



A dangerous wait: Addressing the NHS epilepsy crisis

**EPILEPSY
ACTION**

 **EPILEPSY RESEARCH
INSTITUTE UK**



 **THE
NEUROLOGICAL
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 **Young
Epilepsy**

 **Angelini
Pharma**

This non-promotional report is an outcome of a collaborative working project that has been initiated, organised and funded by Angelini Pharma, working alongside patient organisations, healthcare organisations and consultant neurologists with the intention of benefiting patient care.

The views and opinions expressed by the working group throughout this report are entirely their own and based on their extensive personal knowledge and expertise in the field of neurology and epilepsy.

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Endorsed by the ILAE British Branch

The ILAE British Branch is pleased to endorse this report and supports the implementation of its recommendations to help improve epilepsy services across the United Kingdom.

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Foreword

Systemic delays to epilepsy diagnosis and treatment are potentially putting lives at risk by limiting timely access to appropriate assessment and care.¹ Without urgent action, uncontrolled seizures, poor mental health, reduced quality of life and risk of Sudden Unexpected Death in Epilepsy (SUDEP) remain a reality for people living with epilepsy in the UK.²

We hear day in, day out, that front-line NHS neurology staff continue to battle under extraordinarily difficult conditions, leading to a healthcare system that is often unresponsive, difficult to navigate and too slow to act.^{3,4} This leaves many people affected by epilepsy without the care they need when they need it most.^{1,5} Urgent reform is needed to protect the approximately 630,000 people in the UK living with epilepsy, as well as the workforce who care for them.^{1,5}

In response, we established this working group to build a comprehensive understanding of how NHS neurology and epilepsy services across England, Scotland, Wales and Northern Ireland have evolved in recent years. This report highlights key findings, recommendations and best practice examples from across the UK. The views and opinions expressed by the working group throughout this report are entirely their own and based on their extensive personal knowledge and expertise in the field of neurology and epilepsy.

Based on these findings, we are urging NHS leaders and the government to prioritise epilepsy services, work with key stakeholders and make better use of existing resources, particularly in the most deprived communities. We have the chance to help hundreds of thousands of people living with epilepsy across the UK live healthier and more fulfilled lives – an opportunity we cannot afford to miss.

Working group members

Georgina Carr
Neurological Alliance
(England)
Chief Executive

Alison Fuller
Epilepsy Action
Director of Health
Improvement & Influencing

Kirsten McHale
Young Epilepsy
Nurse Consultant & Head
of Health - Nursing

Dr Lara Carr
Epilepsy Research
Institute UK
Director of Research
and Impact


Tom Shillito
Epilepsy Action
Improvement & Research
Manager

Fiona Short
Epilepsy Nurses Association
(ESNA)
Nurse Specialist for complex
epilepsy patients

Dr Rhys Thomas
Consultant Neurologist

Dr Dominic Slowie
GP with a special interest
in epilepsy

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“The NHS belongs to the people. It is there to improve our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives.”

NHS constitution⁶

Executive summary

Across the UK, healthcare services are working to deliver on renewed long-term reform plans, including the *NHS 10 Year Health Plan for England: Fit for the Future*.⁷ Since 2020, waiting lists for elective care have risen sharply. In England alone, the list has grown from 4.4 million people in February 2020 to around 7.3 million by September 2025,⁸ illustrating how demand has outpaced capacity after the COVID-19 pandemic.

Neurology services are no exception. Over the last few years, care provision has remained stretched and waiting times have increased significantly, with outstanding neurology referrals having more than trebled in Scotland, almost quadrupled in England and increased more than 100-fold in Wales over the last five years.⁸⁻¹⁰ Despite this, neurology continues to be an overlooked and under-supported area of the NHS, as demonstrated by the omission of neurology-specific commitments in the *NHS 10 Year Health Plan for England: Fit for the Future*.⁷

Looking at epilepsy specifically, people with this condition place considerable demand on both elective and urgent care services. Epilepsy patients in England made up the largest proportion of non-elective admissions across all neurological conditions in 2023/24, and accounted for the highest proportion of excess bed days*, with numbers doubling between 2020/21 and 2023/24.¹¹

To help improve NHS epilepsy services, a working group was convened to review the current challenges and deliver consensus-driven recommendations and practical solutions to key stakeholder groups, including the government, devolved administrations and NHS leaders. Findings from research into neurology and epilepsy care closely reflect the day-to-day reality for anyone living with or managing epilepsy; highlighting that services are under considerable strain, with substantial regional disparities in workforce provision, service capacity and quality of care.^{1,12} However, it is the belief of this working group that substantial change and improvement in care is possible if practical steps are taken now to optimise the use of available resources and target areas with the potential to drive positive change for the most disadvantaged patients.

This working group was established, funded and supported by Angelini Pharma UK-I Limited under collaborative working agreements with the following organisations: Epilepsy Action, Young Epilepsy, Epilepsy Research Institute UK, Epilepsy Nurses Association, The Neurological Alliance (England), and with the consultancy of Drs Rhys Thomas and Dominic Slowie.

*Excess bed days refer to patients who remain in hospital beyond a set expected length of stay due to complications, complex or specialist medical needs as well as delayed discharge because of a lack of available social/community services and care.

Key findings: Adult neurology services remain stretched and waiting times have risen significantly, with **delayed referrals increasing by 357% in England, 236% in Scotland and from fewer than 30 referrals to over 4,000 in Wales between December 2019 and September 2025.**⁸⁻¹⁰ Delayed referrals have **decreased by 14% in Northern Ireland** between quarter ending June 2019 and quarter ending June 2025.¹³

Over 85,000 patients with a primary diagnosis of epilepsy attended A&E in 2023/24, the **largest proportion of A&E attendance across all neurological conditions** in England.¹¹ The **key driver** has been identified as **missed referral waiting time targets.**

Risk of **further seizures and mental health problems** were identified as the highest risk factors for patients who do not receive timely epilepsy care. Notably, over **90% of healthcare professionals (HCPs) surveyed believe that the failure to meet National Institute for Health and Care Excellence (NICE) referral guidelines has a detrimental impact on patients' mental health, and over 30% of patients stated that their mental health has suffered because of delays in accessing their healthcare team.**¹⁴

Service delivery varies widely across England, with stark differences in waiting times, excess hospital stays and emergency admission rates. Our research showed that in the North West and North East, where there are some of the fewest Epilepsy Specialist Nurses (ESNs) per capita, there are also **longer waiting times and higher per capita emergency admissions.**^{11,12}

Priority recommendations: The working group is calling on the UK government, devolved administrations and NHS leaders to take immediate action to:

- 1. Futureproof neurology and workforce provision**
Prioritise and futureproof neurology services and workforce, especially in deprived areas, by setting workforce guidance, funding training and protocol development, strengthening primary and community care and accelerating adoption of proven innovations and targeted initiatives.
- 2. Protect, expand and fund ESN training and posts**
Protect and expand ESN and Epilepsy Specialist Pharmacist (ESP) posts, especially in deprived areas, by filling vacancies, creating new roles, and promoting career pathways with early career education and structured placements to meet demand and improve patient support.
- 3. Identify, agree and prioritise key epilepsy sub-groups**
Identify, agree and prioritise key epilepsy sub-groups using local data and insights to develop tailored models of care at a regional health system level that reflect their varying clinical, social and psychological needs.
- 4. Embed a holistic approach to brain health**
Embed mental health provision into epilepsy multidisciplinary teams (MDTs) so that children, young people and adults with epilepsy receive timely, integrated support; also provide tailored training to mental health practitioners to understand epilepsy-specific challenges.

There is an opportunity to dramatically improve the care and quality of life for thousands of people living with epilepsy across the UK today. **Complacency is not an option.**

That is why we are calling on the UK government, devolved administrations and NHS leaders to critically review the findings of this report and take immediate action to save lives and ensure that the NHS delivers on its mission to help every person with epilepsy in the country live their lives to the fullest.

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Report structure

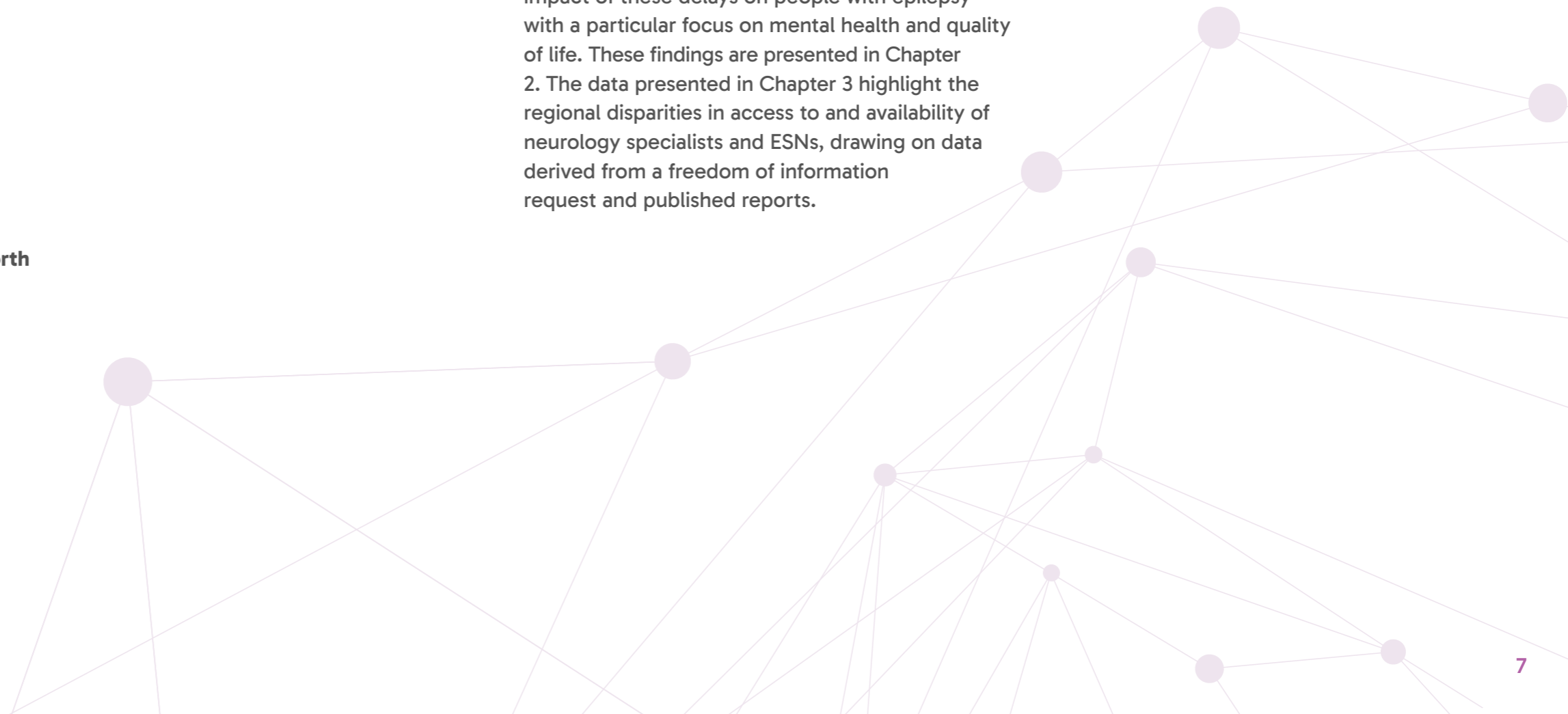
This report brings together original research combined with published reports and peer-reviewed studies to provide a comprehensive picture of epilepsy care in the UK, and offers concrete recommendations for improvements from the convened expert working group.

