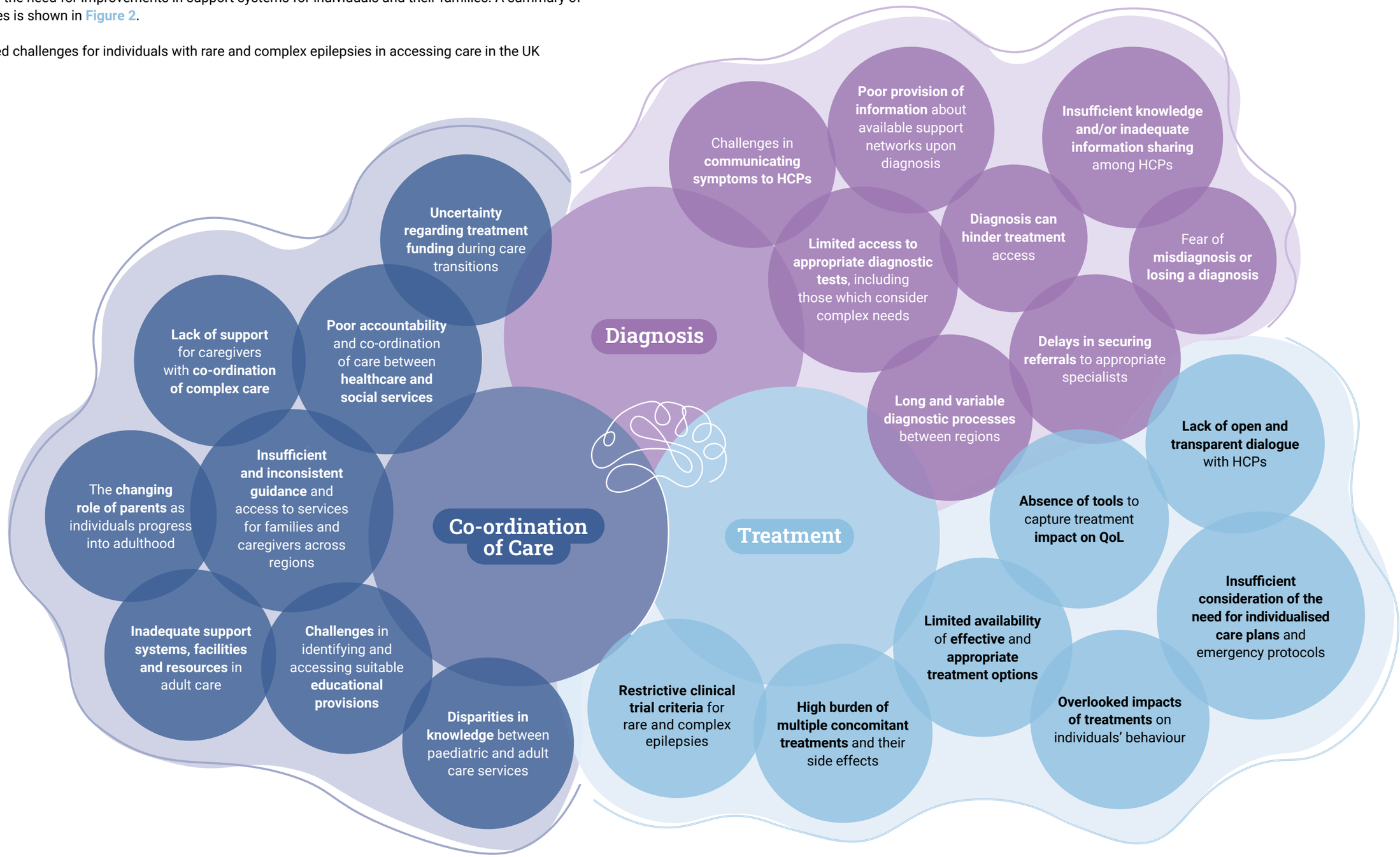
Findings from the 'challenges' roundtable subsequently informed the agenda for the 'solutions' roundtable. To generate a comprehensive set of solutions, a diverse range of stakeholders were invited to contribute their ideas and perspectives through a virtual half-day meeting, including PAG representatives, HCPs (clinicians and ESNs) and policymakers. Solutions were brainstormed, discussed and refined during the meeting and key solutions and their impacts were summarised, assessing their ease of implementation, whether they had a localised or wide impact and if they could be implemented now or over a longer time period.

The solutions were grouped into themes based on interactive exercises within the 'solutions' roundtable and validated by meeting attendees.

Challenges

Nine leaders of rare epilepsy patient groups in the UK, many of whom are caregivers themselves, shared their lived experiences and those of individuals and families in their communities. Discussions covered challenges with diagnosis, treatment and co-ordination of care. Roundtable participants emphasised the importance of being heard by HCPs and the need for improvements in support systems for individuals and their families. A summary of identified challenges is shown in Figure 2.

Figure 2. Key shared challenges for individuals with rare and complex epilepsies in accessing care in the UK



Why Does Overcoming These Challenges Matter?

Diagnosis

During the meeting, it was discussed that the process of getting a diagnosis for a rare and complex epilepsy can be difficult and stressful for individuals and their families. Those affected may need to push for referrals and may have to repeatedly explain their symptoms to different HCPs, **leaving them feeling ignored and overwhelmed. This was identified as being tough and unfair for those without the means or skills to advocate for themselves**. Furthermore, while some individuals might quickly receive an initial diagnosis of epilepsy, finding the root cause can often take years due to a lack of awareness about more rare and complex conditions, **leading to frustration and uncertainty**.

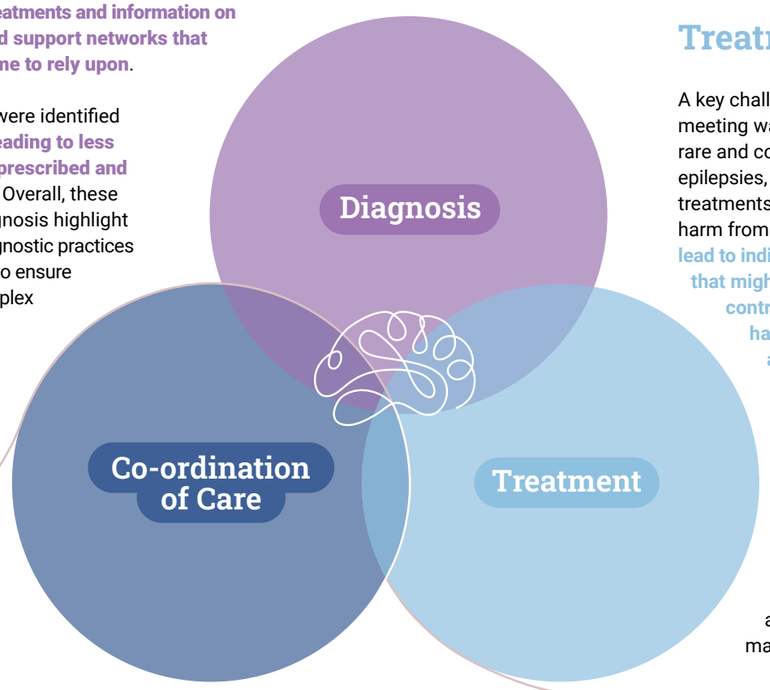
> I repeatedly hear of the struggle of being heard by HCPs

> We've also had it where an individual had to wait for 30 years to receive a diagnosis of Dravet syndrome. They went to visit a neurologist last year and after 15 years of believing they had Dravet syndrome, they were told that it wasn't actually Dravet syndrome that they had

> There's real variability in ease of getting a diagnosis – it often comes down to regional postcode lottery

Even with recent advancements, genetic testing doesn't always provide answers quickly, or at all. It was discussed that HCPs can either over-rely on certain tests in isolation, potentially overlooking other diagnostic methods (e.g. immunological, metabolic and chromosomal testing) which may contribute to a more accurate diagnosis. Additionally, due to the rapidly changing nature of diagnostic guidelines, HCPs may be uncertain about which tests to request and may fail to seek advice and share learnings. **This can prolong the diagnostic journey and prevent timely access to available treatments and information on comorbidities, prognosis and support networks that individuals and families come to rely upon**.

