

NNAG Epilepsy event write up

October 2018

epilepsy *action*



THE
NEUROLOGICAL
ALLIANCE

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The Strategy Unit, hosted by Midlands and Lancashire CSU, has been employed by the Neurological Alliance to provide programme management for the National Neuro Advisory Group. This document has been produced as part of this package of work. Please direct any queries to Lucy Hawkins, Senior Consultant, lucy.hawkins4@nhs.net. More examples of The Strategy Unit's work can be found at strategyunitwm.nhs.uk/.

Event description

The National Neuro Advisory Group (NNAG) exists to seek alignment between programmes in NHS England, the Department of Health's Arm's Length Bodies and system partners, such as charities relevant to people with neurological conditions, and to guide the strategic development of work to improve outcomes for people living with neurological conditions. One of the aims of NNAG is to bring together all the different professionals that need to work together to achieve improvement in neurology services, including clinicians, patients, commissioners and academics.

As part of the NNAG's wider scheme of work several condition specific groups have been identified to lead the development of pathways to complement the revised neurosciences specification.

These groups have been identified by conditions that share similar challenges in ensuring access and equity of care, as well as where pathways between services could be improved. The groups are as follows:

- Neuromuscular
- Headache and migraine
- Epilepsy
- Neurorehabilitation
- Parkinson's, dementia and psychiatry

A number of initial workshops have been arranged by these groups in order to facilitate the improvement of services nationally through the sharing of good practice and identification of areas where more work is needed. Different models of care will work in different parts of the country but equity in the standard of care is the goal.

This report describes the fourth workshop that focused on Epilepsy and was held on the 11th October 2018. It summarises each of the presentations and highlights next steps and opportunities

The presentations have been kindly made available by the speakers and may be used to support the further exploration of the themes and outcomes of the day.

1. Introduction

Epilepsy is one of the most common neurological conditions in the world and affects approximately 600,000 people in the UK¹. The main symptom of epilepsy is repeated seizures that start in the brain, these seizures can affect people in different ways depending on which part of the brain is affected. Epilepsy can start at any age and present in a number of different ways. Some types of epilepsy will last for a limited amount of time and the person will eventually stop having seizures, but for many people Epilepsy is a life-long condition.

For some epilepsy is their primary condition, for others it can be a consequence of other conditions such as head injury, stroke, a brain tumour, brain infection such as meningitis, lack of oxygen at birth².

There has been a recent focus on Epilepsy due to a striking correlation between Epilepsy deaths and deprivation as highlighted in the Public Health England (2018), Deaths associated with neurological conditions in England 2001 to 2014, report³. Therefore, the key aims for epilepsy services nationally should be for a reduction in variation, morbidity and mortality.

The diagram below outlines a potential optimal pathway for the organisation of services at an STP level. The event on the 11th October aimed to discuss and add more detail to the pathway below and then working in conjunction with RightCare produce an optimal pathway for patients with epilepsy.