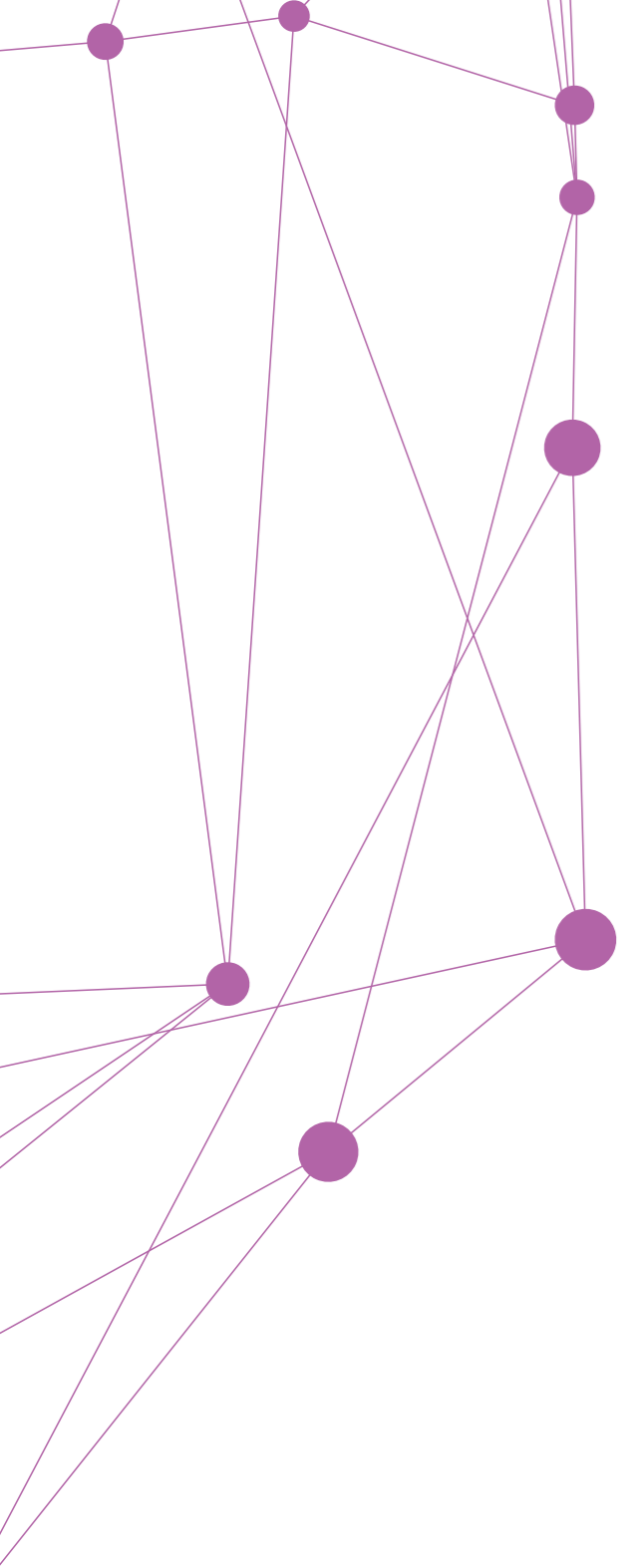
The report begins with an analysis of waiting times for neurology services in the UK using publicly available data sources from the NHS, comparing the current picture with waiting time targets for each of the four nations. Using NHS Hospital Episode Statistics (HES) data, excess bed days and A&E attendance for the five most frequent neurological conditions in England, including epilepsy, were also examined. The findings from the data, presented in Chapter 1, are primarily displayed in graphs with the key take-outs summarised in the text.

Additionally, two original surveys were undertaken evaluating the patient and HCP perspective of the impact of these delays on people with epilepsy with a particular focus on mental health and quality of life. These findings are presented in Chapter 2. The data presented in Chapter 3 highlight the regional disparities in access to and availability of neurology specialists and ESNs, drawing on data derived from a freedom of information request and published reports.

The final section of the report, Chapter 4, brings together the expert working group consensus on actions needed to address the research findings. This section of the report clearly defines the key priority areas and recommendations for much-needed improvements to epilepsy care in the UK. It is very much hoped that national leaders will take note and act with urgency.

NHS data availability is variable across the UK and – with the exception of waiting time figures, which are available for all four of the devolved nations – the reported information is largely limited to England. However, anecdotal evidence and the extensive experience of the expert working group suggest all the report findings and subsequent recommendations are applicable and relevant to all areas of the UK.





Introduction

The COVID-19 pandemic placed unprecedented pressure on the NHS, exacerbating workforce shortages and creating a surge in patient waiting times for diagnosis, treatment, and specialist care.^{3,15}

In September 2025, 7.3 million people in England were waiting for an appointment, procedure or operation, with around 40% being seen after the NHS 18-week referral target⁸. By the end of 2025, **one in ten people** in England were waiting for elective care – around **one million more** than in February 2022.⁸ Furthermore, a rise in the number of people with multiple long-term conditions and the growing mental health epidemic has added further pressure to an NHS that is already facing severe capacity challenges.³

Although some progress has been made in recent years following the 2022 *Delivery Plan for Tackling the COVID-19 Backlog of Elective Care*,¹⁵ waiting lists remain high and public satisfaction with the NHS has reached an all-time low, according to a 2024 survey by the King's Fund and Nuffield Trust.^{16,17}

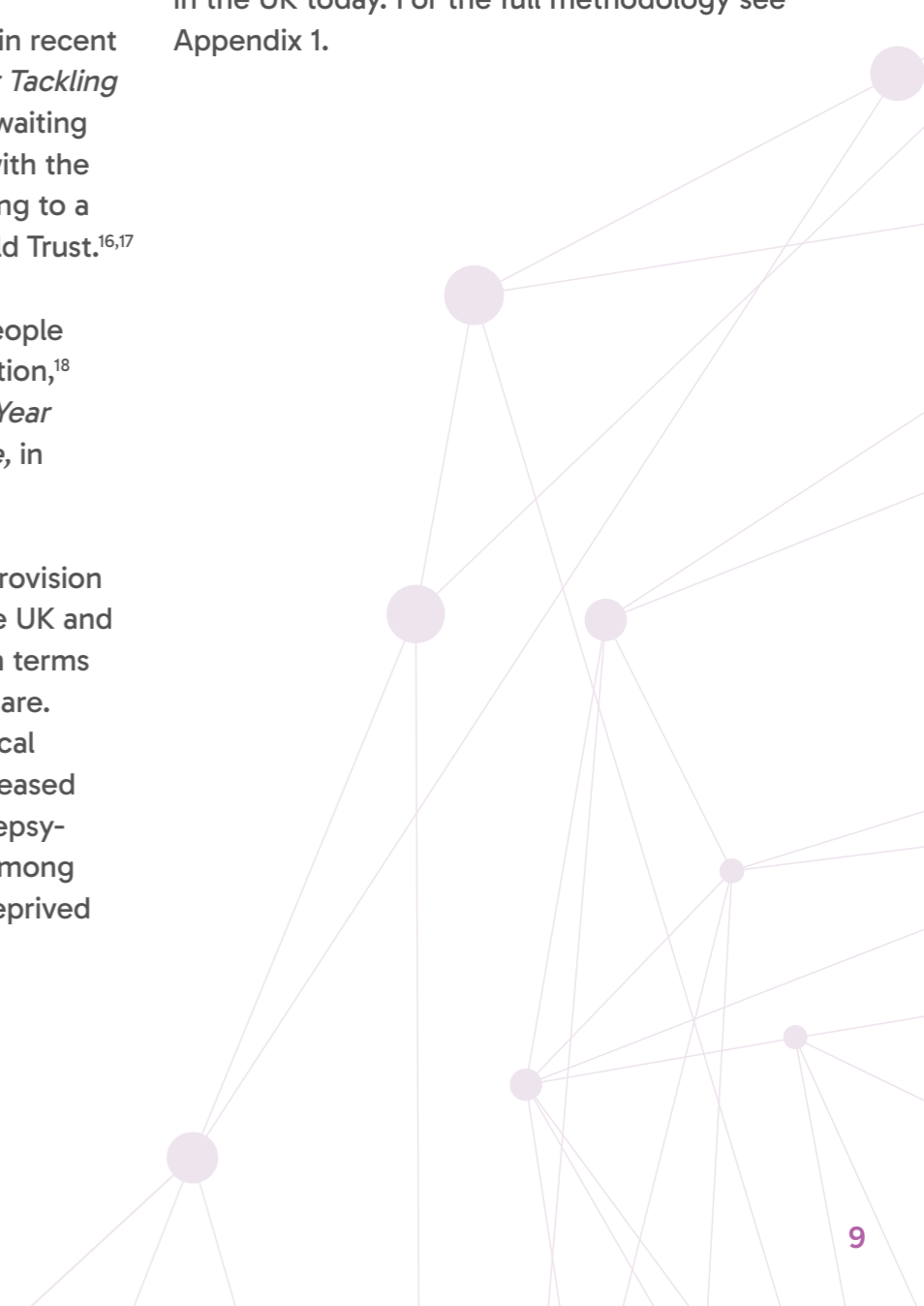
Disappointingly, and despite **one in six** people in the UK living with a neurological condition,¹⁸ neurology was omitted from the *NHS 10 Year Health Plan for England: Fit for the Future*, in favour of other priority areas.⁷

Looking at epilepsy specifically, service provision for these patients varies widely across the UK and there are significant regional disparities in terms of both workforce provision and patient care. This results in a higher incidence of physical and mental health comorbidities and increased mortality, despite the fact that many epilepsy-related deaths are avoidable, especially among people with epilepsy living in the most deprived areas of the country.¹

Epilepsy patients need a voice. Epilepsy patients must be prioritised.

In response to this crisis, a working group was convened to establish a national picture of current NHS neurology and epilepsy services, with the goal of identifying practical recommendations and solutions to greatly improve epilepsy patient care.

This report draws on original survey data, national data from publicly available sources, NHS Hospital Episode Statistics (HES), peer-reviewed research and data from organisations represented on the working group. Together, these insights provide a comprehensive national picture of epilepsy care in the UK today. For the full methodology see Appendix 1.



Chapter 1

Status quo
Suboptimal neurological care

Key finding: Neurology services remain stretched, and waiting times have increased significantly over the last few years across England, Scotland and Wales⁸⁻¹⁰

According to NHS guidelines, the maximum waiting time for non-urgent, consultant-led treatment is between 9 and 36 weeks depending on whether a patient lives in England, Scotland, Wales or Northern Ireland. However, this target waiting time for neurology services is consistently being missed across most of the UK. As a result, epilepsy patients are often forced to seek care through A&E visits and subsequently spend more time in hospital.^{1,3,11} This situation is placing increased strain on the NHS and is leaving thousands of epilepsy patients to cope without the specialist care they so urgently need.^{1,3}

“Neurological conditions are the leading cause of disease burden worldwide – and epilepsy is one of the most common and treatable. Yet too many people are not receiving timely, proactive care, particularly in deprived communities. Regional inequalities, long waiting times, workforce shortages, and gaps in specialist support are driving avoidable complications and preventable emergency admissions. As neurology continues to be overlooked in major national strategies, this unmet demand risks deteriorating patient outcomes and places even greater pressure on urgent and emergency pathways.”