Additionally, misdiagnoses were identified as a common occurrence, **leading to less effective treatments being prescribed and more confusion and stress**. Overall, these challenges surrounding diagnosis highlight an urgent need for better diagnostic practices and comprehensive support to ensure individuals with rare and complex epilepsies and their families receive the help they need.



Co-ordination of Care

A key challenge identified during the meeting was the lack of support for individuals with rare and complex epilepsies and their families during their transition from paediatric-to-adult care. For adults, the focus shifts to purely seizure management and, for some, access to a multidisciplinary team disappears. Non-pharmacological treatments such as ketogenic dietary therapy are less well provisioned, often overlooked or inappropriately discontinued in older children. Combined with the possibility of expensive treatments being stopped, this **limits the available range of treatments and hinders care**. With limited access to specialist care, individuals typically receive a lower standard of care. This issue is exacerbated for adults who, for referrals, may have to rely on their general practitioner (GP), who knows little about their condition.

The PAGs highlighted that regardless of age, although perhaps worse in adult care, there is still inadequate support with co-ordination of care and limited access to care co-ordinators, forcing individuals and families to handle all appointments and referrals independently. **This responsibility increases the burden of care on families**, who must juggle these tasks whilst providing care. It was discussed that families often encounter poor guidance and information, even on important topics like care plans, emergency protocols and Sudden Unexpected Death in Epilepsy (SUDEP). This is likely due in part to a shortage of ESNs, limited use of SUDEP and seizure safety tools and a confusing healthcare system. These factors collectively **increase the risks that can endanger the lives of individuals with these epilepsies**.

Challenges around navigating paperwork and financing for broader social support, including accessing a social worker, benefits and healthcare plans, **can be daunting for families who are already overwhelmed**. Added challenges include the lack of referrals for individuals and families to support services such as counselling, mental health care and intrafamilial genetic testing. **As a result, families may not be accessing all the support available**.

> Trust is essential; it's challenging for doctors to openly say they don't know

> The individual voiced that he wished to come off the drug but imagine how terrible it must be for kids who can't voice how they're feeling

> There's no single 'solution' treatment that will work for the condition, even for two family members with the same condition

Treatment

A key challenge that was identified during the meeting was the lack of treatment guidelines for rare and complex epilepsies, including refractory epilepsies, resulting in HCPs often continuing to add treatments for these individuals, fearing potential harm from removing existing ones. In turn, **this can lead to individuals receiving numerous treatments that might be ineffective in improving seizure control, whilst being potentially addictive or harmful, resulting in serious side effects and a reduced HRQoL**.

The PAGs highlighted that the HRQoL for individuals with rare and complex epilepsies can vary within and between conditions, and that monitoring of treatment effectiveness typically concentrates solely on seizure control, neglecting other comorbidities. PAGs call for a balance to be sought, and whilst managing seizures is crucial, seizure freedom isn't always achievable, so attention must also be given to the impact of treatments on overall wellbeing, behaviour, sleep and any additional health concerns. Families often attempt to convey these needs but feel overlooked by HCPs, **resulting in individuals not receiving holistic care and management**.

Across rare and complex epilepsies, individuals' response to treatment varies, therefore, HCPs can often adopt a trial-and-error approach to treatment. The impact of this process, and how diagnosis and local funding may limit available treatments, is often not clearly communicated to individuals and their families. **This lack of transparency may lead to mistrust, leaving families feeling isolated and unempowered**. Furthermore, it was identified that there was a shortage of appropriate tools to assess treatment effectiveness and impact on HRQoL, as well as a lack of clinical trials for individuals with rare and complex epilepsies, **leaving individuals and families feeling stuck with limited options and support**.

> As soon as you fall over the cliff into adult neurology, they primarily focus on seizure control, and trying to access a multidisciplinary team is a lost cause

> Maintaining support through the NHS continuing healthcare [CHC] scheme can be challenging

> The presence of a social worker is crucial, but not all families have access to one

> Often 1.5 ESNs are assigned to 460 epilepsy patients whereas nurses in paediatric oncology have 45 patients on their caseload. ESNs should be available to all individuals with epilepsies equitably, people with rare epilepsies will need more interaction with ESNs due to changes in treatments and requiring access to more services

Findings from the 'challenges' roundtable informed the agenda for the 'solutions' roundtable meeting.

Solutions

The ‘solutions’ roundtable explored actionable solutions to overcome the characterised challenges that individuals with rare and complex epilepsies and their families face when accessing appropriate care in the UK, as well as thoughts on what better services could look like.

Here, five overarching themes for the solutions were identified: **effective collaboration between HCPs**, **streamlining and optimising current processes**, **increasing HCP education and engagement**, **increasing education and engagement for individuals with rare and complex epilepsies and their families**, as well as **paediatric-to-adult care transitional support**.

Within each theme, the solutions are discussed sequentially, along with their anticipated impact on the care pathway: diagnosis, treatment and co-ordination of care.

Whilst increased funding for the NHS and research into rare and complex epilepsies are overarching strategies that can address many challenges, the ‘solutions’ roundtable focused on generating pragmatic, targeted actions that can be implemented within the UK healthcare system by HCPs and PAGs, as well as individuals and their families to directly enhance access to high-quality care.

1 Effective Collaboration Between HCPs

The need for more effective collaboration between HCPs was a prominent theme during the ‘solutions’ roundtable, to address a number of challenges surrounding the management of rare and complex epilepsies within the NHS. Communication between HCPs can be improved on a local level between multidisciplinary teams (MDT) and on a regional level between epilepsy specialists, to help streamline care and increase the sharing of knowledge and resources. Outlined below are the key identified solutions around increasing collaboration and knowledge sharing between HCPs.

MDTs: HCPs from all specialities involved in the care of individuals with rare and complex epilepsies, including primary, secondary and tertiary care teams.

Epilepsy specialists: HCPs who specialise in the diagnosis and treatment of epilepsy and seizure disorders e.g. epileptologists.

1.1 Increase Collaboration Across MDTs at a Local Level

Providing more holistic and joined-up care

Who Can Action?

