

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



## 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.<sup>1-4</sup> 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.<sup>3</sup> By ensuring individuals receive effective treatments promptly, disease progression can be prevented, and emergency admissions and complications can be mitigated.

HCPs		
<b>1 Effective Collaboration Between HCPs</b>		
<b>1.1 Increase Collaboration Across MDTs at a Local Level</b>		
<ul style="list-style-type: none"> <li>✓ Compile and disseminate a holistic set of 'indicators' for MDTs to identify when to suspect rare and complex epilepsies</li> <li>✓ Establish collaborations with the NHS Genomics Medicine Service to optimise genetic testing requests</li> <li>✓ Encourage and organise joint outreach clinics between MDTs across primary, secondary and tertiary care to support efficient and streamlined care of individuals</li> <li>✓ Discuss disease impact and individuals' concerns to deliver patient-centric care</li> <li>✓ Understand current connections, and gaps in connections, between healthcare and social services and evaluate how to best bridge these gaps</li> </ul>		
<b>1.2 Increase Collaboration Between Rare and Complex Epilepsy Specialists on a Regional Level</b>		
<ul style="list-style-type: none"> <li>✓ Set up a collaboration platform and establish a list of attendees</li> <li>✓ Consider topics of value to discuss, with a clear approach and structured agenda for the meetings, to ensure productive discussions and clear outcomes</li> <li>✓ Align on the use of diagnostic tools and referral pathways, based on specialists' experiences, to establish best practice within the NHS</li> <li>✓ 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</li> </ul>		
HCPs	PAGs	Individuals and their families
<b>1.3 Increase the collection and sharing of RWE</b>		
<ul style="list-style-type: none"> <li>✓ To consider data that would be valuable to collect and share, and the platforms that can be used for distribution</li> </ul>	<ul style="list-style-type: none"> <li>✓ 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</li> </ul>	<ul style="list-style-type: none"> <li>✓ To consistently opt to provide details on symptoms, HRQoL, daily life and societal costs when opportunities arise</li> </ul>
<ul style="list-style-type: none"> <li>✓ To remain engaged with the progression of the Epilepsy12 project and support its promotion and public engagement once it becomes available</li> </ul>		

\*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.



HCPs	PAGs	Individuals and their families
<b>2 Streamlining and optimising existing care pathways</b>		
<b>2.1 Establish rare and complex epilepsy guidelines</b>		
<ul style="list-style-type: none"> <li>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</li> </ul>	<ul style="list-style-type: none"> <li>To conduct gap analyses to identify gaps in current guidelines through roundtable discussions or surveys with HCPs, individuals and their families, alongside industry</li> </ul>	<ul style="list-style-type: none"> <li>To continue sharing personal experiences, highlighting successful parts of the care pathway and identifying areas that need improvement</li> </ul>
<ul style="list-style-type: none"> <li>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</li> </ul>		
<b>2.2 Streamline and optimise current care pathways</b>		
<ul style="list-style-type: none"> <li>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</li> </ul>		<ul style="list-style-type: none"> <li>To share personal experiences, highlighting successful parts of the current care pathway and identifying areas that need optimising</li> </ul>
<ul style="list-style-type: none"> <li>To start discussions with relevant stakeholders to action the above solutions</li> </ul>		
<b>2.3 Develop an adaptable template care plan</b>		
<ul style="list-style-type: none"> <li>Identify relevant stakeholders for the development and review of template care plans</li> <li>Understand how care plans are currently completed and by whom across different UK regions and settings.</li> <li>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</li> </ul>		<ul style="list-style-type: none"> <li>To share, based on experience, the minimum necessary elements required, as well as optional elements, for an adaptable care plan</li> </ul>
HCPs	PAGs	
<b>3 Education and engagement to HCPs</b>		
<b>3.1 Enhance training and educational opportunities for neurologists</b>		
<ul style="list-style-type: none"> <li>Spark discussions with certain UK professional bodies to provide in-depth training in rare and complex epilepsies</li> </ul>		
<ul style="list-style-type: none"> <li>Establish fellowships through discussions with certain UK professional bodies</li> </ul>		
<b>3.2 Provide additional support for HCPs</b>		
<ul style="list-style-type: none"> <li>Discuss with colleagues regarding the support and advice offered by current collaborations and networks for HCPs</li> <li>Explore strategies with local NHS bodies to increase clinic time</li> <li>Review PAG websites for individual testimonials on specific rare and complex epilepsies to aid HCPs understanding of the patient journey</li> <li>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</li> </ul>		

HCPs	PAGs/Charities	Individuals and their families
<b>4 Education and engagement for individuals with rare and complex epilepsies and their families</b>		
<b>4.1 Develop and collate resources for individuals and their families</b>		
<ul style="list-style-type: none"> <li>To share existing resources with newly diagnosed individuals and their families for practical support and connections in the community</li> </ul>		<ul style="list-style-type: none"> <li>To share, based on experience, where further information would be beneficial</li> </ul>
<ul style="list-style-type: none"> <li>To evaluate current available resources to identify content gaps and to determine what needs to be developed de novo</li> <li>To engage with relevant stakeholders to discuss how best to develop information packs and launch a joint up platform resource hub</li> </ul>		
<b>4.2 Improve HRQoL outcome measurements for rare and complex epilepsies</b>		
<ul style="list-style-type: none"> <li>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</li> </ul>		<ul style="list-style-type: none"> <li>Provide data on symptoms, HRQoL and daily life impacts through established care networks</li> </ul>
<b>5 Paediatric-to-adult care transitional support</b>		
<b>5.1 Develop a structured paediatric-to-adult transition pathway template</b>		
<ul style="list-style-type: none"> <li>To understand existing support and infrastructure for adult care, identify gaps, and determine who should participate in MDT discussions</li> <li>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</li> </ul>		<ul style="list-style-type: none"> <li>To share, based on experience, where further information would be beneficial</li> </ul>
<ul style="list-style-type: none"> <li>To ensure individuals are transitioned at both secondary and tertiary levels of care (not just one level), for ongoing local and specialist input</li> <li>To schedule MDT clinics specifically for young adults</li> <li>To assess whether a care co-ordinator role would be beneficial or explore alternative structures for care co-ordination from the CONCORD study</li> </ul>	<ul style="list-style-type: none"> <li>To host surveys or meetings to understand where the CHC criteria fails to support individuals with rare and complex epilepsies</li> </ul>	

**References**

- EpiCARE. About Epilepsies. Available from: <https://epi-care.eu/about-epilepsies>. Last accessed: May 2025.
- Scottish Government. Rare Disease Action Plan. 2022. Available from: <https://www.gov.scot/publications/rare-disease-action-plan/>. Last accessed: May 2025.
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