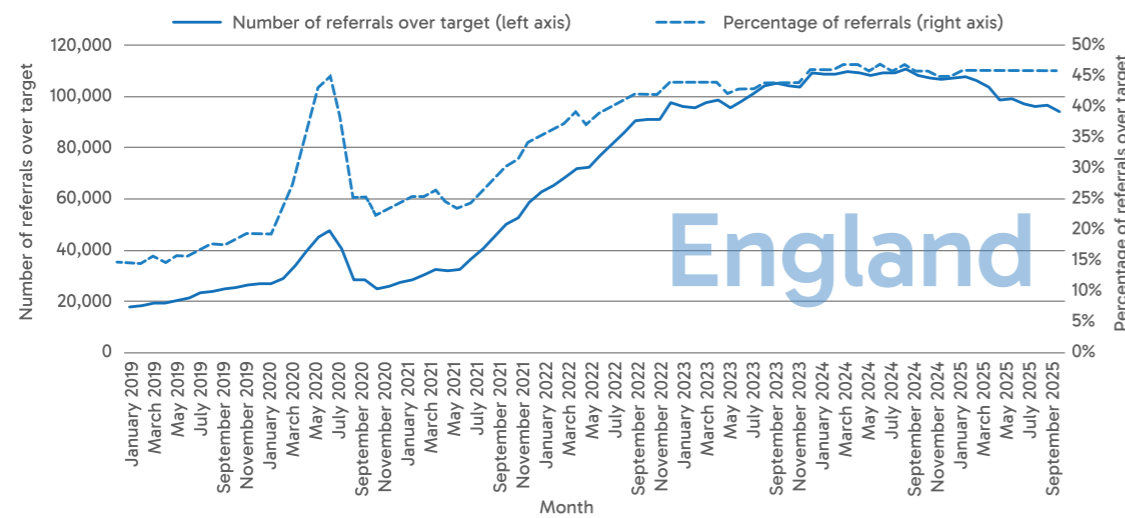
This is a problem we can solve. With the right leadership and targeted investment, government has a real opportunity to transform epilepsy care – improving outcomes, reducing health inequalities, and easing pressure on the wider NHS.”

Georgina Carr, Neurological Alliance (England)

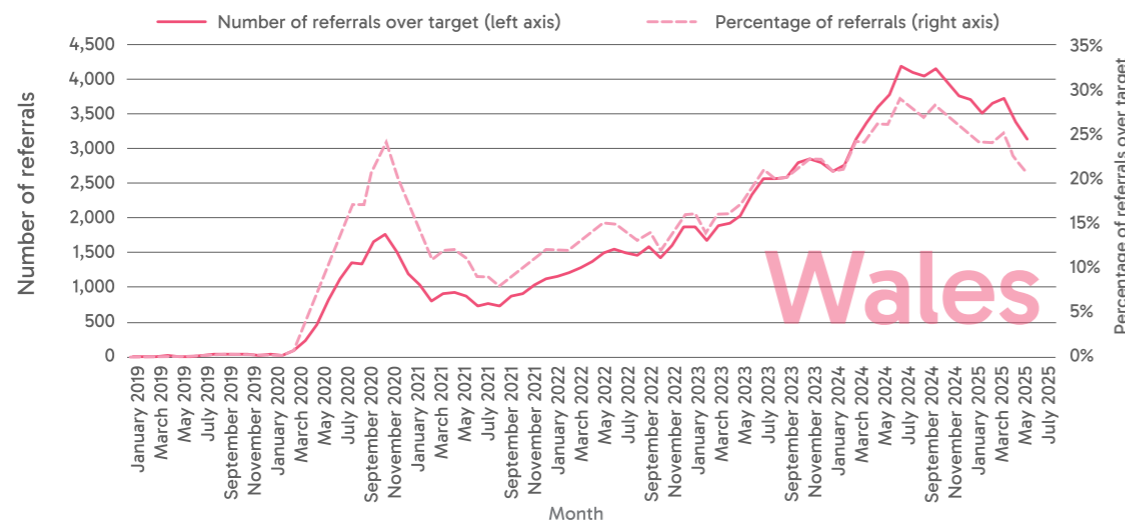
The national picture

1. Delayed referrals comparison: delayed referrals in England, Scotland and Wales have increased over the last five years, with those in Northern Ireland increasing with the onset of the COVID-19 pandemic before returning to pre-pandemic levels:^{8-10,13}

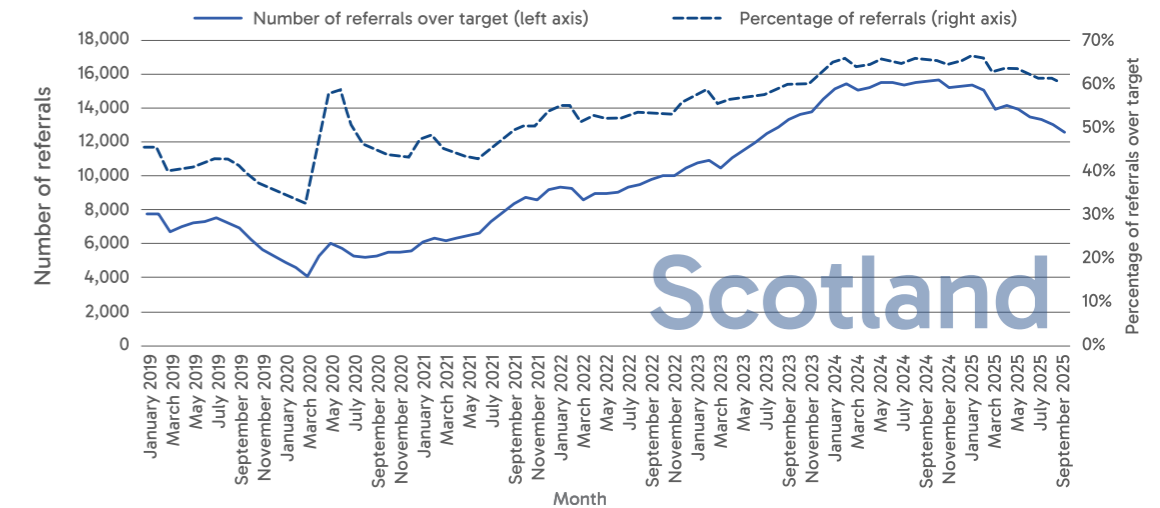
Number of outstanding neurological referrals for consultant-led care over the 18-week target waiting time in England.⁸



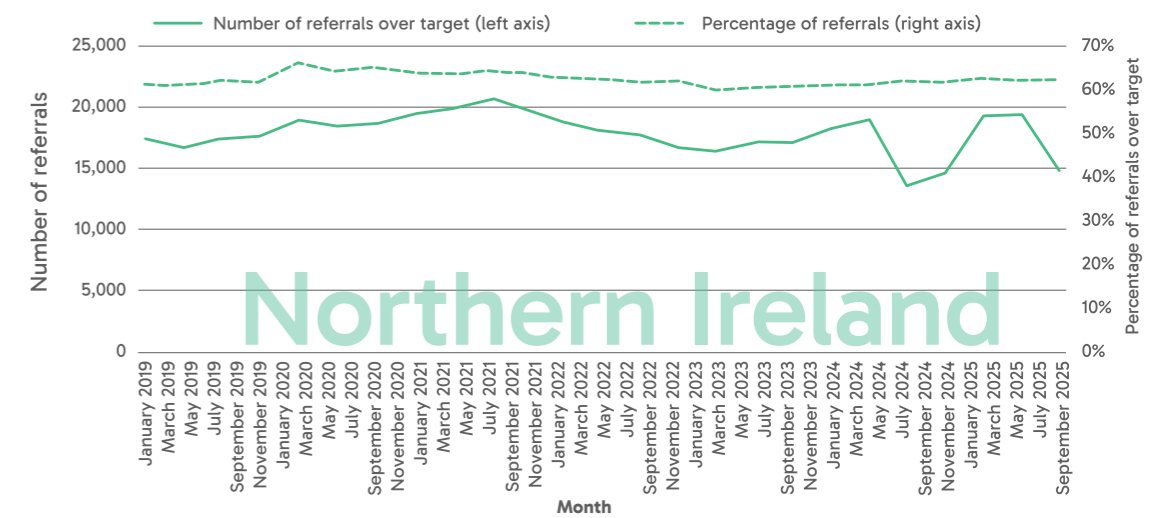
Number of outstanding neurological referrals for consultant-led care over the 36-week target waiting time in Wales.¹⁰



Number of outstanding neurological referrals for consultant-led care over the 12-week target waiting time in Scotland.⁹



Number of outstanding neurological referrals for consultant-led care over the 9-week target waiting time in Northern Ireland.¹³



Delayed referrals have increased by 357% in England, 236% in Scotland, and from fewer than 30 referrals to over 4,000 in Wales over the last five years, while they have decreased by 14% in Northern Ireland over the same period.

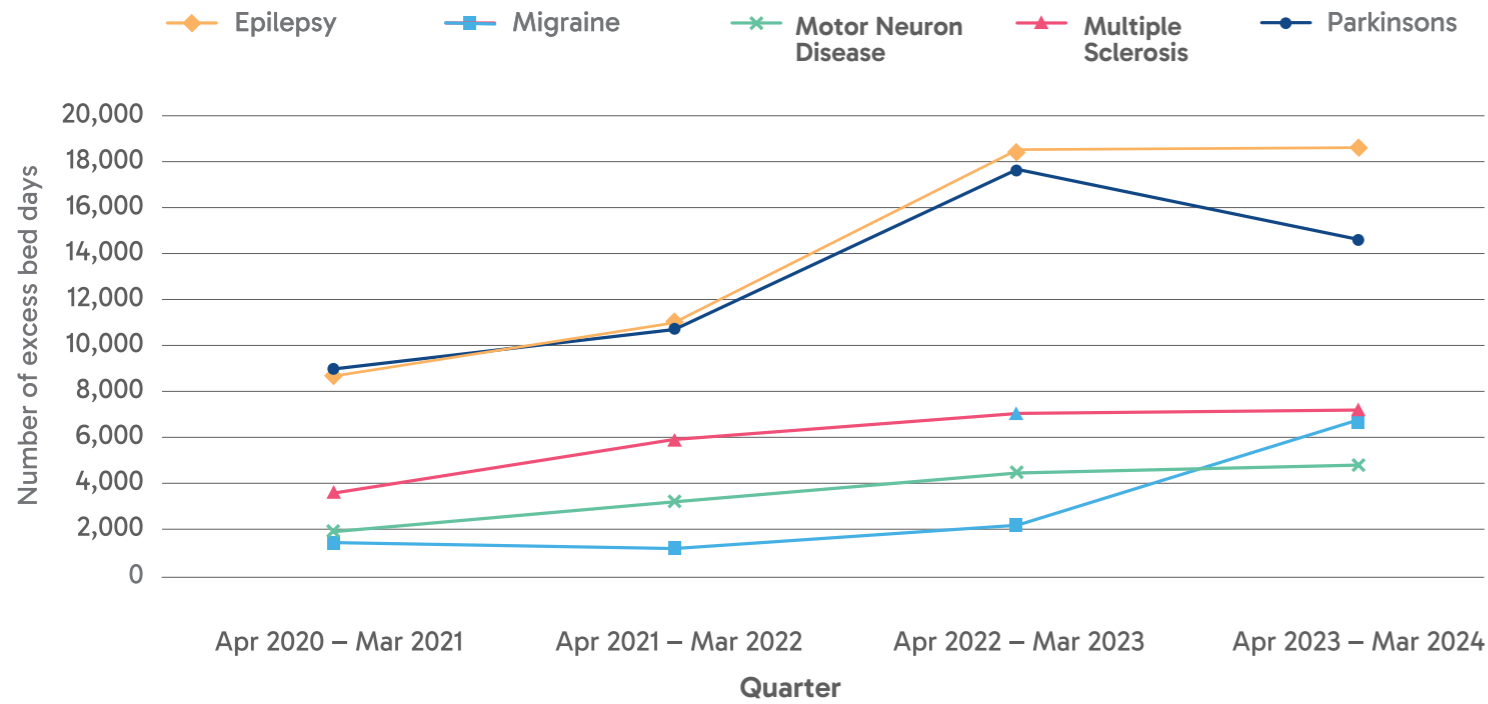
“These figures are alarming, but they don’t reflect the true impact and daily reality we see on the ground. The ESNs we support tell us that they’re supporting patients living with uncontrolled seizures who are waiting far too long just to be seen, heightening their anxiety, and leaving them with a constant real fear about their safety.