HCPs: MDT members (e.g. neurologists, paediatricians, ESNs, GPs, geneticists, psychologists or psychiatrists, social workers, genetic counsellors, speech and language therapists, occupational therapists and care co-ordinators).

What is the Impact?

Strengthening connections and increasing collaboration within and between MDTs would establish a strong platform to encourage joint discussions about the care of individuals, leading to more holistic and joined-up care.

What You Can Do Now:

Identify the most suitable members within the local MDT to involve (ensuring representation across services and sectors), then establish and build connections. Determining the most effective platform for collaboration within MDTs is likely the initial step. It was suggested that MDTs could schedule regular virtual meetings, set up drop-in forums, or create group chats/channels for sharing updates and thoughts.

Compile and disseminate a holistic set of ‘indicators’ for MDTs to identify when to suspect rare and complex epilepsies.	Improving timely diagnosis referrals by delineating a holistic set of ‘indicators' accessible to MDTs (e.g. seizure onset in children under three years, antiseizure medication resistance alongside neurodevelopmental comorbidities), establishing checkpoints for diagnostic referral or expert consultation. These can be developed through collaborative input from individuals, families and PAGs.
Establish collaborations with the NHS Genomics Medicine Service to optimise genetic testing requests.	Staying up-to-date with the latest developments and optimal testing options, ensuring the most appropriate test(s) listed within the National Genomics Test Directory are used. Discussing variants of uncertain significance (VUS: genetic variations where the clinical impact is unknown) provides a deeper understanding of the disease mechanism and individual symptoms, enabling targeted future therapeutic development leading to improved standards of care.
Establish roles and responsibilities through improved communication between MDTs across primary, secondary and tertiary care to support efficient and streamlined care of individuals.	Encouraging shared care with defined responsibilities ensures clear information sharing and holistic care whilst minimising duplication of efforts (e.g. naming an epilepsy lead on the NHS trust's website). This supports efficient services enabling quicker, smoother referrals, allowing tertiary specialists to see more individuals (e.g. reducing follow-ups, freeing capacity for new referrals and treatment planning) and enhances the skills of local specialists (in line with the English government's 10-Year NHS Plan moving care from hospitals to communities).[31]
Discuss disease impact and individuals' concerns to deliver patient-centric care.	MDTs can support holistic management by regularly and collectively evaluating care plans and assessing the overall impact of burden of disease and multiple concomitant treatments on an individual’s HRQoL. Engaging regularly with individuals and families to discuss their primary concerns and experiences is key in ensuring the patient voice is heard and in delivering patient-centric care, beyond seizure control.
Understand current connections, and gaps in connections, between healthcare and social services and evaluate how to best bridge these gaps.	Increasing the co-ordination of care between healthcare and social services by having discussions to improve relationships and links between services on a local level, leveraging appropriate information sharing to expedite support and reduce duplication of effort (e.g. assigning a named social care co-ordinator, whose contact details are on the individual's care plan).

Case Study – Identifying Red Flags in Rare Diseases

In 2018, Medics for Rare Diseases (M4RD) worked with rare disease patients, carers, clinicians and advocates to co-create a survey, completed by PAGs, to investigate the commonalities of rare diseases and identify red flags or clinical clues that point to an individual having an underlying rare condition.[32]

GeNotes are genomic notes for clinicians which contain quick, concise information to help HCPs make the right genomic decisions at each stage of a clinical pathway.[33] Examples of in-clinic scenarios include discussing when to consider genomic testing, for infants, children and adults.[34, 35]

Case Study – Multidisciplinary Genetic Evaluations

At Great Ormond Street Hospital, MDT clinics have been established with neurologists, geneticists and clinical scientists to discuss VUS (genetic variations where the clinical impact is unknown). These discussions with experienced professionals are crucial for determining if specific genetic mutations are linked to clinical symptoms.

An R14 service offers a rapid whole genome sequencing test (R14 test) for critically ill babies under one year with a likely monogenic disorder and has contributed to diagnosing individuals with rare and complex epilepsies.[2] Through virtual MDT meetings, allowing more frequent and accessible communication, teams have improved efficiency in interpreting the genetic tests accurately.

1.2 Increase Collaboration Between Rare and Complex Epilepsy Specialists on a Regional Level

Improving and standardising care across the UK

Who Can Action?

HCPs: Epilepsy specialists (e.g. epileptologists), with representation from all NHS regions in the UK.

What is the Impact?

As described in **Challenges**, there are currently inconsistencies, and therefore inequities, in the access and provision of care across the UK for individuals with rare and complex epilepsies. When discussing solutions, it was emphasised that collaboration should occur regionally between epilepsy specialists across the UK, leading to enhanced knowledge sharing and aligned care pathways, addressing inconsistencies in care, especially by taking a patient-centric approach.

Key Solutions Include:

- Discussing how HCPs across the UK can provide consistent and timely diagnostic care in line with up-to-date guidelines. This includes sharing techniques and insights, for example, collecting all parental and patient blood samples simultaneously to prevent delays in genetic testing.
- Discussing complex cases of diagnosis and treatment through addressing open questions and sharing individuals' experiences and resources.
- Keeping updated on emerging, current and combination treatments. Discussion on experiences of treatment effectiveness, safety and impacts on individuals' HRQoL would allow patient-centred, holistic care.
- Discussing the best standard of care, how it can be delivered locally and by whom to reduce inconsistencies in the care pathways provided across the UK.

What You Can Do Now:

Key initial steps in organising these partnerships include choosing a collaboration platform and identifying participants, considering whether paediatric and adult specialists should meet separately or jointly on occasion. Platforms such as virtual meetings, drop-in forums or group chats/channels could be used with the meeting discussions disseminated via email, so specialists can proactively share learnings with their colleagues.

- **HCPs to set up a collaboration platform and establish a list of attendees.**
- **Consider topics of value to discuss, with a clear approach and structured agenda for the meetings, to ensure productive discussions and clear outcomes.**
- **Align on the use of diagnostic tools and referral pathways, based on specialists' experiences, to establish best practice within the NHS.**
- **Stay informed on the latest advancements in treatments and treatment combinations/algorithms, gaining insights into their benefits and limitations centred on the individual's experience, amplifying their voice.**

Case Study – Rare Disease Collaborative Network (RDCN), CDKL5

RDCNs are an important part of the NHS architecture, initiated by NHS England and NHS Improvement, to improve care and support for patients with rare diseases. They are made up of a group of providers who are committed to progressing research, increasing knowledge and improving the patient experience.[36]

CDKL5 UK has established an RDCN and funds a Care and Research Co-ordinator role to support children with CDKL5 Deficiency Disorder (CDD) and their neurology teams, as well as adults with CDKL5 by supporting their parents and neurologists. This helps families to navigate the condition, find support, access resources and participate in research.[36]

Research from this network has contributed to the development of recommendations for the assessment and management of CDD, enhanced the understanding of the burden of CDD based on family and caregiver perspectives and informed approaches to ensure high-quality care in routine clinical practice across Europe.[37–39]

Case Study – Refractory Epilepsy Specialist Clinical Advisory Service (RESCAS):

RESCAS is a service that covers the provision of a specialist clinical advisory service, supporting clinicians working with patients to optimise the treatment of refractory epilepsies in the UK. The service hosts a platform for virtual conferences that bring together paediatric neurologists with expertise in epilepsy based across the UK to provide advice and support in the management of patients.[40]

1.3 Increase the Collection and Sharing of Real-World Evidence (RWE)

Enhancing the understanding of individuals' care

Who Can Action?

