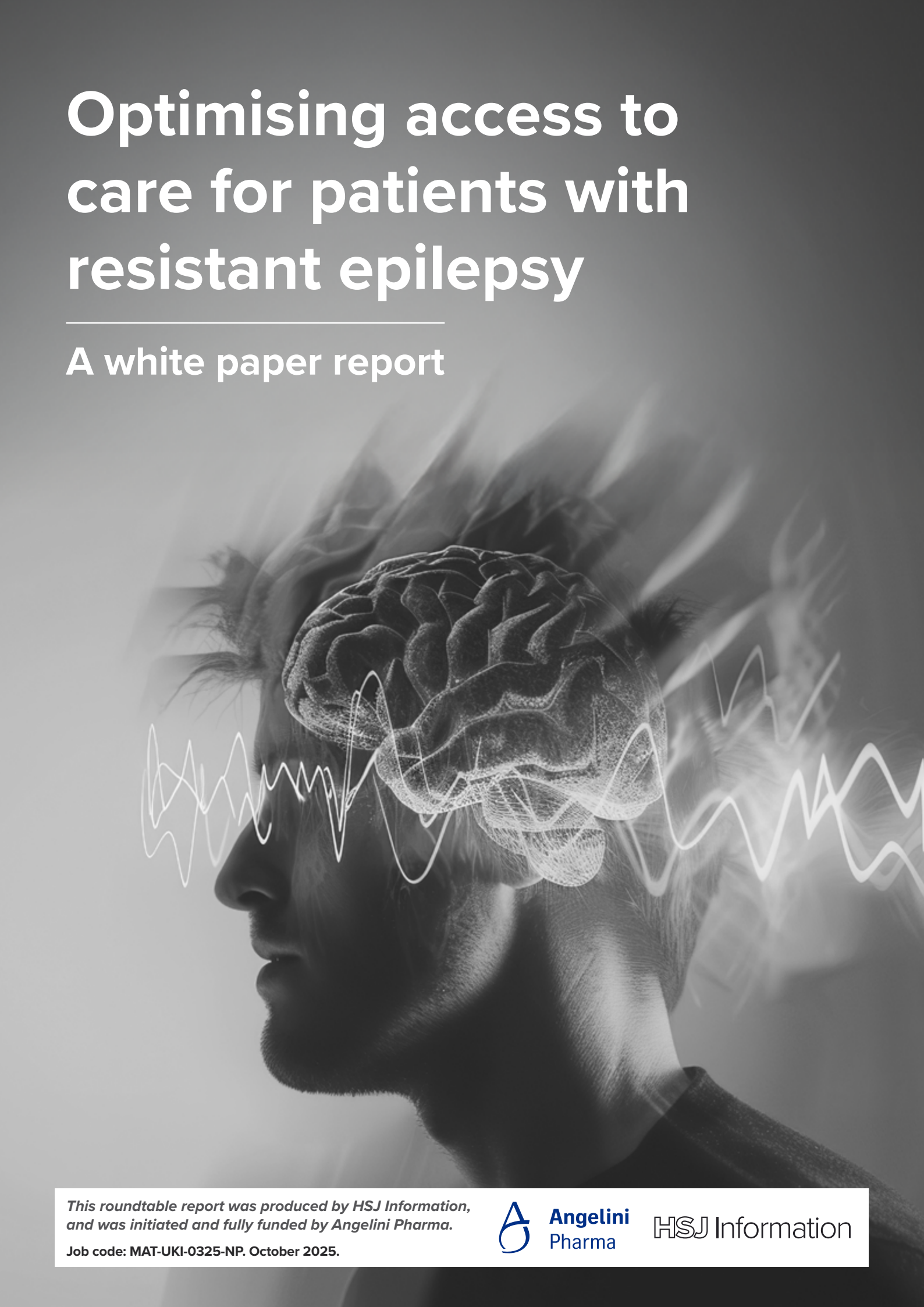
Optimising access to care for patients with resistant epilepsy

A white paper report



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Foreword

Epilepsy care is prevention: prevention of seizures, and the injuries and impediments caused by seizures. The NHS 10 Year Health Plan draws upon a groundswell of interest in prevention of long-term conditions as an attractive strategy for making the UK healthier. When looking at health systems and pathways, this is the equivalent of turning the tap off — or at least slowing it — as you are busy bailing out the bath.

Flooding the health services with epilepsy specialist nurses would undoubtedly meet our goals of safe and equitable care for all people with epilepsy — uncoupled from whether they have the geographic or societal fortune to be under a specialist centre. We are currently unable to land the argument that we deserve an adequately funded and safe epilepsy service, which increases the slice of the NHS pie allocated to this serious long-term condition. Until attitudes shift, we must be prudent and make the best use of current resources, which includes seeing the right people, at the right time, in the right place for them (and their clinical team).

Prevention of unnecessary healthcare utilisation becomes our new focus. This white paper looks at the benefits of preventing unnecessary ambulance calls, conveyances, and reducing the duration of unscheduled admissions. Other themes are closer working with all members of the multidisciplinary team who care for people with epilepsy, and a renewed focus on community based practitioners. The centralisation of epilepsy care has helped us create standards of care and launch our most critical tool — the epilepsy specialist nurse. But we must now also ensure equity and integrate ourselves into community teams; multidisciplinary community hubs are the new vehicle for care delivery, and we call upon commissioners to use epilepsy as their vanguard example to demonstrate their value.

We can then move away from the paternalistic, out-patient reliant models of long-term care and towards more self-directed and patient-led management. We are at the infancy of what webinars, podcasts, digital tools and AI-backed chatbots can do to help a sub-set of our patients not live a seizure-free life but live well. Bespoke advice is preferable, but much of what is provided changes slowly, such as knowledge of safety of drugs in pregnancy or driving eligibility advice, and it would empower patients to have immediate answers to questions.

Yes, the white paper is ambitious, as are our aims. But change is needed, and we cannot accept the status quo. The quote, attributed to Desmond Tutu is pertinent here

> ***There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they're falling in.***

Rhys Thomas
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Executive summary

This report explores the systemic challenges and innovations in the management of people with treatment-resistant epilepsy, highlighting the burden on the individual and healthcare services, and outlining strategic opportunities to ensure more equitable access to treatment.