The lack of specialist practitioners means we’re doing all we can, but it’s not enough. We’re constantly firefighting rather than providing the consistent, proactive care people with epilepsy desperately need. The human cost behind these delays is something no statistic can capture fully.”

Alison Fuller, Epilepsy Action

2. Hospital Episode Statistics (HES) data for the five most frequent neurological conditions by excess bed days¹¹

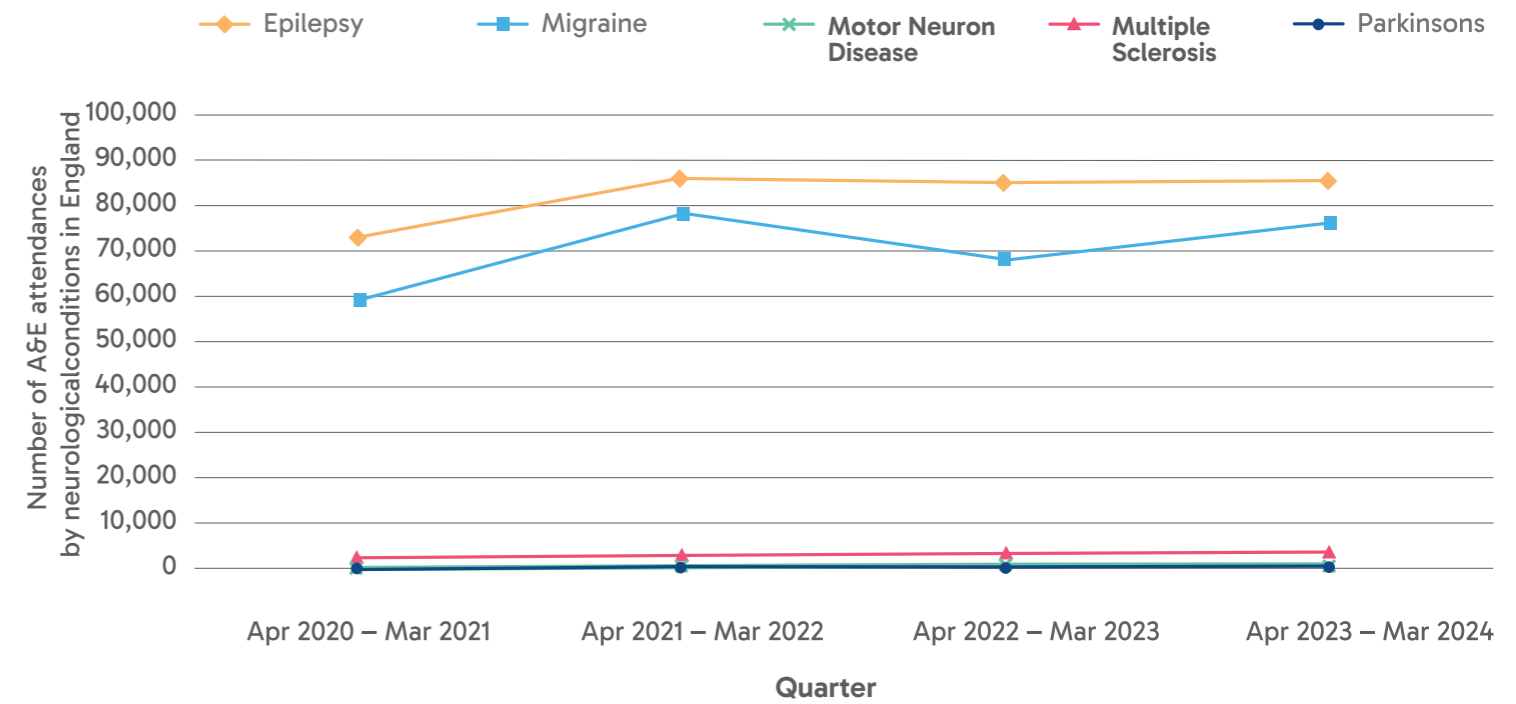
Patients with a primary diagnosis of epilepsy have the highest number of excess bed days among all neurological conditions



The number of excess bed days for people with epilepsy has doubled in the four years since 2020, from approximately 9,000 to more than 18,000 in 2023/24.

3. HES data for the five most frequent neurological conditions by A&E attendances¹¹

Patients with a primary diagnosis of epilepsy have the highest A&E attendance among all neurological conditions



Approximately 85,000 epilepsy patients attend A&E each year – more than for any other neurological condition – costing the NHS almost £20 million for the financial year 2023/24, and rising by approximately 20% since 2020/21.

Please refer to Appendix 6 for further details of the HES data used in these graphs showing A&E attendance and excess bed days for people with epilepsy by Integrated Care System (ICS) in England.

Chapter 2

The patient and HCP experience

Impact of delays and suboptimal access to epilepsy care

Key theme: Risk of further seizures and mental health problems were identified as the highest risk factors for patients who do not receive timely epilepsy care

Impact on physical health

It is well documented that epilepsy poses a significant risk to health. People with epilepsy have a two to three times greater risk of premature death than the general population, and the risk of sudden death is **20 times higher**.¹⁹ Of greater concern is that mortality risk is dependent on geographical location; epilepsy-related deaths in the most deprived areas of England are almost **three times higher** than in the least deprived areas.¹

Our research found that:¹⁴

More than half (58%) of HCPs perceived patients to be at higher risk of further seizures, and 17% of HCPs considered patients to be at increased risk of SUDEP if not assessed within two weeks of a seizure.

Over 80% of HCPs noted that not meeting target referral waiting times increases the number of epilepsy patients who attend A&E each year.

Almost 25% of epilepsy patients reported that not being able to see their healthcare team more frequently negatively impacted their physical health.

Almost half (49%) of all patients wish they could see their healthcare team more often than they currently do.

For full survey methodology see Appendix 2. Due to the small number of HCPs who completed the survey, findings from this group should be interpreted with caution. Twelve HCPs from across the UK took part in the survey made up primarily of neurologists (58%) and ESNs (33%), with most working in hospital-based settings. Academic hospitals were the most common workplaces, accounting for 75% of responses.

Impact on mental health and quality of life

There is growing awareness of the mental health burden associated with epilepsy. While around **one in six people** in the UK experience depression, this rises to **one in three** among those with epilepsy.⁵ Unfortunately, delays in diagnosis and treatment can lead to poorer outcomes and worsen the situation, and are associated with a negative impact on cognitive function, morbidity and mortality.^{1,20} Furthermore, in the 2024 Mental Health Survey conducted by Epilepsy Action with 1,646 participants from across the UK, **87.2%** of people reported that epilepsy had affected their mental health, and more than **two-thirds (69%)** reported that epilepsy has limited their independence.¹⁴

“People living with epilepsy are at a much higher risk of anxiety, depression and other mental health comorbidities. The unpredictable nature of epilepsy and the unknowns that often come with a diagnosis can have a big impact on mental health. This is further exacerbated when patients are asked to wait for many weeks or months for an appointment with a specialist or for essential investigations and procedures.

Patients and their families are often left without any support from healthcare services while on waiting lists. They report feeling abandoned and

alone. This not only impacts their mental health, but also their independence, ability to work, and participation in ordinary activities.

These problems can be avoided by reducing the waiting times to a reasonable level. Epilepsy will always carry a higher risk of mental health comorbidities, but the prevalence and severity of these is drastically increased when patients are abandoned by the systems that should be caring for them.”

Tom Shillito, Epilepsy Action

In children and young people with epilepsy (CYPwE), the risk of seizure and medication complications results in isolation from activities such as school, social clubs, residential trips and sports camps, which can contribute to the loss of independence and depression. Studies have suggested that **37%** of CYPwE have depression, compared with **9%** of the general population,²¹ highlighting the urgent need for effective mental healthcare provision in both adults and CYPwE.

Alongside mental health challenges, many people with epilepsy face barriers to finding and staying in work. A 2023 report from Epilepsy Action on epilepsy discrimination in the workplace highlighted that only **43%** of those who listed epilepsy as their main health condition were in employment, **amongst the lowest rates for disability**.²² The report included findings from a survey of 1,403 participants with epilepsy from across the UK showing that almost **two thirds (60%)** experienced unequal treatment or discrimination at work, and **over a third (36%)** said colleagues, managers or employers had made derogatory remarks about their condition.²²

Our research found that:¹⁴

Over a third (35%) of patients reported that their mental health had suffered as a direct result of struggling to see their healthcare team.

Over 90% of HCPs believe that not meeting NICE referral time guidelines negatively impacts patients’ mental health.

Over half (54%) of patients reported that their epilepsy had a “negative to very negative” impact on their mental health.

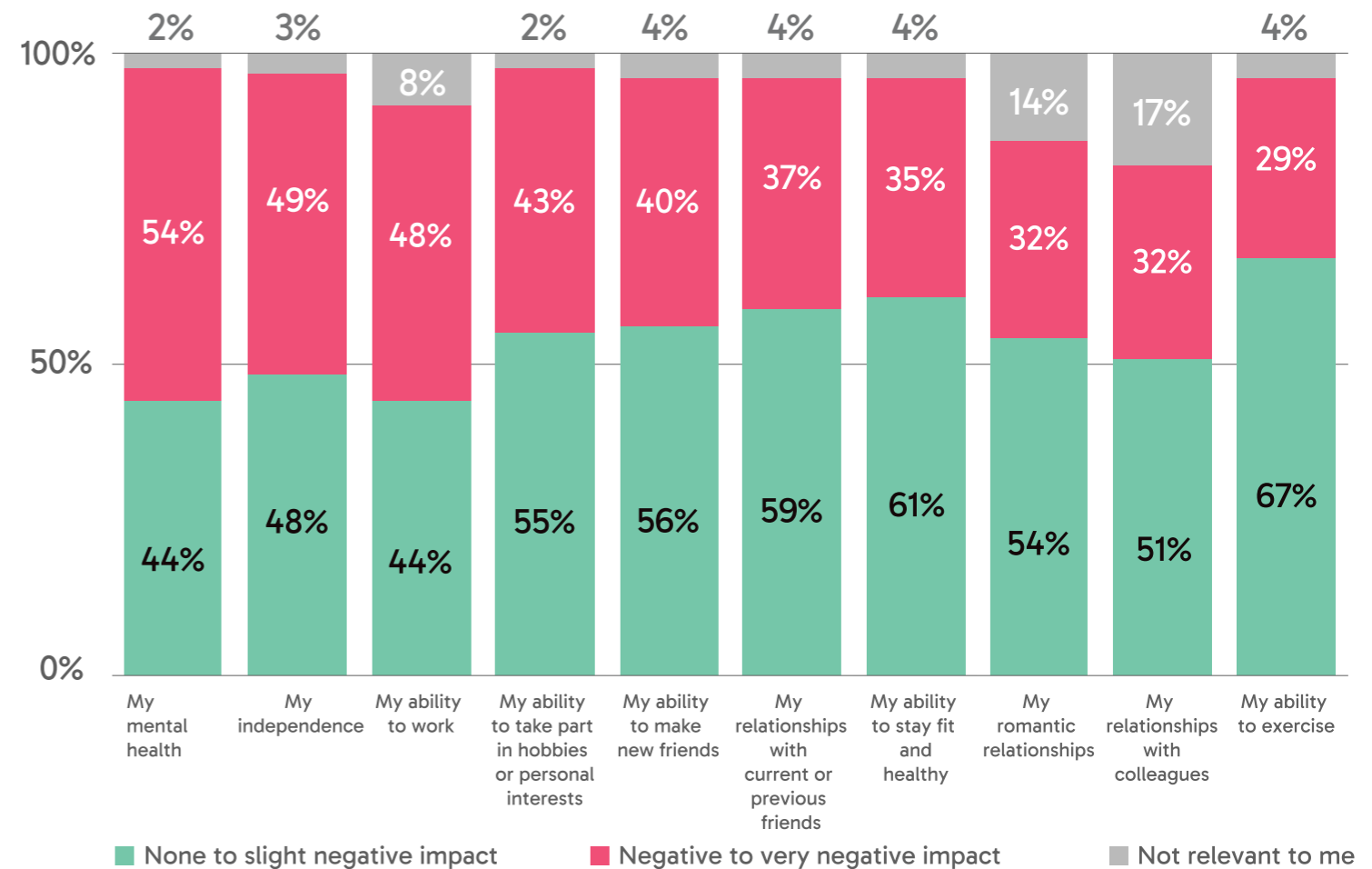
Almost half of patients reported that their epilepsy had a “negative to very negative” impact on their independence (49%) and ability to participate in hobbies or personal interests (43%).