HCPs (epilepsy specialists, non-epilepsy specialists), PAGs and individuals and their families.

What is the Impact?

Given the limited availability of high-quality research on rare and complex epilepsy management, it was suggested that the collection of RWE at the point of care should be increased and shared on a digital platform. This would improve knowledge sharing, accelerate research, fill data gaps and boost collaboration among HCPs to help guide and improve patient care.

Key Data to Compile Would Include:

- Case studies regarding diagnostic pathways, highlighting key diagnostic tools, signs and symptoms that led to referral and data on the accuracy of specific diagnostic tools.
- Comprehensive details on symptoms, HRQoL and daily life (e.g. driving, working, education, starting a family) and how these are influenced by current/future treatments, treatment combinations and social care resources (e.g. mental health services, financial assistance, resources for managing daily living challenges).
- Data on the economic impact on families and NHS healthcare resource use associated with caring for an individual over a lifetime. This would provide insights into the overall financial impact of caring for individuals with rare and complex diseases and help to determine whether high-cost drugs offer a more economical solution (e.g. cost of illness model).

An open platform for sharing RWE across the UK would be beneficial, albeit time- and resource-intensive to set up and manage. Currently, a restrictive factor is the limited recording of HRQoL and daily life impacts by HCPs on an individual's health record. Encouraging HCPs to increase the collection of these data at the point of care would, in turn, increase the robustness and impact of data sets collected by projects such as the Epilepsy12 project, please see **case study**.[41] Insights from the Epilepsy12 project alongside collaboration between stakeholders, including PAGs and industry, may support future platform development. Future efforts should also aim to better understand the minimal data recording requirements for individuals with refractory epilepsies, as well as adult populations. In the meantime, data should be collected and shared proactively through MDT and specialist meetings.

What You Can Do Now:

- **HCPs and MDTs to consider data that would be valuable to collect and share, and the platforms that can be used for distribution.**
- **PAGs to set up forums/databases for families to report their experiences and stories regarding wider societal costs or impacts on HRQoL, and to include existing testimonials on PAG websites.**
- **Individuals and their families to consistently opt to provide details on symptoms, HRQoL, daily life and societal costs when opportunities arise.**
- **HCPs, MDTs and PAGs to remain engaged with the progression of the Epilepsy12 project and support its promotion and public engagement once it becomes available.**

Case Study – Epilepsy12 Project

The Royal College of Paediatrics and Child Health (RCPCH) is completing a project to support the automated data flow between trust/health boards, health records and national audit platforms, using Application Programming Interfaces to support connections between individual, local and national systems. RCPCH have commenced work with the Professional Record Standards Body to co-create a UK open-source minimum core data standard for NHS HCPs logging patient-facing records, and are calling for collaborations within the epilepsy community to select what should routinely be recorded as a minimum for young people with epilepsy.[41]

2 Streamlining and Optimising Existing Care Pathways

There are currently inconsistencies in the access, provision and management of care across the UK for individuals with rare and complex epilepsies and their families, leading to inequity and an increased emotional and procedural burden on families. Streamlining and optimising existing care pathways would ensure efficient delivery of high-quality care nationwide, alleviating the burden on individuals, families, and HCPs without necessitating entirely new pathways and processes.

2.1 Establish Rare and Complex Epilepsy Care Guidelines

Ensuring high-quality care is being delivered consistently across the UK

Who Can Action?

HCPs, PAGs, industry, policymakers and individuals and their families.

What is the Impact?

Whilst individuals require personalised, holistic care, it is key to establish a set of rare and complex epilepsy guidelines in the UK, to complement the current, broad NICE/Scottish Intercollegiate Guidelines Network (SIGN)/Health Service Executive (HSE) guidelines for epilepsy, to ensure all individuals have equitable access to high-quality care. Guidelines would provide diagnostic, treatment and care options nationwide, allowing individuals access to the most appropriate care and reducing geographical disparities.

Key Areas to Consider When Establishing Specialised Guidelines:

- Conduct a gap analysis (via roundtable discussions or surveys) to identify gaps in the current guidelines. Categorise any specific information to be included in the rare and complex epilepsy guidelines (e.g. defining criteria on who should be referred for genetic testing, and what tests they should be receiving and when).
- Develop preliminary guidelines to expand upon with relevant stakeholders regarding clear care pathways focusing on diagnosis, treatment and co-ordination of care, with consideration for paediatric and adult individuals, as well as those with complex comorbidities, considering the structures for co-ordination of care explored in the CONCORD study.[42]
- Establish how often and by whom an individual with uncontrolled seizures and complex comorbidities should be seen regarding ongoing care (e.g. MDT clinics, prioritisation of patient access to ESNs).
- Work to upskill HCPs on the management of rare and complex epilepsies, enabling them to confidently follow specialised guidelines once they are available.
- Communicate and collaborate with organisations such as NICE/SIGN/HSE and policymakers to ensure the guidelines are implemented across the UK, maintaining high-quality of care.

What You Can Do Now:

- **HCPs to utilise previous and current specialist epilepsy meetings and collaborations to proactively raise awareness of the best practices discussed and gather interest for participation in the development of rare and complex epilepsy guidelines (see Effective Collaboration Between HCPs).**
- **HCPs and PAGs to reach out to individuals within key organisations such as NICE (within the committee guidelines team) or SIGN, to explore the best approach for instigating change and developing rare and complex epilepsy guidelines that are responsive to community needs.**
- **PAGs, alongside industry, to conduct gap analyses to identify gaps in current guidelines through roundtable discussions or surveys with HCPs, individuals and their families.**
- **Individuals and their families to continue sharing personal experiences, highlighting successful parts of the care pathway and identifying areas that need improvement.**

Case Study – CONCORD Study

The CONCORD study was designed to explore how care for people with rare conditions is co-ordinated in the UK, and to understand how individuals living with rare conditions would prefer their care to be co-ordinated. The study identified six domains involved in co-ordinating care for rare conditions, and explored different models of care within each domain: ways of organising care (centralised, local or hybrid), ways of organising teams (low or high collaboration), responsibilities (administrative, formal and informal roles), how often care appointments and co-ordination take place (regular, on demand or a hybrid), access to records (full or restricted access) and modes of communication (digital, telephone or face-to-face). The study explored different models of care co-ordination in the UK, including 'hybrid' options, where specialist and local care were combined.[42]

2.2 Streamline and Optimise Current Care Pathways

Increasing individuals' access to care

Who Can Action?

HCPs, PAGs, industry, policymakers, academics and individuals and their families.

What is the Impact?

To support HCPs in the delivery of efficient and effective care for individuals with rare and complex epilepsies and their families, and to improve individuals' access to care, current care pathways should be streamlined and optimised.