This white paper discusses the management of people with treatment-resistant epilepsy and considers 'why epilepsy', 'why now', and 'why we should pay attention to this problem'. By capitalising on the many themes in the NHS 10 Year Health plan, epilepsy care teams can look at ways to improve seizure prevention, provide care nearer to home, and embrace artificial intelligence (AI) and digital health options that are currently available. Embedding accessible care within primary care settings improves system efficiency, potentially addressing symptom prevention, and integrating care with a view to reducing the burden on hospitals — directly addressing the goals of the NHS 10 Year Health Plan.[i]

The burden of epilepsy is significant

- Epilepsy significantly reduces the quality of life of affected children, young people and adults, even if seizures are well controlled. This is due to the chronic nature of the condition and its unpredictability; it disrupts social interactions, education, and employment. The side effects of anti-seizure medications, combined with the long-term psychological toll of epilepsy, profoundly affects the quality of life for many individuals.
- However, comprehensive management using anti-seizure medications and modification of lifestyle factors where appropriate, enables most individuals with epilepsy to control their seizures effectively and reduce the impact on their daily lives.

There is an urgent need for systemic reform in epilepsy care

- There are major gaps in epilepsy care pathways, especially for people with treatment-resistant epilepsy. Delays in diagnosis, fragmented services, and inconsistent access to specialist support continue to increase pressure on emergency departments and negatively impact on patient outcomes.
- Increased access to epilepsy management within primary care may reduce the need for onward referrals, thereby reducing the wait times for those who require secondary or tertiary care input and the burden on the NHS.

Primary care teams are increasingly de-skilled in epilepsy management

- General practitioners (GPs) and primary care teams have had their epilepsy management skills eroded due in part to the centralisation of care. Targeted education, clearer shared care agreements, and stronger integration with secondary and tertiary services to re-empower primary care is needed.

Expanding multidisciplinary teams can enhance epilepsy care

- Embedding epilepsy specialist pharmacists and specialist nurses within multidisciplinary teams (MDTs) can improve the care of people with epilepsy. These roles enhance medication optimisation, increase concordance, and provide vitally needed counselling services whilst ensuring continuity of care closer to home.

Digital innovation and artificial intelligence (AI) present new opportunities for epilepsy services

- AI-driven chatbots, video diagnostics, and integrated digital records carried by the individual with epilepsy on their mobile device could streamline communication across services and improve efficiencies in care, especially for those with complex care needs.

Equitable access to epilepsy treatment remains a major challenge

- People with epilepsy have diverse needs arising from intellectual disabilities, language barriers, and socioeconomic challenges. Tailored, community-based solutions and proactive outreach are essential when attempting to close the gaps in epilepsy care across the nation.

Reliable access to anti-seizure medications remains a challenge, particularly for those living in more remote geographical locations.

A national call to action is needed to improve epilepsy commissioning

- The NHS should prioritise epilepsy as part of its strategic planning. Dedicated commissioning is needed to support early intervention, community-based care, and post–emergency department (ED) follow-up. A national epilepsy care framework aligned with the NHS 10 Year Health Plan is essential to reduce postcode variation and support those with epilepsy living in deprived areas, where people are more than a third more likely to have epilepsy than those in the least deprived areas.[ii]
- Adequate epilepsy care should be a priority as this treatable condition is associated with an average of 21 deaths per week in the UK.[iii]

References:

i. UK Government. Fit For Future. The 10 Year Health Plan for England. Available at: https://www.longtermplan.nhs.uk/ (accessed September 2025).
ii. Epilepsy Action. UK epilepsy prevalence and incidence update. 2023. Available at: https://www.epilepsy.org.uk/news/uk-epilepsy-prevalence-and-incidence-update (accessed September 2025).
iii. SUDEP Action. Prevent21 Summit on Tackling Epilepsy Deaths: Consensus Recommendations Summary. Available at: https://www.neural.org.uk/wp-content/uploads/2021/04/2018-12-epilepsy-consensus-recommendations.pdf (accessed September 2025).

Background

In July 2025, a panel of healthcare professionals with expertise in epilepsy convened at a peer-to-peer roundtable, which was initiated and fully funded by Angelini Pharma, alongside patient representatives and attendees from the charity, Epilepsy Action.

The aim of the roundtable was to discuss attendees' own perspectives of holistic management of care for patients with epilepsy, share local best practice projects, and consider potential resolutions to some of the shortcomings in current epilepsy pathways. These discussions placed particular emphasis on the management of individuals with treatment-resistant epilepsy.

The objectives of the meeting and the purpose of this white paper was to:

- Gain insight into the burden and challenges in initiating and continuing treatment for treatment resistant epilepsy
- Understand how centres have overcome many of these challenges and look at the innovation approaches being used
- Discuss next steps in strategic planning.

Reflecting the views of the expert group, this white paper has been developed by HSJ Information. It was organised and funded by Angelini Pharma which reviewed the report for accuracy.

Introduction to epilepsy

There are **633,000** people or **1 in 100 people** living with epilepsy in the UK, and a further 600 people are diagnosed each week.[1]

- In 50% of people with epilepsy there is no known cause for their seizures.[1]
- 50% of those diagnosed with epilepsy will have other co-existing physical or psychiatric conditions, with one in three people living epilepsy having depression, which is double the rate of depression when compared with the general population.[1]
- 30% of people with epilepsy live with uncontrolled seizures that do not respond to medication.[1]
- An average of 21 patients with epilepsy die each week in the UK, of which Sudden Unexpected Death in Epilepsy (SUDEP) accounts for about 50%.[2]

Epilepsy is the most common long term neurological condition of childhood and affects an estimated **112,000 children and young people** in the UK.[3]

- Epilepsy has a significant impact on the quality of life of children, young people, and adults and negatively impacts social, educational and employment activity,[3,4] but if managed appropriately with anti-seizure medications, most individuals with active epilepsy can maintain satisfactory control of seizures.[4]

One quarter of those with epilepsy also have an intellectual disability; these individuals are more likely to be drug resistant, and to have more severe seizures.[4-7]

- Data from 2022 show that in those with learning disabilities, epilepsy was the long-term condition that was most strongly associated with dying at a younger age.[8] Prompt and personalised care packages which include advice regarding the use of rescue medications for managing uncontrolled seizures are associated with a lower risk of early mortality and premature death.[8]

The Urgent and Emergency Care Plan for England (2025/26)[9] introduces reforms to reduce hospital admissions and improve community-based care.[9,10] For people with epilepsy, this is likely to mean:

- A focus on paramedic-led care at home or at the scene of a seizure
- Reduced reliance on emergency departments (EDs) and treatment in acute hospital settings
- Faster access to early discharge teams, especially for those recovering from seizures, for whom the emphasis will be on reducing re-admission.