See Appendix 2 for full survey methodology.

4. Patient survey data demonstrating the impact of epilepsy on mental health, day-to-day living and relationships as reported by people living with the condition¹⁴

Patient-reported day-to-day impact of living with epilepsy

Percentages of patients reporting impacts of epilepsy on their relationships and day-to-day life



Chapter 3

The state of epilepsy care in the NHS

The national and regional picture

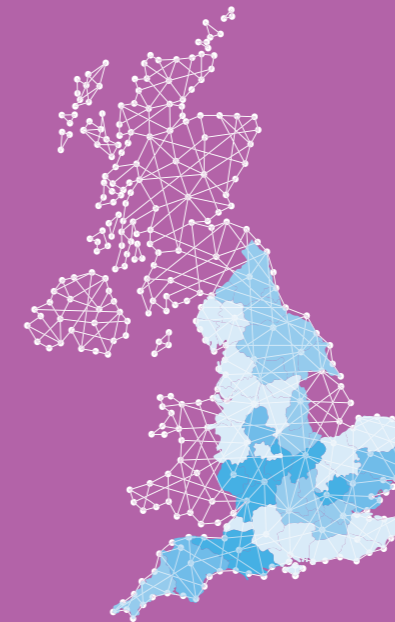


Key finding: Service delivery varies widely across England, reflecting significant differences in waiting times, excess hospital stays and emergency admission rates.¹¹

Across England, Integrated Care Boards (ICBs) with the fewest ESNs per capita, largest proportional waiting times and higher per capita emergency admissions are clustered in the northwest and northeast, whereas ICBs with the highest excess bed days are typically in the southwest.

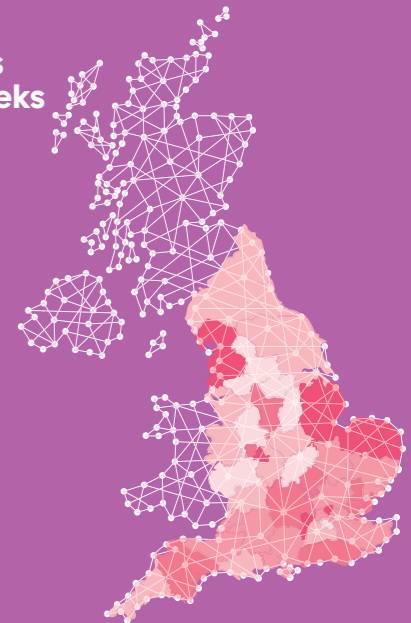
ESN FTE hours per 10K people living with epilepsy*

- Less than 1
- 1 to 2
- 3 to 4
- 5 or more



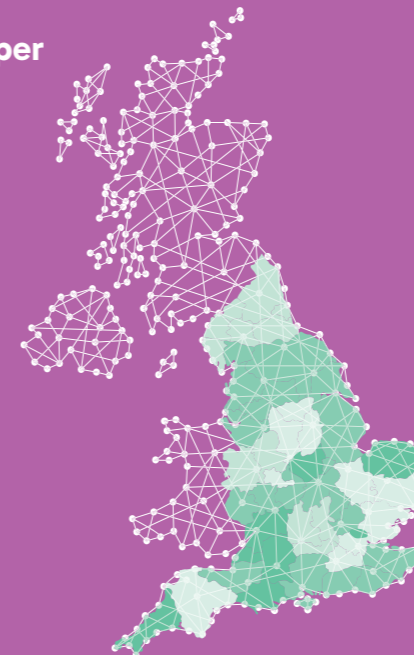
Percentage of neurology referrals waiting over 18 weeks

- Less than 35
- 30 to 39
- 40 to 44
- 45 to 49
- 50 or more



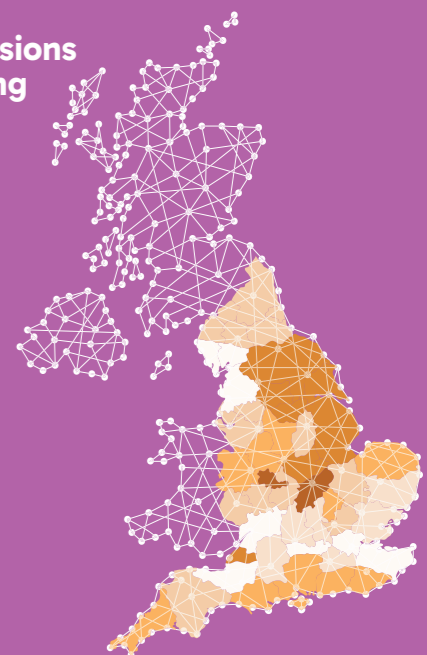
Excess bed days per 100 planned bed days for epilepsy inpatient care

- Less than 9
- 9 to 10
- 11 to 14
- 15 or more



Emergency admissions per 1K people living with epilepsy

- Less than 115
- 155 to 159
- 160 to 209
- 210 to 254
- 255 to 299
- 300 or more



Data sources: Epilepsy Action freedom of information (FOI) request data as of May 2024; NHS England Hospital Episodes Statistics (HES), excess bed days, epilepsy as a primary diagnosis, April 2023–May 2024; NHS England Hospital Episodes Statistics (HES), emergency care epilepsy as a primary diagnosis, April 2023–May 2024. Prevalence data from Quality and Outcomes Framework (QoF), 2023/24 reported by GP surgeries.

See Appendix 6 for a full breakdown of all ICB data included in the analysis.

*Data unavailable for Lincolnshire as no response provided to the FOI request.

Key finding: Across England, there are significant regional disparities in specialist staffing

A 2024 analysis by Epilepsy Action identified significant differences in the distribution of epilepsy specialists across England, with clear regional disparities in access to and availability of both neurologists and ESNs:¹²

London has the most neurologists in England – a total of 326, which is **one for every 191 people with epilepsy (PwE)** and four times as many as the North East of England (39 in total), where there is just one neurologist for every 755 PwE. This is despite the North East of England having the **highest prevalence rate of epilepsy of any area at 1.1%**.¹²

Across England there are approximately **1.94 neurologists for every 100,000** of the population. These figures compare poorly with those for other similar European countries, such as France and Germany, where there is one consultant neurologist for every 25,000 people or fewer.¹²

There is also significant variation in the number of ESNs across England:¹²

Yorkshire and the Humber has the highest ratio, with **one ESN per 1,137 PwE**.

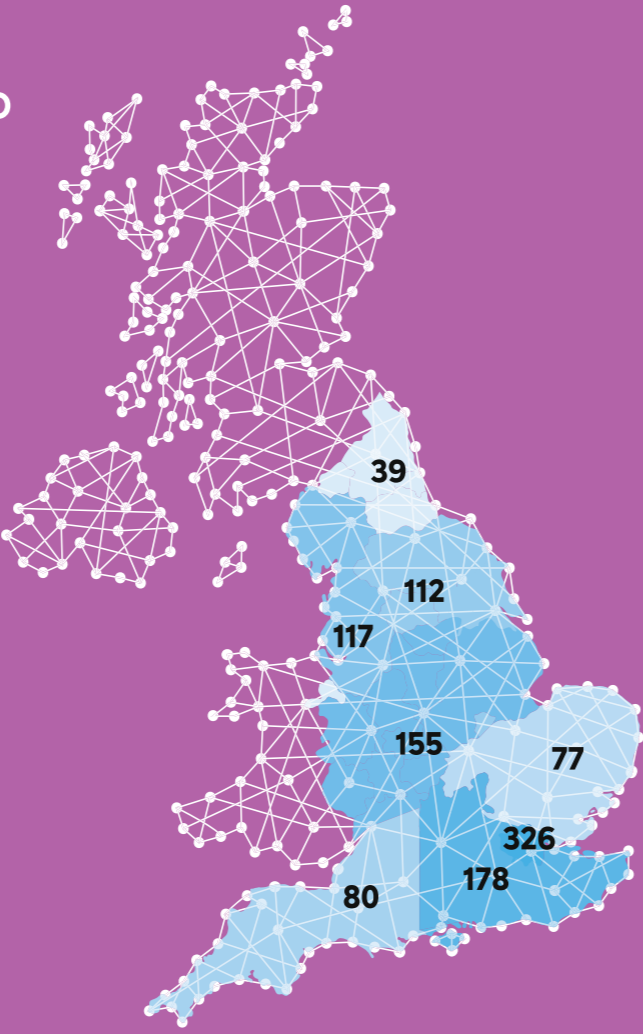
The Midlands area has the lowest ratio, with **one ESN per 2,718 PwE**.

London also has a low number of ESNs, 23 in total, with a ratio of 1 per 2,714 PwE, and has the **lowest average number of ESNs, at just one per NHS Trust**, despite having the highest ratio of neurologists to PwE.