A Variety of Solutions to Streamline and Optimise Current Care Pathways Were Discussed:

- Establish regular 'hot' clinics providing rapid-access services (e.g. local social services, treatment services) for individuals needing urgent, specialist care. These clinics would allow quick assessments and diagnostic work-ups, particularly for those presenting with complex refractory seizures.
- Establish video call appointments to enhance access to specialised care, reducing the travel and financial burden on individuals and families. Emergency video calls can also provide quick assessments of active symptoms in certain cases, ensuring that adult individuals have a representative present (family or carer) where appropriate, to support understanding and communication.
- When clinically appropriate, facilitate access to a wide range of available treatments. This can be established through increasing HCPs' understanding of treatments with similar mechanisms of action (e.g. through collaborations with academic institutes or industries), advocating for relaxed prescription restrictions across broader conditions and engaging with policymakers to ensure additional therapeutic options are available when standard treatments are not effective.
- Consider the need for industry collaboration to manage certain medications which require increased monitoring by neurologists (e.g. provision of funding or resources to support monitoring programmes) and therefore have associated high costs. As more treatments emerge, this support from industry is vital to ensure safe and effective care amid limited NHS resources.
- Develop and implement a benchmarking tool to monitor the management of rare and complex epilepsies, supporting ongoing improvements in patient care. This tool could gather data on key indicators (e.g. time to accurate diagnosis, treatment optimisation, individuals' HRQoL), allowing comparison against set targets and established guidelines for rare and complex epilepsies.
- Enhance access to expert guidance on non-pharmacological treatments such as vagal nerve stimulation and ketogenic diet therapy, ensuring individuals understand their options. Engage with organisational and funding bodies (e.g. Integrated Care Boards in England) to address variability in access to non-pharmacological treatment, particularly the limited number of adult ketogenic diet centres.
- Assign a designated care co-ordinator role within each MDT, to reduce the burden of care co-ordination on individuals and families through providing more efficient care.

What You Can Do Now:

- **HCPs to assess current care management services within their region to identify which of the above proposed solutions would enhance individuals' access to care in their region.**
- **HCPs and PAGs to start discussions with relevant stakeholders to action the above solutions.**
- **Individuals and their families to share personal experiences, highlighting successful parts of the current care pathway and identifying areas that need optimising.**

Case Study – MendelScan Study

Mendelian, a London-based MedTech company, has created a digital software known as MendelScan that is focused on shortening the diagnostic odyssey of rare and hard-to-diagnose diseases. The MendelScan algorithm captures disease features from electronic health records to flag individuals that may meet the criteria for a suspected disease and provides a report to their HCP for further review and potential expedited diagnosis, without accessing personal identifiable data. A pilot study demonstrated that MendelScan was a feasible tool to be used at a population level.[43–45]

2.3 Develop an Adaptable Template Care Plan

Improving and standardising care pathways across the UK

Who Can Action?

HCPs, PAGs and individuals and their families.

What is the Impact?

Care plans are key tools which contain personalised information regarding an individual's condition and related care, enabling them to communicate essential information to different people (e.g. new care team, people at school or work). Currently, care plans are not standardised across the UK for individuals with rare and complex epilepsies, inviting the possibility that people may experience different levels of support and experiences in communicating with HCPs. To standardise high-quality care and ensure a positive patient experience across the NHS, it was suggested to develop a national care plan template that would be adaptable for each individual. Allowing for regular updates through open consultations with individuals and their families, this would ensure all preferences and daily living needs were considered.

Key Points to Consider:

- Include space to add comprehensive details on the individual's treatments, including administration, side effects and impact on daily HRQoL, sufficient to inform any HCPs who do not have prior knowledge of the individual's care.
- Ensure adaptability of the plan for different life settings (e.g. school, college/university, recreational clubs/activities, residential service, nursery, workplace, respite care, personal assistants), ensuring that there is an understanding of the required elements of care in each setting.
- Ensure the care plan is easy to update by HCPs, individuals and their families and regularly reviewed, e.g. annually.
- Work from existing care plan templates across various regions of the UK to identify best practices, standardise care and ensure compatibility with different regions, in turn facilitating acceptance and uptake.
- Evaluate future applicability of using electronic/digital tools to store these care plans (e.g. apps/websites).

What You Can Do Now:

Collaboration with key stakeholders would be required to set up an adaptable template care plan, taking into consideration the similarities and differences across rare and complex epilepsies and various settings. A well-structured and universally understood care plan would facilitate easier co-ordination of care amongst all involved and improve patient outcomes.

- **HCPs and PAGs to identify relevant stakeholders for the development and review of template care plans (e.g. HCPs, PAGs, individuals with rare and complex epilepsies and their families).**
- **HCPs and PAGs to understand how care plans are currently completed and by whom across different UK regions and settings.**
- **HCPs and PAGs to conduct an assessment (e.g. survey or roundtable discussions) to determine the minimum necessary elements to be included in the care plan for consistency across relevant settings and regions in the UK, balanced with applicability to different rare and complex epilepsies.**
- **Individuals and their families to share, based on experience, the minimum necessary elements required, as well as optional elements, for an adaptable care plan.**

Case Study – 'This is Me' Rare Patient Passport

A 'This is Me' rare patient passport has been developed by the Cambridge Rare Disease Network (CamRARE) community of families and HCPs, to help individuals with rare diseases to convey essential information regarding their condition. The passport was reported to reduce the burden on individuals and families when relaying their medical information, specifically to an unfamiliar care team, and improved HCP awareness of their condition, resulting in individuals feeling more empowered to communicate their choices and decisions.[46]

The personalised passport includes:[46]

- Personal information such as height, weight, mobility, toileting, eating and drinking habits, likes and dislikes and contact information.
- Clinical information including diagnosis/symptoms, medications, previous surgeries and emergency care record (e.g. historical accident and emergency visits).

3 Education and Engagement for HCPs

A lack of targeted training and resources in rare and complex epilepsies places an increased burden on paediatricians and neurologists, many of whom may not be epilepsy specialists. Enhancing educational opportunities would improve the consistency of care standards, foster interest in these conditions and deepen understanding of their impact on individuals and families.

3.1 Enhance Training and Educational Opportunities for Neurologists

Increasing interest in specialising in rare and complex epilepsies

Who Can Action?

HCPs in collaboration with UK professional bodies (e.g. Epilepsy Nurses Association [ESNA], British Paediatric Neurology Association [BPNA], Association of British Neurologists [ABN], International League Against Epilepsy [ILAE], Royal Colleges, Health Education England [HEE] and the Medical Research Council [MRC]) and PAGs.

What is the Impact?

Rare and complex epilepsy care within the NHS is currently challenged by a strain on the tertiary care system, due to an insufficient number of specialists relative to the number of individuals requiring care. Through enhancing learnings and stimulating interest among paediatricians and neurologists in rare and complex epilepsies, the standard of care provided (e.g. diagnostic and treatment capabilities) would improve alongside reducing the strain on the tertiary care system.