Integrated care pathways can help to achieve these objectives and improve management of seizures while supporting the patient's mental health, educational, and social needs.[9,11] Routine epilepsy care is neither high cost nor the preserve of centralised specialist teams. Self-management should be encouraged where possible for people with epilepsy, empowering them to continue to build a social network, return to work, and drive where appropriate.

> ***Epilepsy is estimated to cost the UK £1.7 billion to £2 billion annually. This is over 0.07% of UK's 2019 gross domestic product, with more than half due to lost productivity[1,12,13]***

Challenges of managing epilepsy

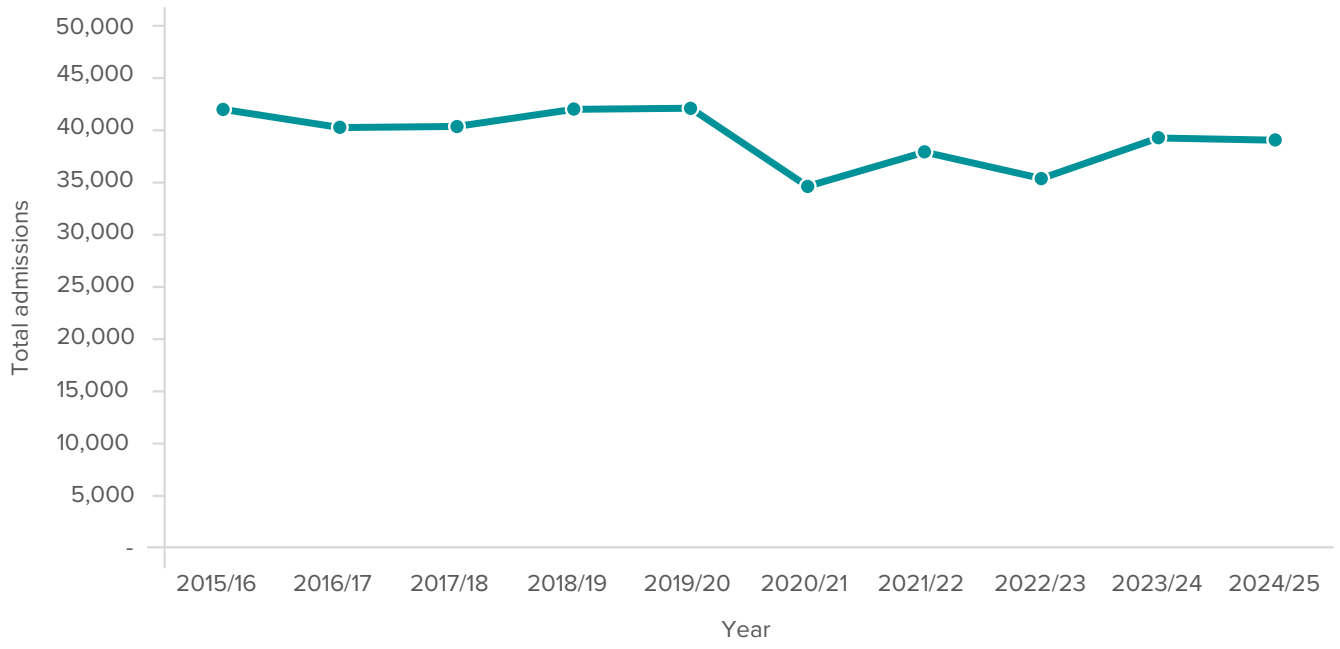
People with epilepsy suffering suspected seizures commonly present to EDs, but most seizures are self-limiting and have low risk of short-term adverse outcomes:[14]

- 2.8% of all ambulance service incidents are for suspected seizures[14]
- 61.7% of these incidents led to dispatch of a rapid-response ambulance (8 minutes), with 72.1% of the patients seen conveyed to hospital.[14]

Most people who present at the ED with seizures will arrive by ambulance as part of an unscheduled admission (89.8%):[14]

- 45.4% of these patients were admitted and 44.5% of these admissions lasted under 48 hours[14]
- This includes first seizures as well as recurrent episodes
- Patient admissions with a primary diagnosis of epilepsy (ICD10 code G40) have remained relatively stable over the last 10 years.[15] (Figure 1).

Figure 1: Patient admissions with a primary diagnosis of epilepsy (G40), 2015/16 to 2024/25 (England only)[15]



Factors responsible for the high number of hospital admissions include:[12,16]

Limited access to specialist care

Social deprivation

Mental health issues

Lack of seizure management knowledge

Data from the National Audit of Seizure Management in Hospitals (NASH) audits show that:

- Wide variability in care, including imaging practices, is seen across hospitals, which suggests that CT scans are booked unnecessarily following acute admission and not in line with evidence-based protocols, as per the first NASH audit of 2011.[17-19]
- Reducing unnecessary CT scans could alleviate financial pressure on the NHS, especially when paired with better referral pathways to epilepsy specialists and improved patient follow-up.[18,19]
- The second NASH audit conducted in 2013 found that only 55% of people with epilepsy were referred to specialist services after their first seizure. Increasing this referral rate may help prevent future seizures and reduce repeat hospital visits.[20]