Neurologists

Total number of neurologists who work in an NHS hospital in each region of England

- London: 326
- South East: 178
- Midlands: 155
- North West: 117
- Yorkshire: 112
- South West: 80
- East of England: 77
- North East: 39

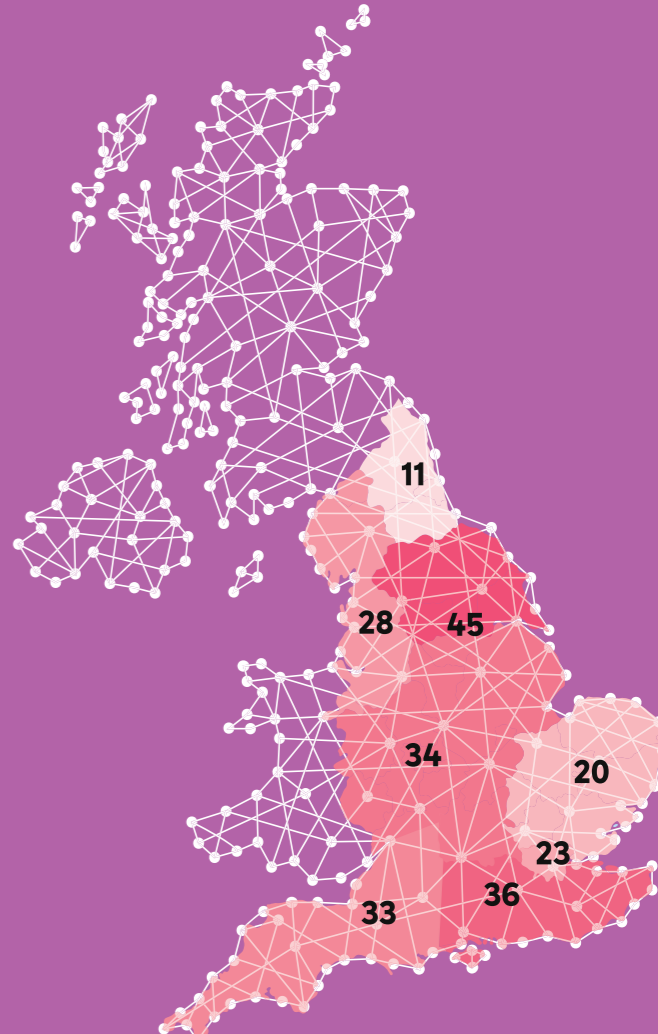


Source: Epilepsy Action - data from freedom of information (FOI) request as of May 2024

Epilepsy specialist nurses

Total number of ESNs who work in an NHS hospital in each region of England

- Yorkshire: 45
- South East: 36
- Midlands: 34
- South West: 33
- North West: 28
- London: 23
- East of England: 20
- North East: 11



Source: Epilepsy Action - data from freedom of information (FOI) request as of May 2024

There are significant variations in the number of ESNs across England, with London, the Midlands, the North East and the North West of the country having amongst the fewest ESNs per capita. Yorkshire has more than four times the number of ESNs than its neighbour, the North East.¹²

Key finding: ESNs are essential to effective epilepsy care, yet remain under-resourced across the UK.

The Epilepsy Action report also found that ESNs are widely recognised by UK epilepsy specialists as essential to the delivery of effective epilepsy services. However, they remain an under-recognised resource within the wider health system.²³

Approximately 230 ESNs currently work across England, equating to just **two ESNs per 500,000 of the population, in contrast to the NICE-recommended nine per 500,000.**¹²

ESNs are not mentioned in the *NHS 10 Year Health Plan for England: Fit for the Future*,⁷ despite the high prevalence of epilepsy across the UK.

ESNs are essential for bridging the gap between different parts of the healthcare system, providing people with epilepsy with consistent, coordinated care, and they would be instrumental in the implementation of the Neighbourhood Health Service as outlined in the *NHS 10 Year Health Plan for England: Fit for the Future*.⁷

These significant variations across England illustrate that where a patient lives will impact the level of care available to them. Despite this, the government failed to mention measures to address shortages in condition-specific workforces in its long-term workforce plan.

Similar reviews across the devolved nations have highlighted a comparable picture in terms of disparities and low numbers of specialist epilepsy staff. In Scotland, a report by Epilepsy Scotland shone a light on the postcode lottery of specialist care facing the approximately 55,000 people living with epilepsy. The report found that:²⁴

- Where ESNs are available, and depending on the region, one ESN cares for between 1,452 and 6,213 adults with epilepsy
- Two health boards in Scotland had no adult ESNs and one had no paediatric ESNs
- The number of ESNs had fallen by an estimated 15% in the year 2021–2022

The situation in the other devolved nations is no better:

- In Wales there are only 14 ESNs for around 36,000 people living with epilepsy, equating to more than 2,500 patients per ESN.²⁵
- In Northern Ireland there are about 20,000 PWE and fewer than five adult ESNs in the entire country, meaning that each ESN has more than 4,000 patients.²⁶

Chapter 4

Working group recommendations

The review of current service provision, patient and HCP experiences and workforce data collectively reveal widespread disparities and systemic challenges in delivery of epilepsy care in the NHS. Findings from this research have identified four key priorities for improving epilepsy care across the UK. Each priority is supported by targeted recommendations to shape system-wide improvements, address the disparity of service provision and improve patient care and outcomes.

Key priority 1. Futureproof neurology and workforce provision
Neurology services and workforce provision must be prioritised and future-proofed by the UK government, devolved administrations and NHS leaders, particularly in deprived areas.

Rationale

Despite the significant impact that epilepsy has on the physical, mental and social wellbeing of those affected, our research has shown that these patients are consistently being under-supported and overlooked by the NHS, leading to poorer outcomes and increased mortality.^{1,4,14} Immediate action is needed to reduce neurology waiting times and referrals to ensure that patients can access the life-changing and life-saving care they deserve. This supports the ambitions of the *NHS 10 Year Health Plan for England: Fit for the Future*, which seeks to improve access to timely specialist care and address inequalities in health outcomes.⁷

Furthermore, studies have shown that people living in the poorest areas of the UK have a **34% higher risk** of developing epilepsy compared with people living in the richest areas, and people with epilepsy are almost **three times more likely to die prematurely**.^{19,27} These findings point to an urgent need to strengthen neurology services and workforce provision across the nation – with a particular focus on deprived areas where epilepsy prevalence and mortality are significantly higher.

The *GIRFT (Getting It Right First Time) Programme Neurology National Specialty Report*, published in September 2021 and led by Dr Geraint Fuller, explicitly addresses the workforce as a core component of its recommendations. It underscores the need to develop the neurology workforce, including neurologists, specialist nurses, allied health professionals and advanced practitioners,

as well as ensure equitable distribution across regions to shift care closer to home and improve patient access.²⁸

The *NHS 10 Year Health Plan for England: Fit for the Future* calls for a shift in care delivery, moving more care out of hospital settings and into the community, with stronger integration between primary, secondary and specialist services.⁷

Similar approaches to improving access to treatment, incorporating care in the community and improving primary and secondary care integration can be seen across the devolved nations.^{29–31}

Achieving this improvement for epilepsy care will require dedicated epilepsy roles in primary and secondary care, and tailored protocols to improve coordination and reduce unnecessary referrals and admissions. Investing in accessible and timely neurology services, such as development of the Neighbourhood Health Service teams, is essential to delivering integrated, person-centred care.

Additionally, accelerating the translation of research and innovation into everyday clinical practice is critical to improvement. Advances in diagnostics, monitoring technology and treatment approaches have the potential to transform epilepsy care, but these innovations can be slow to reach patients.

Recommendations

Prioritise and futureproof neurology services and workforce provision with a particular focus on areas of high deprivation and workforce vacancies.

Develop and publish national minimum per-capita workforce guidance for neurologists and ESNs, ensuring provision is in line with best practice and published NHS, NICE and professional body guidance.

Prioritise filling neurology vacancies and promote neurology as a desirable speciality in the career development of junior doctors.

Every five years undertake a national census of the neurological workforce measured as whole-time equivalents (WTEs) including consultants, resident doctors, nurse specialists, allied health professionals, clinical neuro/psychologists and physician associates.

Ensure neurologists have protected, funded job-planned time to teach and supervise the next generation of clinicians without reducing clinical capacity.

Optimise resource utilisation and address epilepsy service gaps. Implement specialised training at primary care, hospital and board level to promote effective use of available resources and ensure a consistent approach to epilepsy services across the country.

Review and refine referral and treatment pathways.

Improve ambulance transfer guidelines and paramedic training in emergency epilepsy care.

Streamline communication between primary and secondary care providers, to reduce unnecessary referrals and delays.

Strengthen epilepsy care in primary and community settings, equipping local teams with the necessary tools and help needed to provide the best ongoing care and support for people with epilepsy.

Adopt a multidisciplinary team approach with fast routine neurology specialist input.

Improve information sharing and enable shared patient records across primary and secondary care teams.

Expand and strengthen links to voluntary, community and social enterprises (VCSE).

Prioritise implementation of Neighbourhood Health Service teams as outlined in the *NHS 10 Year Health Plan for England: Fit for the Future* in areas of high deprivation or with high epilepsy mortality rates.

Expand access to clinical trials. Ensure equitable access to clinical studies and trials for everybody with epilepsy, regardless of where in the UK they live.

Accelerate adoption of innovations. Commit to swift implementation of proven technological and digital advances to improve outcomes and enhance efficiency in epilepsy care across the NHS.

Key priority 2. Protect, expand and fund ESN training and posts

ESNs play a crucial role in managing both the physical and mental health needs of epilepsy patients. Funding for ESN training and posts must be protected and expanded, particularly in deprived areas.

Rationale

A report published by Epilepsy Action, found that UK epilepsy specialists recognise that effective epilepsy services depend on ESNs.²³ Despite this, the current number of ESNs in England is significantly below the number specified in the NICE guidelines and the situation is no better across other parts of the UK, with significantly low numbers of ESNs in Scotland, Wales and Northern Ireland.^{24–26} The report also found compelling evidence that the ESN role is cost-effective and valued among other healthcare professionals, because they play a vital role in helping patients navigate the healthcare system.²³ As a result, there is an urgent need to protect and increase ESN roles, especially in the most deprived communities.

Additionally, other specialists also play a key role in supporting PwE. Epilepsy Specialist Pharmacists (ESPs) in particular support CYPwE, by providing expert medication management, supporting treatment, and helping to avoid unnecessary emergency admissions. There is an urgent need to protect and increase both ESN and ESP posts, especially in the most deprived communities.

Recommendations

Fill vacant ESN and ESP posts, and create new posts to fulfil current and future demand as the number of people diagnosed with epilepsy continues to rise.

Promote and deliver epilepsy career pathways and training opportunities for ESNs and ESPs, and prioritise these roles in national healthcare strategies.

Roll out successful student or early-career education events, such as neurology career days or epilepsy clinical skills sessions, to raise early-career interest in epilepsy.

Offer structured shadowing and placements in epilepsy services to provide hands-on exposure and build core competencies.

Key priority 3. Identify, agree and prioritise key epilepsy sub-groups

Establish consensus on key sub-groups within the epilepsy patient population to enable more tailored and effective models of care.

Rationale

With approximately 630,000 people living with epilepsy across the UK, there is no 'one-size fits all' approach for these patients.⁵ The complexity and diversity within the epilepsy population mean that broad, generalised interventions often fail to address the nuanced challenges facing sub-populations of the patient community.

It is neither practical nor clinically appropriate to apply the same guidance and support frameworks to individuals with vastly different needs. For example, someone with epilepsy and a learning disability requires very different care to PwE who are pregnant or planning a pregnancy. Similarly, people with rare genetic epilepsies have vastly different needs and require highly specialised services. Developing care strategies that reflect these differences is essential to delivering person-centred, equitable care across the system.

Recommendations

Identify and agree priority sub-groups within local epilepsy populations at the regional health system level, drawing on available data and insights from HCPs, the voluntary sector and patients.

Develop differentiated models of care tailored to the specific clinical, social and psychological needs of these sub-groups.

Provide more personalised and better coordinated specialist care closer to where patients need it and ensure epilepsy patient requirements are addressed as part of the implementation of Neighbourhood Health Teams in England.

Key priority 4. Embed a holistic approach to brain health

Neurology and epilepsy services need a new holistic approach to brain health. Mental health provision must be routinely integrated into epilepsy services and care pathways.

Rationale

Currently, adult epilepsy patients are referred to general/non-specialist mental health services within the NHS, with CYPwE directed to child and adolescent mental health services (CAMHS), or hospital-based paediatric psychology services. These services are overstretched, not tailored to the needs of people with epilepsy and have long waiting lists of up to two years or more.