Suggestions Within the Current System Include:

- Organising specific training sessions or incorporating additional modules on rare and complex epilepsies to complement the HCPs' syllabus (e.g. 2-day intensive training courses or 3–6-month placements in paediatric or adult specialties). This would enhance HCPs' understanding beyond the standard syllabus, leading to improved and more comprehensive care, resulting in increased patient HRQoL.
- Incorporating sessions/symposia at conferences or events that focus on a wider range of rare and complex epilepsies or developmental and epileptic encephalopathies (DEEs), including patient stories for RWE, to share knowledge and foster interest.
- Consider offering fellowships, such as in paediatrics, genetics or metabolic medicine, to neurologists interested in specialisations within rare and complex epilepsies. These fellowships would advance individuals' expertise, improving patient care and fostering advancements in this field.
- Providing materials to specialists that capture key takeaways and updates on rare and complex epilepsy topics (e.g. understanding DEEs, managing comorbidities such as challenging behaviours, learning disabilities, tone, drooling, constipation, scoliosis progression and ability to sit and understanding emerging genetic epilepsies).

What You Can Do Now:

HCPs and PAGs to spark discussions with certain UK professional bodies (e.g. ESNA, BPNA, ABN or ILAE) to provide in-depth training on rare and complex epilepsies.

HCPs to establish fellowships through discussions with certain UK professional bodies (e.g. Royal Colleges of Physicians [RCP], RCPCH, HEE and the MRC).

3.2 Provide Additional Support for HCPs

Enhancing individuals' care and outcomes

Who Can Action?

HCPs in collaboration with UK professional bodies and PAGs/charities.

What is the Impact?

As described in **Challenges**, roundtable participants emphasised the importance of being heard by HCPs throughout their diagnostic journey and care. However, managing rare and complex epilepsies is challenging for HCPs due to their atypical presentation and variable responses to treatments, increasing the difficulty in providing a timely diagnosis and developing holistic care plans.

Key Areas to Consider When Establishing Specialised Guidelines:

- Leverage or establish support networks among HCPs and MDTs to share insights on emerging conditions, seek advice and update care strategies for rare and complex epilepsies (see **Effective Collaboration Between HCPs**).
- Extend time in clinics to ensure experiences and concerns from individuals and families are thoroughly understood, and establish clear next steps for investigations or referrals.
- Create clear infographics for diagnostic workups across all care levels, detailing criteria and areas where further discussion may be required. Regularly evaluate and update materials and distribute widely via email and bulletin boards.
- Provide further training for HCPs on the best practice for delivering a rare diagnosis to individuals and their families (e.g. ensure sufficient time to provide the diagnosis), where limited treatment and/or prognostic information is available.

What You Can Do Now:

Discuss with colleagues the support and advice offered by current collaborations and networks for HCPs.

Explore strategies with local NHS bodies to increase clinic time.

Review PAG websites for individual testimonials on specific rare and complex epilepsies to aid HCPs' understanding of the patient journey.

PAGs/charities to develop targeted educational resources to assist HCPs in engaging with individuals and their families, ensuring a better understanding and management of rare and complex epilepsies.

Case Study – Training Opportunities

M4RD has developed a learning resource hub, with **online training** aimed at medical professionals with little prior knowledge of rare diseases. They aim to shape the medical profession to provide timely diagnosis and excellent care to people living with rare conditions.[47]

Paediatric Epilepsy Training is a series of 1- and 2-day courses developed by the BPNA and aims to improve the diagnosis of epileptic and non-epileptic events, improve the standard of care and raise awareness of when to liaise with a paediatric neurologist.[48]

4 Education and Engagement for Individuals with Rare and Complex Epilepsies and Their Families

An identified challenge for individuals and their families is the inaccessibility of information and support regarding diagnosis, treatment and co-ordination of care for rare and complex epilepsies. Enhancing access to information about underlying causes of epilepsy and available and/or recommended treatments, alongside prognostic information would empower individuals to make informed decisions and communicate effectively with HCPs, thereby improving their own care experience and outcomes.

4.1 Develop and Collate Resources for Individuals and Their Families

Empowering individuals and their families throughout their care

Who Can Action?

PAGs/charities, HCPs, industry and individuals and their families.

What is the Impact?

To empower individuals and their families, an information resource hub was proposed to support them throughout the care pathway. This hub would provide daily assistance, access to resources, treatment information, support group connections and documentation guidance, such as for applying for Direct Payments or CHC support.

Tailored Information Packs on Various Topics, such as:

- Diagnostic information, symptoms and comorbidities, disease progression, important questions to ask HCPs, current treatments and their side effects, guidelines, available healthcare and social services, financial advice and invoking Martha's rule.
- For individuals undergoing a transition from paediatric-to-adult healthcare, resources could include details on what to expect and how this transition should complement moving from paediatric-to-adult social care.
- For family members, information could include details of the impact of the individual's condition on the family and the support available for family members, including siblings.

What You Can Do Now:

- **HCPs and PAGs/charities to evaluate current available resources (e.g. information available on PAG websites) to identify existing content and gaps, and to determine whether resources can be adapted to be applicable for rare epilepsies or if resources need to be developed de novo.**
- **HCPs and PAGs/charities to engage with relevant stakeholders (e.g. PAGs with support from industry) to discuss how best to develop information packs and launch a joined-up platform resource hub.**
- **HCPs to share existing resources with newly diagnosed individuals and their families for practical support and connections in the community (e.g. information leaflets, links to disease-specific PAG websites).**
- **Individuals and their families to share, based on experience, where further information would be beneficial.**

Case Study – Transition Guide

Dravet Syndrome UK has developed a transition guide to help parents and guardians of children with Dravet syndrome prepare for and manage the challenges of transitioning into adulthood. The guide includes information on social care, medical care, NHS CHC, education and residential care alongside financial support and legal deputyship.[49] This guide is a useful material for supporting the development of tailored information packs.

4.2 Improve HRQoL Outcome Measurements for Rare and Complex Epilepsies

Allowing for a more comprehensive assessment of rare and complex epilepsy management

Who Can Action?

PAGs/charities, HCPs, industry and individuals and their families.

What is the Impact?

Reporting HRQoL data in rare diseases is challenging, as current HRQoL tools used in research and development often fail to represent the true experiences of individuals and their families. Therefore, the collection of HRQoL data through different methods is key in ensuring individuals' voices are heard and can inform future research.

Key Suggestions for HRQoL Data Collection Include:

- HCPs to work closely with individuals and families during clinics to understand the wider impacts of specific treatments and polytherapy on HRQoL, ensuring detailed notes are collected more systematically on health records.
- Individuals and their families to share their own experiences through their own networks (e.g. online support communities, PAGs), at epilepsy conferences/events or via a communal platform, such as those set up by organisations to gather patient stories and feedback. These data can then be analysed through PAG and industry/academic collaborations to highlight key HRQoL impacts.
- HCPs and PAGs to explore adapting existing HRQoL measures from a phenotypically similar disease area to rare and complex epilepsies.
- HCPs and PAGs to seek opportunities for collaboration with industry to explore the potential of using wearable technologies to capture data across different environments (e.g. home, hospital, school).