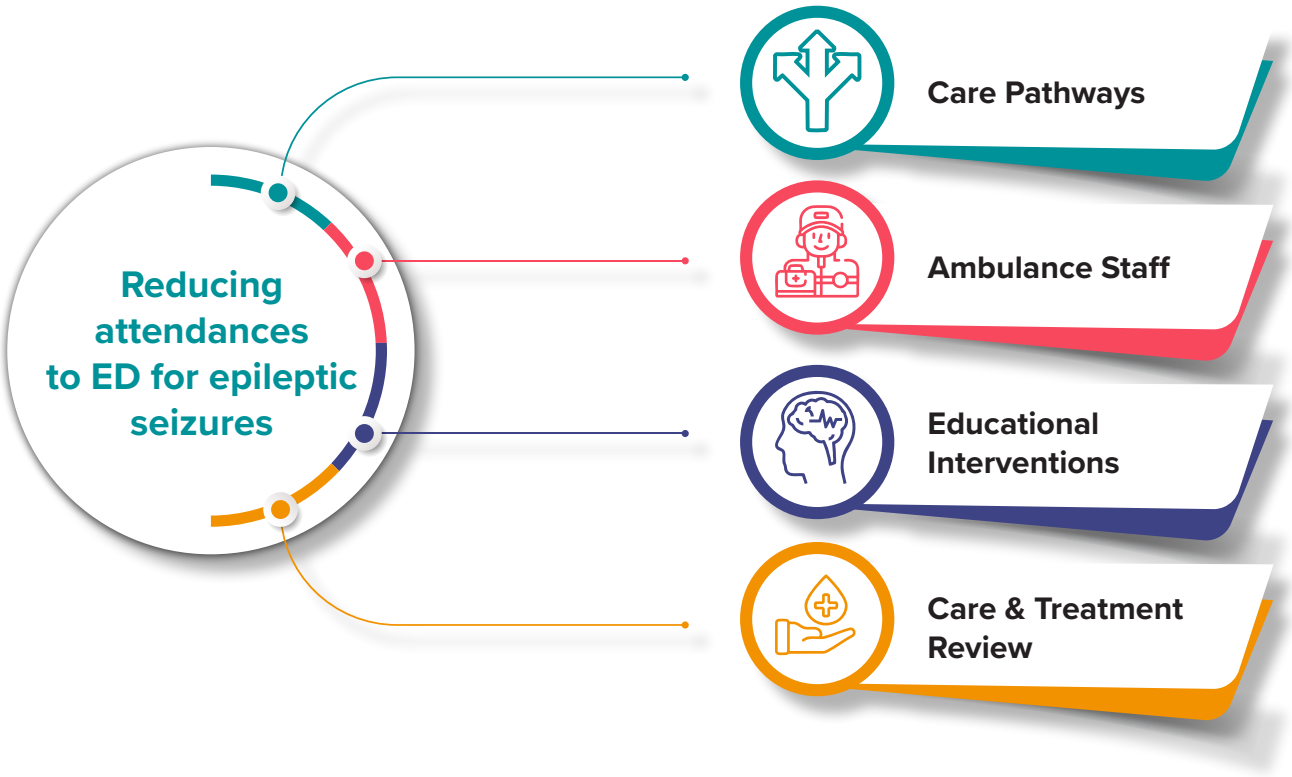
Multidisciplinary teams, including neurologists, epilepsy nurses, psychologists, and social workers, have a vital role to play in delivering comprehensive care.[11,12] By collaborating with acute trusts and ambulance services, they can provide targeted education, support, and guidance to paramedics, reducing hospital readmission rates and facilitating early discharge. Ongoing support in the community reflects patient choice and potentially reduces the carbon footprint by minimising excessive transport to and from hospitals.[16]

> ***In the UK, more than 60,000 ED attendances per year are suspected to be related to seizures—this is 2% to 3% of all ED attendances[12,14]***

Box 1: Situations where conveyance is recommended

Conveyance is recommended in some situations including for first seizure, prolonged convulsive seizure, and seizures associated with high fever and injury. The more widespread use and access to video captured by ambulance services can be used to better diagnose epilepsy seizures and differentiate them from their mimics.

Figure 2: Reducing ED attendance requires an interlinked approach (adapted from Burrows et al.)[16]



High volumes of ED calls, unnecessary hospital conveyancing, and unscheduled admissions

Epilepsy places a considerable burden on the NHS and 2% to 3% of all ED attendances are for suspected seizures[10,12]

- Conveyance decisions often reflect a need to balance individual safety with choice. However, paramedics may lack access to relevant clinical information, and decisions can be influenced by time pressures, limited confidence, and gaps in epilepsy-specific knowledge. Addressing these challenges through better training and access to patient records could support more appropriate, patient-centred care.

In 2019, the trust responsible for University Hospitals Birmingham appointed an epilepsy specialist nurse who worked 3 days a week in the ED to manage patients with epilepsy.

- By using an epilepsy specialist nurse to manage ED patients, University Hospitals Birmingham was able to reduce hospital stays and re-admission rates by 30% from previous levels within a 3-month period.
- The approach uncovered additional challenges at the hospital, including difficulties in diagnosing seizures accurately and the correct coding of seizure episodes.

Ensuring access to other areas of support

Accessing additional support can often be challenging for patients. Epilepsy specialist nurses play a key role in bridging this gap by providing individuals with epilepsy information and contact details for relevant support services following their visit to the ED. This may include help with medication concordance, addiction and substance misuse (which can exacerbate seizures), and improved access to social care and financial assistance to help address social deprivation.

> ***The referral process between primary, secondary, and tertiary care is complex and often difficult to navigate.***

Multiplicity of management pathways and streamlining referrals

People with epilepsy present through multiple routes, including the ED, Acute Medical Unit (AMU), primary care, and referrals from other hospital departments. This variety in presentation pathways increases the complexity of managing epilepsy effectively.

In many neuroscience centres, individuals presenting to the ED with a convulsive seizure and no prior epilepsy history are triaged directly to a first seizure service. This should be available to all individuals with a suspected first seizure no matter where they present, and they should be seen within two weeks.