This approach does not support the concept of holistic brain health, which recognises the importance of integrating mental and neurological care.³² A whole brain health approach depends on a strong MDT that can look beyond seizures to the person's overall health picture. Neurologists, ESNs, mental health practitioners, pharmacists, social care professionals and others all have a role to play in delivering joined-up, person-centred care. Embedding mental health provision within epilepsy services would enable earlier intervention, improve outcomes, and promote a more holistic model of care. Several NHS pilot schemes have successfully implemented initiatives to integrate mental health services with epilepsy clinics and should be considered as potential blueprints for a nationwide approach (See Appendix 3).

Recommendations

Embed mental health provision into MDTs to ensure CYPwE and adults with epilepsy have timely access to integrated mental health support.

Embrace digital solutions, where appropriate, to reach more people and facilitate access to mental health support.

Provide tailored training to mental health practitioners to ensure they understand the specific challenges facing patients with epilepsy, so that they can provide appropriate care.

Conclusion and call to action

Our report demonstrates the vast improvements necessary to ensure that healthcare services and care for the **approximately 630,000 children, young people and adults living with epilepsy in the UK⁵** not only meet their needs but also:

- | **Improve outcomes and quality of life**
- | **Reduce inequalities**
- | **Prevent unavoidable premature deaths**

The current state of epilepsy services in the UK is alarming. Patients are routinely under-supported and overlooked by the NHS, service provision varies widely and investment in services and workforce lag behind other long-term conditions. This neglect is having a devastating effect on the epilepsy community, leading to widening disparities, poorer outcomes and increased mortality.

There is no room for apathy, despondency or procrastination: this is a time for action. As we developed our recommendations, we were mindful of the pressure that the NHS finds itself under. We feel our practical and pragmatic solutions, if implemented, would not only greatly improve epilepsy patient care but also enable the better use of currently available NHS resources.

We are urging NHS leaders, devolved administrations and the government **to end the wait and address the NHS epilepsy crisis.** We ask them to listen, to review our report findings and take urgent action. If we are to save lives and support those with epilepsy to live their life to the full, epilepsy services need to be prioritised. We need to ensure that this vulnerable patient group is no longer overlooked and that the essential care they need and deserve is provided.

There is an opportunity to dramatically **improve the care and quality of life for thousands of people** living with epilepsy across the UK today.

Complacency is not an option. That is why we are calling on the UK government, devolved administrations and NHS leaders to critically review this report and take immediate action to save lives and ensure that the NHS delivers on its mission to help every person with epilepsy in the country live their lives to the fullest.



What you can do to help

If you or a loved one has epilepsy, share this report widely, with your MP, local councillors and NHS organisation, urging them to take note and action. If you are in a position to influence policies and drive change, we call on you to work with us to implement the recommendations in our report. Together we can make change happen and bring about much needed significant improvements to epilepsy care in the UK.



Appendices

Appendix 1.
Report research methodology

Appendix 2.
Survey methodology

Appendix 3.
NHS mental health pilot schemes

Appendix 4.
Epilepsy Action case study

Appendix 5.
Epilepsy Action and NHSE North West Regional Maternity Team case study

Appendix 6.
Full ICB-level dataset for regional epilepsy metrics

Appendix 1. Report research methodology

This report draws on:

Original survey data from people with epilepsy and healthcare professionals across the UK. Epilepsy Action and Epilepsy Research Institute conducted survey fieldwork among their members between September and November 2024 (survey methodology is included below in Appendix 2).

National data from all publicly available sources for Referral to Treatment Waiting Times (RTT) from NHS England, Health and Social Care Northern Ireland, Public Health Scotland, Digital Health and Care Wales.

HES data available from NHS England Digital, accessed October 2024, acquired for Angelini Pharma UK&I by Harvey Walsh Limited, part of the OPEN Health Group.

Other data sources including peer-reviewed research, published reports and data from research undertaken by the Neurological Alliance, and Epilepsy Action.

Appendix 2. Survey methodology

Two online surveys were conducted to explore perceptions of the quality, timeliness and wider impacts of epilepsy care in the UK: one with PwE, and one with HCPs involved in epilepsy diagnosis and treatment.

Fieldwork and distribution

The PwE survey was conducted between 5 September and 22 November 2024 and distributed by Epilepsy Action and Young Epilepsy.

The HCP survey ran from 19 September to 22 November 2024 and was disseminated by the Epilepsy Research Institute. Both surveys were completed online.

Survey design and content

The PwE survey explored key themes:

Background questions to ensure demographic and regional representation, enabling comparative analysis by age, gender and geography.

Timeliness and experience of NHS care, with a focus on patient journeys, diagnostic pathways, and the impact of delays in access to care.

Impact of epilepsy on daily life and quality of life, including the effects on social relationships, employment, education and general wellbeing.

The HCP survey addressed:

Perceived causes and frequency of delayed diagnosis and treatment for epilepsy patients.

The impacts of delayed care on patient outcomes, from the clinical perspective.

Views on current epilepsy care provision and its perceived effectiveness.

Sample details

A total of 164 PwE, age 18+ years, completed the survey. Of these, 61% were women, 38% men, and 1% identified their gender as other. One-third of participants were over 65, and a majority (75%) had been diagnosed with epilepsy for over 20 years. Respondents included a mix of retired individuals (42%), those in full- or part-time employment (27%), and students (4%).

Twelve healthcare professionals took part in the survey. The sample consisted primarily of neurologists (58%) and ESNs (33%), with most working in hospital-based settings. Academic hospitals were the most common workplace, accounting for 75% of responses.

Participants were drawn from across all UK regions. Due to the small number of healthcare professionals surveyed, findings from this group should be interpreted with caution.

Appendix 3. NHS mental health pilot schemes

The following NHS pilot schemes have successfully integrated mental health services with neurology departments, delivering positive patient outcomes:

A) NHS Lothian: Piloted Psychology Adding Value Epilepsy Screening (PAVES)²¹

The initiative consists of mental health screening within epilepsy clinics alongside a stepped care intervention pathway

Screening identified that 53% of CYPwE, not already receiving children and Adolescent Mental Health Services (CAMHS) input, were experiencing high levels of mental health difficulties

Based on clinician opinion the CYPwE were offered appropriate interventions and support

The PAVES approach was shown to decrease epilepsy-related referrals of CYPwE to CAMHS services by 62%

Read more about the pilot at:

<https://www.england.nhs.uk/long-read/national-bundle-of-care-for-children-and-young-people-with-epilepsy-appendix-5/>

B) UCL Great Ormond Street Institute of Child Health trial: Mental Health Intervention for Children with Epilepsy (MICE) study³³

During the trial, mental health treatment was integrated with epilepsy services. Participants were randomised (1:1) to receive the Mental Health Intervention for Children with Epilepsy (MICE) in addition to usual care, or assessment-enhanced usual care alone

The primary outcome measure was the parent-reported Strengths and Difficulties Questionnaire (SDQ) at six months post-randomisation.

At six months, the mean SDQ difficulties were favourably lower in the MICE group: 17.6, compared with 19.6 for the control group

Additionally, physical health benefits were observed: 14 patients (8%) in the MICE group experienced at least one serious adverse event compared with 24 (14%) in the control group.

68% of serious adverse events (50 events) were hospital admissions due to seizures

Read the full paper published in *The Lancet*: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(23\)02791-5/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)02791-5/fulltext)

Appendix 4. Epilepsy Action case study

'Be Epilepsy Aware' (<https://www.epilepsy.org.uk/professional/be-epilepsy-aware>) is a collaborative project between Epilepsy Action and the NHS to address the needs of a specific sub-group of epilepsy patients and reduce the burden on health services.

Epilepsy Action and the North East and North Cumbria Learning Disability Network worked in partnership with PwE to create an epilepsy self-management resource for people living with epilepsy and a learning disability (PwELD). A training course was created to equip PwELD with the skills to manage their epilepsy more independently, improve their wellbeing, and to reduce the burden on health services.

The training covers what epilepsy is, diagnosis and treatment, how to manage risks, and approaches for maintaining good mental health. The goal was to decrease mortality, emergency admissions and elective appointments, as well as increase wellbeing.

Be Epilepsy Aware was codeveloped with PwE during 2024 and launched in February 2025. The training course was accessed by over 1,700 people in the first six months and has received overwhelmingly positive feedback both from patients and from epilepsy and learning disability nurses. Nurses have reported that they believe Be Epilepsy Aware will reduce the number of phone calls and appointments for patients needing advice and support and help patients to better track symptoms and side effects, making appointments more efficient and improving safety.

Appendix 5. Epilepsy Action and NHSE North West Regional Maternity Team case study

Reducing pregnancy risks for people with epilepsy

PwE in the UK face significantly higher risks during pregnancy. Maternal mortality is ten times higher than in the general population and maternal deaths have more than doubled over the 3 years prior to 2026 despite being largely preventable. Risk factors for SUDEP are the leading cause of death among pregnant PwE. There are also increased risks of miscarriage, preterm birth, stillbirth and neonatal intensive care (NICU) admissions, as well as a higher rate of congenital malformations and neurodevelopmental conditions resulting from anti-seizure medication use in pregnancy.

To drive change and improve the care, safety and experiences of pregnant PwE, Epilepsy Action partnered with NHS England's North West regional maternity team to implement a regional quality improvement initiative. The region was chosen because of its high epilepsy prevalence, population diversity and marked health inequalities.

A multidisciplinary steering group, comprising up of midwives, obstetricians, neurologists, ESNs, primary care and people with lived experience of epilepsy, undertook a comprehensive gap analysis across all NHS Trusts in the region, alongside listening events with PwE and healthcare professionals. Together these shone a light on the current provision of services and compliance with national guidelines.

The findings informed the co-development of a clinical guideline and service specification supported by benchmarking and audit tools to improve the safety, quality and consistency of preconception, pregnancy and perinatal care for PwE.

The service specification aims to standardise care across the pregnancy pathway for PwE, and addresses the importance of data collection and ongoing monitoring to ensure patient safety and the delivery of high-quality services focusing on:

- Clear referral mechanisms for preconception advice and specialist support including mental health and other common comorbidities as well as all birthing PwE to the UK Epilepsy Pregnancy Register
- Written preconception information
- Provision of epilepsy-specific pregnancy risk management with personalised seizure risk reduction plans
- Annual training needs analysis, audits and service user reviews

The clinical guideline targets the key risks identified in the gap analysis:

- First seizures and reducing risk of seizures during pregnancy
- Content for preconception counselling
- Use of anti-seizure medications during pregnancy and breastfeeding
- Schedule for and HCP representation at pregnancy appointments
- Care and birth planning and risk management
- Preparation for parenthood with a focus on epilepsy-specific risks

All guidance has been piloted across maternity providers in the North West with impact and useability measured to inform further refinement. The initiative is currently being rolled out nationally.³⁴

Appendix 6. Full ICB-level dataset for regional epilepsy metrics

The following ICBs were included in the analysis of regional epilepsy service metrics presented in this report. This list corresponds to the available data on neurology referral delays, excess bed days for epilepsy treatment, and emergency admissions for people living with epilepsy.