What You Can Do Now:

- **HCPs and PAGs/charities to increase the collection of evidence regarding the HRQoL of individuals with rare and complex epilepsies to complement current HRQoL tools and inform future research, which should be made available on previously mentioned digital platform(s) to accelerate research and fill data gaps (see Effective Collaboration Between HCPs).**
- **Individuals and families to provide data on symptoms, HRQoL and daily life impacts through established care networks) to discuss how best to develop information packs and launch a joined-up platform resource hub.**

Case Study – De Novo Methods for HRQoL Data Collection

Neurological Alliance England has partnered with related companies representing Scotland, Wales, Northern Ireland and Ireland alongside Revealing Reality, a social research company. This collaboration aimed to distribute three surveys to provide insights to inform future advocacy, influencing and service improvement at national and local levels for people living with neurological conditions. Two separate surveys were developed for adults (18 years of age and above) and children and young people (below 18 years of age). These surveys explored people's experiences of different symptoms and health issues, how their neurological condition impacted their ability to complete daily tasks (socialising, being active, working or studying), the impact on mental health and whether they felt supported by the health system. A third survey was completed by carers to establish the range of care provided (e.g. financial, emotional, physical) to individuals with neurological conditions.

Case Study – Sanius

Through the use of artificial intelligence, wearable technologies and disease-specific apps, Sanius helps individuals to better monitor their symptoms, providing personalised tools to help track health trends, detect changes and gain clarity around complex conditions.[50] This technology can be used to track HRQoL across a variety of conditions, including rare diseases. Sanius already partners with NHS trust organisers and PAGs across the UK and has the potential to partner with the NHS to expand these efforts to reach more individuals and families.[51]

5 Paediatric-to-Adult Care Transitional Support

A key challenge faced by individuals and their families is the reduction in holistic care management when transitioning from paediatric-to-adult services. The importance of improving this transition for epilepsy and rare diseases generally has been well established, but little change has been made across service delivery. As recognition of and advancements in the field of rare and complex epilepsies continue, it is essential to have a healthcare system in the UK equipped to facilitate this transition with comprehensive support, improving HRQoL for individuals and their families.

5.1 Develop a Structured Paediatric-to-Adult Transition Pathway Template

Improving individuals' access to care

Who Can Action?

PAGs, HCPs and individuals and their families.

What is the Impact?

With the transition to adult care, many individuals and their families feel lost within the system and do not receive the ongoing care they need. Developing a national transitional care plan template could improve standardisation and establish requirements for support during this transition, ensuring appropriateness and continuity of care.

The Plan Should Consider:

- Determining the most appropriate age to start to transition an individual with rare and complex needs to adult services, considering retention in paediatric services to up to 25 years of age where appropriate, in line with the UK's Education, Health and Care Plan.
- Starting early involvement of joint transition meetings between paediatric and adult MDTs, including all the required specialties and joint outreach clinics across primary, secondary and tertiary care, to ensure that the individual's medical history and ongoing needs are understood before starting transition.
- Considering the potential for a care co-ordinator to oversee the transition and serve as a communication point between individuals, families and MDTs.
- Determining the best methods for transitioning for not only healthcare but also social care (e.g. assessment by adult social services for funding towards home or community support, respite care and/or support for unpaid carers and evaluating whether individuals are eligible for CHC versus Direct Payments).

What You Can Do Now:

- **HCPs and PAGs to understand existing support and infrastructure for adult care, identify gaps and determine who should participate in MDT discussions.**
- **HCPs and PAGs to leverage existing guidance, such as the National Bundle of Care for Children and Young People with Epilepsy, to develop a framework or set of standards for transitioning individuals specific to rare and complex epilepsies, and engage with organisations for implementation.**
- **HCPs to ensure individuals are transitioned at both secondary and tertiary levels of care (not just one level) for ongoing local and specialist input.**
- **HCPs to schedule MDT clinics (virtual or in-person) specifically for young adults.**
- **HCPs to assess whether a care co-ordinator role would be beneficial or explore alternative structures for care co-ordination from the CONCORD study.**
- **PAGs to host surveys or meetings to understand where the CHC criteria fails to support individuals with rare and complex epilepsies.**
- **Individuals and their families to share, based on experience, where further information and support would be beneficial.**

Case Study – RDCN, Tuberous Sclerosis Complex (TSC)

The TSC Clinical Network RDCN brings together TSC clinics from across the UK with a key focus on providing smooth transitions from paediatric to adult care. The RDCN facilitates referrals between paediatric and adult TSC clinics, ensuring continuity of care for patients as they enter adulthood.[36]

Summary of Recommendations

This project generated a range of actionable solutions to improve access to care for individuals with rare and complex epilepsies and their families within the UK, tailored for implementation by various stakeholders. Five overarching themes for the solutions were identified, and for each, its anticipated positive impact on the care pathway was discussed.

1. Increase effective collaboration between HCPs on a local and regional level by building on connections between HCPs through the sharing of knowledge and resources and the collation of RWE, to provide holistic and joined-up care. This would help to improve and standardise care across the UK and enhance the understanding of individuals' care, reducing delays in diagnosis and improving co-ordination of care between MDT members.

2. Streamline and optimise existing care pathways, including establishing rare and complex epilepsy guidelines and developing an adaptable template care plan to ensure the delivery of equitable, high-quality care nationwide, alleviating the burden of care co-ordination on individuals, families and HCPs without necessitating entirely new pathways and processes. Consistently implementing small, efficient improvements across the care pathway, such as establishing 'hot' clinics, video call appointments, enhancing access to expert guidance and assigning care co-ordinators can yield significant positive impacts on the daily management of individuals' care.

3. Increasing education and engagement for HCPs, including expanding opportunities for neurologists, offering additional support in managing rare and complex epilepsies through more courses, fellowships or information packs, and leveraging HCP and MDT support networks. In addition, clinic times should be extended and educational materials should be provided to HCPs to help them communicate effectively with individuals and their families. Together, these solutions would deepen the understanding amongst HCPs of individuals' specialised needs and the impact of their condition on themselves and their families, improving the consistency of care standards provided and fostering interest in these conditions to drive a larger HCP workforce.

4. Improve education and engagement for individuals with rare and complex epilepsies and their families through increasing access to key information regarding their condition through a resource hub and improving HRQoL outcome measurements. Educating individuals on their condition and its management would empower them to make informed decisions regarding treatments and care and to communicate effectively with HCPs, ultimately enhancing their own care experience and outcomes. Furthermore, engaging with individuals to gain more insight into their condition, its management and how this impacts their HRQoL would help to ensure that the individuals' care pathway appropriately addresses their HRQoL needs and preferences.

5. Develop a structured paediatric-to-adult care transitional pathway template, taking into consideration key areas where adult care requires improvement, the appropriate age to initiate the transition process, joint transition meetings involving MDT members, the appointment of a care co-ordinator and strategies for transitioning across health and social care systems. A structured paediatric-to-adult transition would help to prevent individuals and families from feeling lost within the system and not receiving the ongoing care they need.

These recommendations are aligned with UK-wide rare disease strategies and emphasise the importance of faster diagnosis, increased HCP awareness, better care co-ordination and improved access to specialist services.[2–5] Furthermore, the recommendations align with all three strategic shifts outlined in the recently published NHS England 10-year plan, which aims to transition care from hospitals to community settings, embrace digital innovation and move from sickness to prevention.[3] By ensuring individuals receive effective treatments promptly, disease progression can be prevented, and emergency admissions and complications can be mitigated.