In many secondary care centres, the first seizure service is triaged so people are fast-tracked for an urgent review if they have multiple events, no diagnosis, are pregnant, etc. This reduces the frequency of people with clear syncope or non-epilepsy collapses being added to first seizure waiting lists. People with established epilepsy are also sign-posted to more appropriate services.

First seizure service

- The first seizure service offers rapid access to specialist care, which may not always be available to patients in smaller, local hospitals.
- **High referral acceptance:** Over 80% of referrals to the first seizure clinic are accepted by secondary care.
- **Timely access for complex cases:** People with multiple seizures, no formal diagnosis, or not on anti-seizure medication are typically seen within the two-week target
- Delayed access for less complex cases: People with milder presentations often wait six weeks or more for their first appointment.
- **Streamlined care for people with known epilepsy:** Individuals with an existing epilepsy diagnosis who experience a seizure can be referred directly to a nearby secondary care hospital for a prompt medication review.

In many centres, first seizure clinic referrals from GPs or the ED are triaged by a consultant, a process that may not be the most efficient use of consultant time.

Figure 3: First seizure service: Reasons for non-acceptance and lack of timely referral

Treat and discharge

- In some regions, people with epilepsy will be managed using a 'see, treat, and discharge' model, where care is delivered by a local multidisciplinary team (MDT), including roles such as a clinical pharmacist, psychiatrist, or GP with a special interest, ensuring timely assessment and intervention without the need for hospital admission.

Multidisciplinary team

- Alternatively, the person with epilepsy may continue their care within secondary or tertiary services care, via an MDT, which may include input from a specialist nurse, a pharmacist, or a psychiatrist as needed.

Referral process

- People who live in deprived areas, those with limited literacy, non-native English speakers, and/or individuals who miss appointments are at risk of becoming lost in the system.
- Epilepsy is significantly more prevalent in the homeless population, yet support is severely lacking, often limited to emergency care through ED.[21]
- Some of these individuals may eventually present to the ED with uncontrolled seizures
- Streamlining the referral process is essential to ensure continuity of care, enabling regular check-ups via 'hot' clinics where prior booking is not required, and access to epilepsy-specific advice, including guidance on driving in the community.

For people with established epilepsy, management pathways are harder to map out and will differ according to geographic location.

Figure 4: Keeping people with epilepsy out of hospital remains a challenge:

Hospital is often the first point of contact and perceived as the 'safe' option, highlighting a need to strengthen confidence and accessibility in primary care	A more seamless transition from specialist to primary care is needed to ensure continuity, reduce fragmentation, and support patient outcomes	Delays in maintenance prescribing within primary care may be linked to increased risk of hospital admissions
Limited information sharing and poor communication among professionals can undermine coordinated care and lead to fragmented patient experiences	The lack of meaningful dialogue between primary and secondary care can hinder continuity, delay decision-making, and compromise patient outcome	ACPs in primary care and may lack the skills to manage individuals with epilepsy, highlighting a need for targeted training and support
A lack of shared understanding among professionals involved in patient care can lead to fragmented decision-making and inconsistent support for patients	Early diagnosis and alignment with a recognised care pathway can empower people with epilepsy with a sense of volition and ensure the support they receive is genuinely suited to their individual need	GPs are increasingly reliant on advice and guidance before referring patients, which may contribute to clinical deskilling over time
A flexible and responsive system is needed, one that can adapt to the diverse and evolving needs of individual patients	Epilepsy knowledge outside of neurology departments may be limited	Geographic location can restrict patient choice, limiting access to services and specialists based on where they live

ACP = advanced clinical practitioners; GP = general practitioner.

Areas for change

Personalised, flexible, accessible, and adaptable care

Individuals with epilepsy experiencing uncontrolled seizures need urgent, tailored responses, while those seeking treatment reassessment require a different approach. Care pathways must be:

- **Personalised** to individual needs
- **Flexible** in response to changing circumstances
- **Accessible** across geographic locations
- **Adaptable** to the nature and urgency of the individual's condition

Current systems often lack this agility, especially in rural areas, where limited options restrict patient access and choice.

Rural inequities and over-reliance on hospitals

In rural communities, people with epilepsy frequently depend on secondary care teams for even basic queries due to limited local resources. This over-reliance on hospital-based care can lead to:

- **Frustration** from lack of alternatives
- **Reduced** care or continuity of care
- **Increased pressure** on hospital services

Knowledge gaps and poor coordination

Professionals outside neurology often lack epilepsy-specific knowledge. Coordination between neurologists, psychiatrists, GPs, and maternity teams remains inconsistent. Local GPs may have limited experience and be unfamiliar with managing people with epilepsy due to frequent referrals to specialists, which leads to:

- **Reduced confidence** in managing epilepsy
- **Lack of access** to quick advice for dose adjustments or medication changes within community settings can lead to longer wait lists for specialist teams
- **Fragmented care** and delayed interventions
- **Decline of shared care agreements** and primary care prescribing of anti-seizure medications.

Variable local provision and specialist demand

Local hospital care varies widely. Given epilepsy's unpredictability and risks, many people with epilepsy prefer ongoing care from specialist hubs rather than visiting a neurologist at their local hospital. As a result:

- People with epilepsy often remain partially under specialist care.
- Sometimes there is also a reluctance to refer from secondary to tertiary care meaning that candidates for surgical interventions or vagus nerve stimulation (VNS) often go unassessed, missing opportunities for potentially life-changing treatment.
- Tertiary centres function as both general and specialist hubs.
- Services must flexibly expand and contract to meet demand.

One critical gap in epilepsy care is the transition from paediatric to adult services. This period is often poorly coordinated, leaving young people vulnerable to disrupted care and reduced engagement. The challenge is compounded by the fact that some anti-seizure medications are commissioned exclusively for paediatric use, creating barriers to continuity of treatment as the individual ages.

- Addressing this requires clearer commissioning pathways, better cross-service communication, and dedicated transition support to ensure young people receive consistent, age-appropriate care.