ICB Code	ICB Name	Percentage of neurology referrals waiting longer than target of 18 weeks (September 2025)	HES excess bed days (epilepsy primary diagnosis) 2023–2024	HES A&E attendance (epilepsy primary diagnosis) 2023–2024	HES excess bed days per 100 planned in-patient bed days for epilepsy treatment 2023–2024	Number of emergency admissions per 1,000 people living with epilepsy 2023–2024
ICB average		41%	440	1880	14.80	195
Region: North East and Yorkshire						
QOQ	Humber and North Yorkshire ICB	36%	405	3765	10.75	273
QHM	North East and North Cumbria ICB	35%	1271	4900	18.51	188
QF7	South Yorkshire ICB	28%	378	3070	11.24	258
QWO	West Yorkshire ICB	33%	661	4005	12.93	219
Region: North West						
QYG	Cheshire and Merseyside ICB	37%	1567	3915	24.56	179
QOP	Greater Manchester ICB	33%	1318	4210	20.33	188
QE1	Lancashire and South Cumbria ICB	55%	369	1560	12.06	107
Region: Midlands						
QHL	Birmingham and Solihull ICB	51%	360	3235	8.90	328
QUA	Black Country ICB	41%	928	3035	27.24	317
QWU	Coventry and Warwickshire ICB	38%	238	1280	11.30	189
QGH	Herefordshire and Worcestershire ICB	22%	375	1220	21.21	205
QJ2	Derby and Derbyshire ICB	45%	259	1935	12.20	224
QJM	Lincolnshire ICB	60%	125	1660	9.24	272
QT1	Nottingham and Nottinghamshire ICB	22%	178	1905	7.45	209
QK1	Leicester, Leicestershire and Rutland ICB	38%	660	1985	22.88	261
QPM	Northamptonshire ICB	32%	409	1780	27.16	347
QOC	Shropshire, Telford and Wrekin ICB	36%	126	945	13.98	232
QNC	Staffordshire and Stoke-on-Trent ICB	35%	98	2335	4.45	236

Region: East of England						
QHG	Bedfordshire, Luton and Milton Keynes ICB	48%	365	1535	14.14	254
QUE	Cambridgeshire and Peterborough ICB	41%	201	1110	20.43	183
QM7	Hertfordshire and West Essex ICB	45%	339	1570	11.75	168
QH8	Mid and South Essex ICB	50%	175	2445	8.05	301
QMM	Norfolk and Waveney ICB	57%	420	1975	23.23	232
QJG	Suffolk and North East Essex ICB	43%	133	1060	8.18	138
Region: London						
QMJ	North Central London ICB	48%	591	810	17.06	101
QRV	North West London ICB	44%	859	1240	11.79	104
QMF	North East London ICB	44%	557	980	12.03	99
QKK	South East London ICB	42%	487	1045	11.75	106
QWE	South West London ICB	34%	257	620	6.84	72
Region: South East						
QU9	Buckinghamshire, Oxfordshire and Berkshire West ICB	46%	380	1485	13.88	127
QNQ	Frimley ICB	54%	256	455	12.87	97
QRL	Hampshire and Isle of Wight ICB	43%	447	3040	8.83	228
QKS	Kent and Medway ICB	40%	455	965	13.38	71
QXU	Surrey Heartlands ICB	38%	341	795	18.80	126
QNX	Sussex ICB	47%	561	2635	15.44	214
Region: South West						
QOX	Bath and North East Somerset, Swindon and Wiltshire ICB	41%	192	1045	12.81	157
QVV	Dorset ICB	39%	199	1305	14.58	243
QSL	Somerset ICB	40%	195	370	17.26	83
QUY	Bristol, North Somerset and South Gloucestershire ICB	41%	286	2120	12.77	299
QR1	Gloucestershire ICB	36%	703	575	40.15	113
QT6	Cornwall and Isles of Scilly ICB	36%	113	1045	9.25	224
QJK	Devon ICB	47%	244	2010	10.08	200

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The outputs may only be used for the following purposes: uptake and implementation of innovation and national policy guidelines; commissioning support; patient pathway analysis; benchmarking; disease burden analytics; business cases; epidemiology research; health economic research; quality and outcomes analysis.

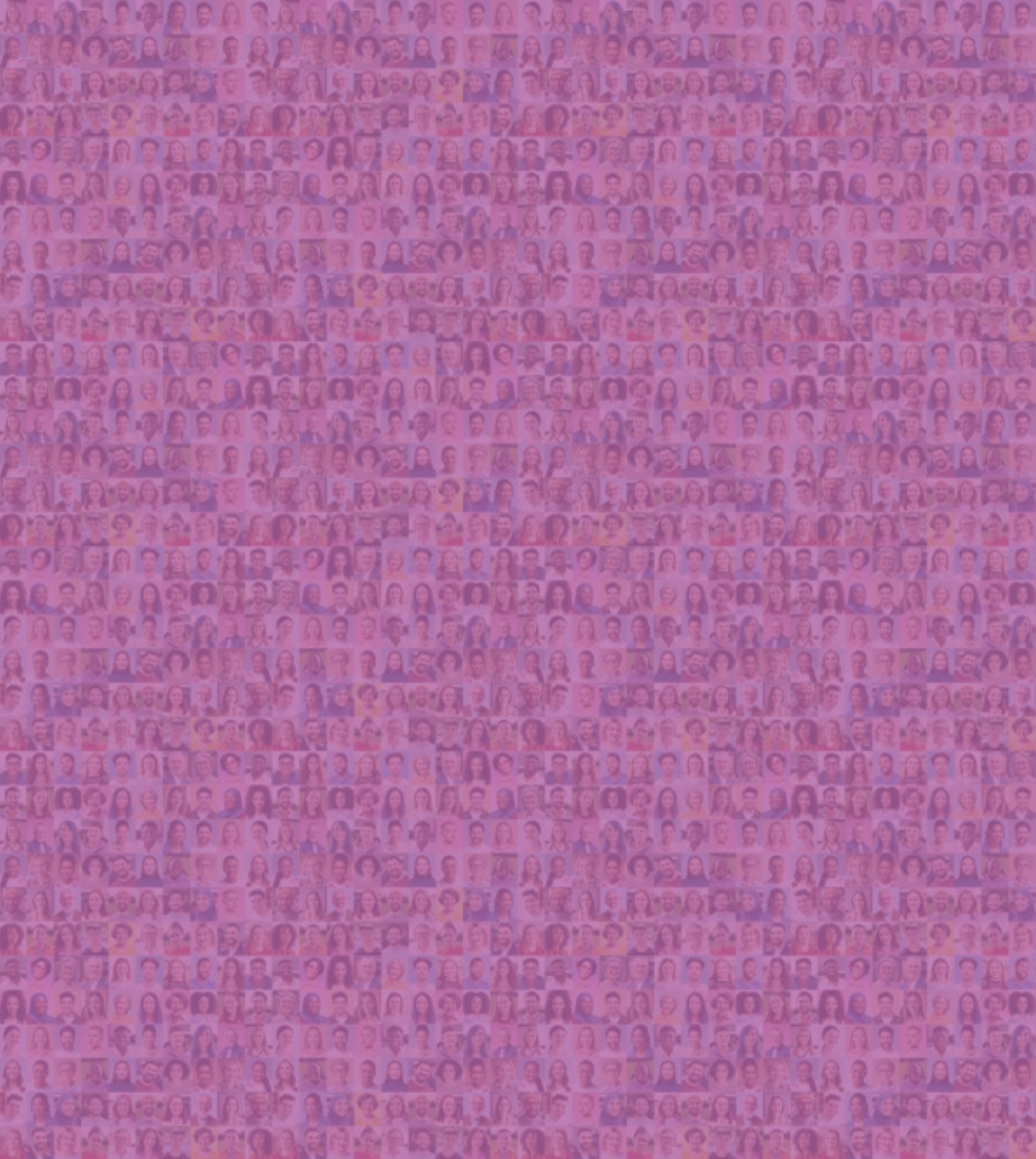
What cannot be done with the data or outputs? The data may not be used (directly or indirectly) for sales or marketing purposes, which includes that the data may not be used to target sales individuals towards specific healthcare professionals and the data shall not be used within sales collateral used by sales/marketing teams: this includes sales brochures, emails, direct mailing or advertising of pharmaceutical products.

Glossary

Term	Abbreviation	Meaning
Accident and emergency	A&E	Emergency or casualty department of a hospital for serious injuries and life-threatening emergencies such as heavy bleeding, choking and seizures.
Allied health professional	AHP	Working across a range of areas from emergency response to diagnosis and rehabilitation, AHPs are mainly degree level professionals supporting and managing patient care. They focus on prevention and improving health and wellbeing to enable people to live their fullest lives. There are 15 recognised AHP roles in the UK including: <ul style="list-style-type: none"> • Diagnostic and therapeutic radiographers • Dietitians • Occupational therapists • Paramedics • Physiotherapists
Children and adolescent mental health services	CAMHS	A range of mental health support services, usually delivered by the NHS, for children and young people under 18 years of age.
Children and young people with epilepsy	CYPwE	People under the age of 18 years diagnosed with epilepsy.
Epilepsy Specialist Nurse	ESN	Nurses who specialise in epilepsy exclusively and can work both in a hospital and community setting supporting adults, children and young people with epilepsy. They provide much needed support with all aspects of living with epilepsy and play a key role in ensuring continuity of care.
Excess bed days		Patients who remain in hospital beyond an expected set length of stay, due to complications and/or complex or specialist medical needs, including those whose discharge becomes delayed because of a lack of available social/community services and care. Lengths of stay are set by the NHS for healthcare resource groups (HRGs) – groupings of clinically similar treatments or interventions that use comparable levels of healthcare resource.
Full-time equivalent	FTE	The number of full-time or equivalent employees counted as the total number of hours worked rather than the number of employees and calculated to show the full time equivalent e.g. if full time is defined as a 40-hour week, and four employees each work 10 hours per week, this equates to 1 FTE. Accounting for employees in this way ensures that real resource and availability is accurately captured and includes part-time employees in real terms rather than as a head count.
Healthcare professional	HCP	A qualified, registered person, such as a doctor, nurse, physiotherapist or paramedic, providing medical services and adhering to standards set by regulatory bodies.
Hospital episode statistics	HES	A curated data set containing details about admissions, outpatient appointments and A&E attendance at NHS hospitals in England.
Integrated care board	ICB	ICBs replaced clinical commissioning groups (CCGs) in the NHS in England in 2022 and commission the vast majority of NHS care and services in their local area. As well as planning and funding healthcare they work with partners – local authorities and community groups – to provide joined-up care and services as a key strategic component of integrated care systems (ICS).
Multidisciplinary team	MDT	A group of health and social care professionals (doctors, nurses, allied health professionals and social workers) from different disciplines and specialities (neurology, psychiatry and emergency medicine) who all work together to plan and coordinate a patient's care, ensuring a holistic and joined-up approach to care and treatment.
Neurology		A branch of medicine focused on the nervous system – brain, spinal cords, nerves and muscles – treating a range of disorders including epilepsy, Parkinson's, multiple sclerosis and migraines.
<i>NHS 10 Year Health Plan for England: Fit for the Future</i>		Published in July 2025, this plan sets out a new operating model and the government's vision for the delivery of healthcare by the NHS in England.
National Institute for Health and Care Excellence	NICE	An executive, non-departmental public body sponsored by the Department of Health and Social Care providing guidance for the NHS and wider health and care system.
People with Epilepsy	PwE	People, usually adults, diagnosed with epilepsy.
Referral to treatment waiting times	RTT	Monitors the length of time from elective (non-urgent) referral through to first treatment. The NHS constitution for England sets a standard that 92% of patients should wait no longer than 18 weeks from the day the hospital received the referral letter or the appointment is booked through the NHS e-referral service, to receipt of first consultant-led treatment. For Wales, the target is 100% of patients waiting 36 weeks or less until commencement of treatment. For Scotland 95% of patients should be seen at a new outpatient appointment within 12 weeks of referral and for Northern Ireland 50% of patients should wait no longer than 9 weeks for a first consultant-led appointment.
Sudden Unexpected Death in Epilepsy	SUDEP	The sudden or unexplained death of someone with epilepsy who is otherwise healthy.

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