HCPs

1 Effective Collaboration Between HCPs

1.1 Increase Collaboration Across MDTs at a Local Level

- Compile and disseminate a holistic set of 'indicators' for MDTs to identify when to suspect rare and complex epilepsies
- Establish collaborations with the NHS Genomics Medicine Service to optimise genetic testing requests
- Encourage and organise joint outreach clinics between MDTs across primary, secondary and tertiary care to support efficient and streamlined care of individuals
- Discuss disease impact and individuals' concerns to deliver patient-centric care
- Understand current connections, and gaps in connections, between healthcare and social services and evaluate how to best bridge these gaps

1.2 Increase Collaboration Between Rare and Complex Epilepsy Specialists on a Regional Level

- Set up a collaboration platform and establish a list of attendees
- Consider topics of value to discuss, with a clear approach and structured agenda for the meetings, to ensure productive discussions and clear outcomes
- Align on the use of diagnostic tools and referral pathways, based on specialists' experiences, to establish best practice within the NHS
- Stay informed on the latest advancements in treatments and treatment combinations/algorithms, gaining insights into their benefits and limitations centred on the individual's experience, amplifying their voice

HCPs	PAGs	Individuals and their families
1.3 Increase the collection and sharing of RWE		
To consider data that would be valuable to collect and share, and the platforms that can be used for distribution	To set up forums/databases for families to report their experiences and stories regarding wider societal costs or impacts on HRQoL, and to include existing testimonials on PAG websites	To consistently opt to provide details on symptoms, HRQoL, daily life and societal costs when opportunities arise
To remain engaged with the progression of the Epilepsy12 project and support its promotion and public engagement once it becomes available		

HCPs	PAGs	Individuals and their families

2 Streamlining and optimising existing care pathways

2.1 Establish rare and complex epilepsy guidelines

HCPs	PAGs	Individuals and their families
To utilise previous and current specialist epilepsy meetings and collaborations to proactively raise awareness of the best practices discussed and gather interest for participation in the development of rare and complex epilepsy guidelines	To conduct gap analyses to identify gaps in current guidelines through roundtable discussions or surveys with HCPs, individuals and their families, alongside industry	To continue sharing personal experiences, highlighting successful parts of the care pathway and identifying areas that need improvement
To reach out to individuals within key organisations such as NICE or SIGN, to explore the best approach for instigating change and developing rare and complex epilepsy guidelines that are responsive to community needs		

2.2 Streamline and optimise current care pathways

HCPs	PAGs	Individuals and their families
Assess current care management services within your region to identify which of the above proposed solutions would enhance individuals' access to care in your region		To share personal experiences, highlighting successful parts of the current care pathway and identifying areas that need optimising
To start discussions with relevant stakeholders to action the above solutions		

2.3 Develop an adaptable template care plan

HCPs	PAGs	Individuals and their families
Identify relevant stakeholders for the development and review of template care plans		To share, based on experience, the minimum necessary elements required, as well as optional elements, for an adaptable care plan
Understand how care plans are currently completed and by whom across different UK regions and settings.		
Conduct an assessment to determine the minimum necessary elements to be included in the care plan for consistency across relevant settings and regions in the UK, balanced with applicability to different rare and complex epilepsies		

HCPs	PAGs

3 Education and engagement to HCPs

3.1 Enhance training and educational opportunities for neurologists

HCPs	PAGs
Spark discussions with certain UK professional bodies to provide in-depth training in rare and complex epilepsies	
Establish fellowships through discussions with certain UK professional bodies	

3.2 Provide additional support for HCPs

HCPs	PAGs
Discuss with colleagues regarding the support and advice offered by current collaborations and networks for HCPs	
Explore strategies with local NHS bodies to increase clinic time	
Review PAG websites for individual testimonials on specific rare and complex epilepsies to aid HCPs understanding of the patient journey	
PAGs/charities to develop targeted educational resources to assist HCPs in engaging with individuals and their families, ensuring a better understanding and management of rare and complex epilepsies	

HCPs	PAGs/Charities	Individuals and their families

4 Education and engagement for individuals with rare and complex epilepsies and their families

4.1 Develop and collate resources for individuals and their families

HCPs	PAGs/Charities	Individuals and their families
To share existing resources with newly diagnosed individuals and their families for practical support and connections in the community		To share, based on experience, where further information would be beneficial
To evaluate current available resources to identify content gaps and to determine what needs to be developed de novo		
To engage with relevant stakeholders to discuss how best to develop information packs and launch a joint up platform resource hub		

4.2 Improve HRQoL outcome measurements for rare and complex epilepsies

HCPs	PAGs/Charities	Individuals and their families
To increase the collection of evidence regarding the HRQoL of individuals with rare and complex epilepsies to complement current HRQoL tools and inform future research		Provide data on symptoms, HRQoL and daily life impacts through established care networks

5 Paediatric-to-adult care transitional support

5.1 Develop a structured paediatric-to-adult transition pathway template

HCPs	PAGs/Charities	Individuals and their families
To understand existing support and infrastructure for adult care, identify gaps, and determine who should participate in MDT discussions		To share, based on experience, where further information would be beneficial
To leverage existing guidance, such as the National Bundle of Care for Children and Young People with Epilepsy, to develop a framework or set of standards for transitioning individuals specific to rare and complex epilepsies, and engage with organisations for implementation		
To ensure individuals are transitioned at both secondary and tertiary levels of care (not just one level), for ongoing local and specialist input	To host surveys or meetings to understand where the CHC criteria fails to support individuals with rare and complex epilepsies	
To schedule MDT clinics specifically for young adults		
To assess whether a care co-ordinator role would be beneficial or explore alternative structures for care co-ordination from the CONCORD study		

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Abbreviations

ABN: Association of British Neurologists; **BPNA:** British Paediatric Neurology Association; **CamRARE:** Cambridge Rare Disease Network; **CDD:** CDKL5 deficiency disorder; **CEO:** Chief executive officer; **CHC:** Continuing healthcare; **DEE:** Developmental and epileptic encephalopathies; **EpiCARE:** European Reference Network for Rare and Complex Epilepsies; **ESN:** Epilepsy specialist nurse; **ESNA:** Epilepsy Nurses Association; **GP:** General practitioner; **HCP:** Healthcare professional; **HEE:** Health Education England; **HRQoL:** Health-related quality of life; **HSE:** Health Service Executive; **ID:** intellectual disability; **ILAE:** International League Against Epilepsy; **M4RD:** Medics for Rare Diseases; **MDT:** Multidisciplinary team; **MRC:** Medical Research Council; **NICE:** National Institute for Health and Care Excellence; **PAG:** Patient advocacy group; **RCP:** Royal College of Physicians; **RCPCH:** Royal College of Paediatrics and Child Health; **RDCN:** Rare Disease Collaborative Network; **RWE:** Real-world evidence; **SIGN:** Scottish Intercollegiate Guidelines Network; **SMC:** Scottish Medicine Consortium; **SUDEP:** Sudden unexpected death in epilepsy; **TLR:** Targeted literature review; **TSC:** Tuberous Sclerosis Complex; **UCL:** University College London; **UK:** United Kingdom; **UKRET:** UK Rare Epilepsies Together network; **VUS:** Variant of uncertain significance.

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