Rebuilding confidence within primary care

Over the past two decades, primary care physicians have become increasingly deskilled in epilepsy management. This disconnect can alienate people with epilepsy and reduce trust in local care. Solutions include:

- **Upskilling GPs** through targeted training
- **Leveraging epilepsy nurses and pharmacists** for specialist support
- **Improving communication** during transitions from tertiary to primary care

Poor handovers and unclear guidance can delay treatment, increase seizure risk, and undermine epilepsy control. Support for GPs should include:

Support for GPs should include:

- Rapid, frictionless access to specialist advice, providing answers to quick queries such as "Can I increase this medication?" or "Is this drug safe to prescribe alongside an anti-seizure medication?
- Specialist advice in addressing serious concerns and enabling timely and appropriate escalation when needed.

A stretch goal is to facilitate greater electronic record sharing between hospitals, GP practices, and ambulance services, particularly for emergency care protocols and safeguarding information, which can ensure coordinated and informed decision-making across the system.

See Box 2 for details of how Northumbria Primary Care have been addressing the deskilling of GPs.

Box 2: Tackling GP deskilling through community engagement

Northumbria Primary Care is actively addressing GP deskilling by partnering with Epilepsy Action to deliver targeted support, awareness, and training. A newly appointed clinical director is leading this initiative by:

- **Engaging directly with GPs in the community**
- **Providing hands-on training and support**
- **Expanding access to specialist care at the local level**

This approach leverages the voluntary sector's deep understanding of epilepsy-related challenges and builds GP confidence and capability over time.

Charities like Epilepsy Action play a vital role in supporting both individuals with epilepsy and healthcare professionals. They:

- **Offer people with epilepsy and their families an additional point of contact** for advice and reassurance
- **Provide peer-led support,** especially valuable when delivered by individuals with lived experience of epilepsy
- **Bridge communication gaps** between people with epilepsy and clinical teams

People with epilepsy often feel more comfortable discussing their condition with a specialist nurse or a charity worker with personal experience, than with a consultant, making these roles essential to holistic care.

Build multidisciplinary community hubs through partnerships

Collaborations between epilepsy organisations and government initiatives can drive the development of multidisciplinary community hubs. These hubs can:

- Upskill GPs with targeted training and support
- Improve access, especially in areas with large hospital catchment areas
- Reduce reliance on hospital visits, which are often difficult for people with epilepsy who have driving restrictions in place or mobility challenges

Diabetes care offers a strong example of effective multidisciplinary collaboration. Individuals can access diabetic footcare and ophthalmology services through specialist nurses, who manage ongoing care after initial consultant contact. This model:

- **Empowers nurses** to lead care
- **Streamlines referrals** back to consultants when needed
- **Improves continuity** and patient experience

Shift epilepsy care back into the community

In cities like Newcastle and Birmingham, epilepsy services have been within secondary and tertiary care for many years, partly due to funding and commissioning. Therefore, GPs have never been involved in initiation, titration or management of medications for epilepsy. This is compounded by:

- **Limited epilepsy knowledge** in primary care and low confidence due to lack of training in medical school and while working as a GP
- **Perceived complexity** of epilepsy treatments that stems from limited familiarity with treatment options available to people with epilepsy
- **High patient volumes** in general practice and lack of funding for additional caseloads and responsibilities.

The **10 Year Health Plan** aims to address this, but change will take time. While 30 to 40 health centres are planned in the first five years, around 200 neighbourhood centres will be needed to meet anticipated demand.

Strengthen Primary Care to Reduce Fragmented Epilepsy Care

Upskilling primary care is central to the 10 Year Health Plan. Key steps include:

- Deploying **specialist nurses** in the community
- Enhancing **GP training** in epilepsy management
- Expanding **community pharmacy services.**

These measures will ease the transition from hospital to community care and reduce fragmentation.

Enable prescribing in primary care

To shift epilepsy care into the community, the perception that epilepsy management is overly complex needs to be altered. GPs often see very few epilepsy people compared to hospital settings, and time constraints make it difficult for them to stay current with treatment options.

- Most prescribing challenges relate to **side-effects, tolerability and drug interactions**, not complexity
- Allowing **dose adjustments and prescribing of established therapies** in primary care is crucial to improving treatment optimisation
- Infrequent specialist visits often lead to **delayed care**, increasing the risk of emergency admissions.

Re-skill GPs and leverage community pharmacies

Re-skilling GPs enables them to support people with epilepsy between specialist visits. Community pharmacies and smaller hospitals can:

- **Build prescribing confidence**
- **Support ongoing treatment management**
- **Initiate change** at the local level.

A **national formulary aligned with best practice** would standardise care and reduce regional variation. Pharmacists could also provide **pregnancy and contraception counselling**, making these services more accessible.

Promote patient ownership and improve communication

Poor communication between primary, secondary, and tertiary care undermines patient outcomes. Giving people access to their records via the NHS app can:

- **Improve care coordination**
- **Empower people with epilepsy** to manage their condition
- **Support triage and decision-making.**

However, barriers like low literacy, language challenges, and intellectual disabilities limit the usability of the app for some people with epilepsy.

Develop tailored digital tools for epilepsy

Epilepsy Action is exploring an independent app designed specifically for people with epilepsy. This tool would:

- **Facilitate information sharing** with healthcare providers
- **Support people with diverse needs**, including those with intellectual disabilities or low literacy
- **Reduce unnecessary hospital admissions and ambulance calls**

While not a complete solution, it offers a practical step toward better digital integration.

Epilepsy Action is also trialling an AI-powered webchat to support people with epilepsy outside normal office hours. This tool:

- **Answers queries in real time**
- **Extends support availability** beyond traditional service hours
- **Offers scalable potential**, including behavioural support like referrals for CBT.

While AI tools show promise post-diagnosis, they currently fall short in addressing the complexities of epilepsy diagnosis itself.

- One option would be to use AI to provide an AI-enabled follow-up system that can transform post-hospital care for people presenting with seizures. Much like asthma patients started on steroids are reviewed within 48–72 hours, those who have had a seizure could be automatically flagged for follow-up using AI-driven tools.
- Systems such as automated text messaging, app notifications, or smart scheduling could help ensure timely contact, support medication reviews, and prompt escalation to specialist advice when needed.
- This approach offers a scalable, demonstrable way to improve continuity of care and patient outcomes.

Although AI tools hold significant promise for improving access to care, they are not yet widely implemented in clinical practice.

- Barriers such as digital exclusion, language differences, and low literacy levels prevent many individuals from engaging with these technologies.
- It is essential to recognise these challenges and design inclusive, accessible solutions from the outset to ensure equitable access and avoid exacerbating health inequalities.

Empower people with epilepsy and their families

Encouraging people with epilepsy to take ownership of their care from the point of diagnosis improves long-term outcomes. Individuals can revisit key topics when they become relevant, such as:

- **Contraception and preconception planning**
- **Unexpected pregnancy**
- **Driving advice**

Tailored digital tools can deliver focused support for challenging aspects of epilepsy care by:

- **Providing information** on drug side effects and interactions
- **Signposting people with epilepsy** to counselling and support services
- **Offering appointment prompts** to help people prepare for consultations

Because epilepsy affects both the individual and their families, AI tools can also:

- **Support family members** with tailored information and guidance
- **Improve overall care engagement** across the patient's support network

Box 3: Empowering people with epilepsy through patient-initiated follow-up (PIFU) pathway

The PIFU pathway empowers people with epilepsy to take control of their care by allowing them to schedule follow-up appointments based on their symptoms and personal circumstances. After an initial consultation or treatment, people with epilepsy can initiate contact when they feel it's necessary, rather than relying on routine, pre-scheduled visits. This approach:

- **Improves access to specialists** when needed
- **Reduces unnecessary hospital visits**
- **Promotes patient autonomy and engagement**

PIFU has already proven effective across multiple specialties, including dermatology, rheumatology, cancer care, and epilepsy. PIFU pathways in epilepsy are available in Wales and Sussex and these have demonstrated significant improvements in patient care and outcomes.

Box 4: AI tools enhancing epilepsy care in Rutland pharmacies

In Rutland, two AI tools are currently supporting pharmacy services:

- **Patient triage and GP appointment scheduling**: This tool performs the initial contact and triage for patients, assessing the needs of the patients, and facilitates follow-up appointment setting.
- **Patient test advisory system:** Analyses patient records and flags patients who require certain tests.

These innovations are actively used by around nine GP practices and significantly improve the care and management of people with epilepsy.

Box 5: Ongoing need for centralised epilepsy services

While there is a push to move epilepsy care into the community, certain services must remain centralised to ensure comprehensive care:

- **Diagnostic imaging and EEG monitoring:** Essential for diagnosis and surgical pathway assessments.
- **Management of co-morbid conditions:** People with cardiac or sleep-related issues require secondary care oversight.
- **Genetic services:** Centralised support for families with hereditary epilepsy concerns.

Community-based care can be delivered by teams of ACPS, with access to specialists either in person or remotely, as needed.

Ensuring appropriate access to services and treatment

Burden of epilepsy and access to care

The burden of epilepsy is expected to increase, making equitable access to services and treatment critical:

- Patient triage must be carefully considered, whether it is conducted digitally, in person, or supported administratively. For example, Newcastle upon Tyne Hospitals NHS Trust uses a single point of contact through a dedicated phone line. While useful, this can disadvantage individuals who do not speak English as a first language or those who rely on sign language. However, providing numerous access options can unintentionally lead to more individuals with epilepsy falling through the gaps.
- Mental health conditions or substance abuse may also prevent individuals from engaging with services or attending appointments. For such individuals, follow-up appointments are generally offered.

Economic impact and workforce considerations

Improved epilepsy services could yield cost savings for the NHS and benefit the wider economy:

- Epilepsy has the second highest unemployment rate of any disability, second to autism.
- Most people affected are of working-age and often face under-employed due to their condition.
- Supporting people with epilepsy more effectively could enhance workforce participation and productivity.

Tackling inequities and regional disparities

Social and regional disparities are significant, vary region by region, and are often linked to deprivation levels:

- Epilepsy prevalence and incidence is higher in more deprived areas[22] and individuals with epilepsy typically present with multiple comorbidities, including intellectual disabilities, which increase the risk of early death.
- The distribution of HCPs is often inversely proportional to patient need. Subconscious bias in medicine choice, diagnostics, and treatment options are known to compound inequality.
- Acknowledging these biases can help clinicians begin to address these issues, for example, the use of alternative venues that are more accessible can increase patient engagement and improve access.
- Video links may also help provide access to some people with epilepsy who are unable to attend.

Integrating services and specialist support

University Hospitals Birmingham is leading innovative approaches to epilepsy care, all of which are underpinned by efforts to raise awareness and improve care coordination across the hospital, which is supported by specialist nurses. Innovations include:

- The team has pioneered early-discharge telephone consultations, targeting individuals post-diagnosis for continued care.
- The team are also moving to having one clinic a month that is empty and can be utilised for people with epilepsy who need an urgent appointment.
- The team have set up a community clinic for people with epilepsy and intellectual difficulties and will use these clinics to monitor blood test results as well as provide ongoing support.
- Raising the profile of epilepsy across the hospital improves awareness among paramedics and healthcare professionals, enabling more accurate identification of people with epilepsy and better signposting to appropriate support services.

Box 6: Targeted Community Engagement

Northumbria has successfully used council and voluntary sector data to identify communities at high risk for lung cancer. This is of particular benefit in communities that are often difficult to engage with and allows people to be identified at very early stages of disease when intervention is more effective. Similar approaches could be applied to supporting patients with epilepsy.

Patient participation groups can help raise awareness in rural areas, as seen in initiatives for cancer and epilepsy. This approach may also improve attendance at follow-up appointment. This approach can also boost the rate of attendance at follow on appointments.

Support for specific patient groups

The North-West has piloted clinical guidelines and benchmarking tools to improve epilepsy care for pregnant women and people with epilepsy and intellectual disabilities:

- Expanding these initiatives nationally, alongside educational programmes like *Be Epilepsy Aware,* could strengthen support, improve outcomes, and empower people with epilepsy to manage their condition more effectively
- Further educational support can fill any gaps and ensure patients are aware of how best to look after themselves
- Initiatives driven by charities like Epilepsy Action, underscore the vital role that these partnerships can have in leading innovation and the powerful impact of NHS–charity collaboration.

Provision of specialist pharmacies

Embedding specialist pharmacists within epilepsy teams, rather than relying on general neurology pharmacists, can offer targeted support and improve care for people with epilepsy:

- Epilepsy treatments involve a wide range of complex medication regimens with significant drug–drug interactions and side-effects, necessitating detailed counselling.
- Many individuals are prescribed multiple medications for co-existing conditions, and managing polypharmacy safely requires specialist prescribing expertise.

- Epilepsy specialist pharmacists play a critical role across both primary and secondary care settings, and support safe prescribing, as well as conduct medication reviews, and provide patient education through pharmacy-led clinics that offer counselling and monitoring services that can improve patient outcomes.
- Community-based polypharmacy and medication-use reviews, including GP pharmacist involvement, may move epilepsy care away from hospitals and back into primary care, increasing accessibility and continuity of care.

Balancing cost and patient outcomes

Additional cost for newer medicines can be of concern to payers:

- These newer treatments, when proven to be cost-effective, may improve clinical outcomes and/or have fewer systemic effects. This could lead to reduced use of healthcare resources especially at hospital level, while improving the overall health and wellbeing of the individual with epilepsy.

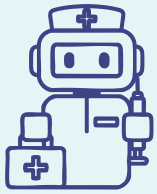
Improving multidisciplinary support

Fostering links between people with epilepsy and various HCPs could provide holistic care and enhanced support.

- A holistic epilepsy care model, linking people with epilepsy with nurses, occupational therapists, psychologists, and benefits advisors could offer more comprehensive support and improve patient outcomes.
- In the mitochondrial clinic in Newcastle, people with epilepsy are given the opportunity to talk to other HCPs such as the epilepsy nurse, the occupational therapist, psychologist, and/or the benefits and welfare officer, after their specialist visit.

The Newcastle mitochondrial clinic model is highly effective, but replicating this model elsewhere will require a realistic assessment of the resources and infrastructure needed.

Summary of service provision challenges in epilepsy

High system burden and fragmented care pathways		• Epilepsy is the leading neurological cause of ED attendance, with high non-elective admissions and long hospital stays • People with epilepsy often fall through gaps between ED, primary care, neurology, and mental health services due to poor integration
Delayed access to diagnosis and over-reliance on secondary care		• First seizure clinic wait times typically exceed 6 weeks, delaying treatment initiation, and increasing risk of readmission • Centralisation of epilepsy care has led to bottlenecks and reduced confidence in community-based management
Deskilling in primary care and need for MDT		• GPs and ACPs feel undertrained and unsupported in managing epilepsy, especially medication titration and side effect management • Strong support for expanding roles of epilepsy specialist nurses, pharmacists, and allied health professionals
Data and communication failures		• Poor interoperability between systems and lack of shared care agreements hinder continuity of care
Commissioning, funding barriers and lack of a national standard		• Services that reduce admissions (e.g., epilepsy nurses in ED) are often defunded due to short-term cost visibility • Participants advocated for a unified, flexible national epilepsy care pathway with clear roles, responsibilities, and outcome measures
Use of digital tools and AI		• Enthusiasm for AI-powered chatbots, video sharing for seizure diagnosis, and digital health records to improve triage and self-management

Call to action

Managing epilepsy:

- Epilepsy continues to place a significant strain on the NHS through non-elective admissions and frequent ED attendances.
- In line with the **NHS 10 Year Health Plan's focus on reducing avoidable hospital use**, leaders must act now to reduce this burden by enabling more people with epilepsy to be safely managed at home. Deploying nurse specialists in EDs can shorten hospital stays, lower re-admission rates, and guide patients toward appropriate follow-up care.
- To support long-term management, leaders should streamline referral pathways and strengthen communication across primary, secondary, and tertiary care.
- This will ensure smoother transitions back into the community and better continuity of care. By investing in these changes, the NHS can improve patient outcomes while easing pressure on hospital services.

Provision of care:

- NHS leaders must prioritise the development of personalised, flexible, and accessible treatment pathways that adapt to individual and service needs—core principles in the NHS 10 Year Health Plan.
- To reduce regional disparities and shift epilepsy care out of hospitals, leaders should invest in upskilling GPs and expanding the role of community pharmacists.
- Collaborating with epilepsy organisations and leveraging government initiatives will be key to creating multidisciplinary community hubs that deliver integrated care.
- While the NHS 10 Year Health Plan provides a strategic framework, its success depends on immediate and sustained action. NHS leaders must commit resources, foster cross-sector partnerships, and drive implementation efforts to ensure that epilepsy care is equitable, community-focused, and responsive to patient needs.

Treatment of patients with epilepsy:

- NHS leaders must challenge the perception that epilepsy treatment is inherently complex and instead promote accessible, community-based care. Re-skilling GPs and expanding the role of community pharmacists will enable more regular patient contact and better management of medication side effects. Empowering patients through access to their own health records with the **NHS 10 Year Health Plan's digital transformation goals**, enhancing personalised care and allow healthcare professionals to tailor treatment more effectively.
- Leaders should also embrace AI-driven tools that support people with epilepsy and their families by answering queries, offering reminders, and prompting discussions during consultations. By investing in education, digital tools, and community resources, the NHS can simplify epilepsy care and improve patient outcomes across the system.

Abbreviations

ACP – advanced clinical practitioners

AI – artificial intelligence

AMU – acute medical unit

CBT – cognitive behavioural therapy

CT – computed tomography

ED – emergency department

EEG – electroencephalogram

GP – general practitioner

HCP – health care professional

MDT – multidisciplinary team

NASH – National Audit of Seizure Management in Hospitals

NHS – National Health Service

PIFU – Patient-initiated follow-up

SUDEP – sudden unexpected death in epilepsy

VNS – vagus nerve stimulation

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