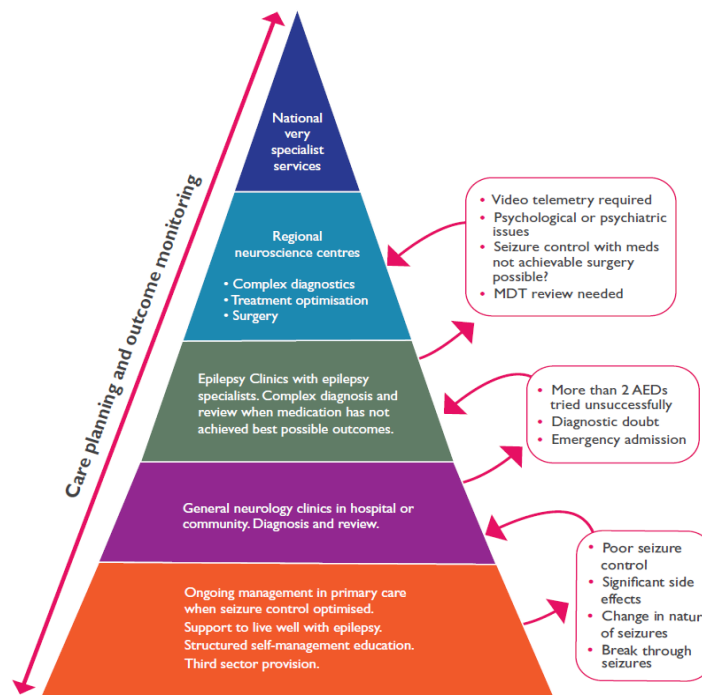


Figure 1 - Produced by Epilepsy Action for use at this event

¹ Epilepsy Action (2016), <https://www.epilepsy.org.uk/info/what-is-epilepsy>

² NHS England (2017), <https://www.nhs.uk/conditions/epilepsy/>

³ Public Health England (2018),

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683860/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf

2. Summary of presentations

This section summarises the presentations from the day, please read the following in conjunction with the corresponding slide pack.

2.1 Professor Adrian Williams

Professor Adrian Williams opened the day with an overview of current schemes of work being undertaken by the Neurosciences Clinical Reference Group, the National Neuro Advisory Group (NNAG) and Getting It Right First Time (GIRFT).

He explained that improving services for patients with Epilepsy is being taken seriously at a national level due to its prevalence and the recently published mortality data. He argued that prevention and reduction in unnecessary deaths should be key objectives to discuss.

Adrian also highlighted that leadership has to happen at all levels of the system and in a joined-up approach for change to happen. The national bodies can advise on best practice however it is down to the regional and local centres to continually improve the services that they deliver. Therefore, one of the aims from this workshop was to support service development at a local level.

2.2 Vittoria Polito, NHS Right Care

Next, we heard from Vittoria Polito, Pathways Lead at NHS RightCare. She explained that RightCare have been in existence since 2015 and work with local health economies to:

- Diagnose, identify issues and opportunities with data, evidence and intelligence
- Develop, solutions, guidance and innovation
- Deliver, improvements for patients, populations and systems.

RightCare are looking to develop an optimal pathway for Epilepsy services. RightCare pathways are designed to support commissioners in reviewing their local services and identifying where potential improvements could be delivered.

Vittoria explained that there are limited CCG level data available to support service improvement in Epilepsy. There are data on recorded prevalence, primary care prescribing and secondary care admissions. As well as a number of general risk factor indicators such as deprivation, obesity, smoking and alcohol consumption, however, there is a need to identify other risk factors that may relate specifically to epilepsy. There are also challenges around gaps in the available data and a lack of indicators on quality of care and outcomes.

From the data that does exist we can see that nationally the prevalence of Epilepsy (QOF data 2016/17) ranges from 0.4% to 1.2% with the average being 0.8%. CCGs with the lowest Epilepsy prevalence are Westminster and Tower Hamlets, with Blackpool and Stoke on Trent having the highest. In terms of secondary care inpatient data, we can see a 13-fold variation in elective spend on admissions between the highest and lowest spend CCG's. It is not currently clear what is driving this variation.

There is still some work to be done to define “What does good look like?” for patients with epilepsy and support service improvement to reduce national variation.

2.3 Michael Jackson, Public Health England

Continuing the theme of available data Michael Jackson from the Neurology Intelligence Network, Public Health England (PHE) then presented on the work that PHE are undertaking in relation to Epilepsy and Neurological conditions more widely⁴. Michael explained that PHE’s report on deaths associated with neurological conditions looked at the deaths of people who had epilepsy not just those who died of epilepsy. He then took us through some of the key findings.

In 2014 there were 3,100 deaths with a mention of epilepsy, 49% of those were classed as premature which means that the individual was under the age of 75.

The comparison of death rate between the most deprived areas and least deprived areas showed a striking difference of 13/100,000 (most deprived) to 5/100,000 (least deprived). We know that social deprivation and social poverty is a determinant of poor general health, so Michael suggested that this needs to be an area targeted to prevent avoidable deaths.

In terms of the differences between men and women, female deaths are more clustered towards the upper end of the age bands, whereas the figures for men show a more even spread across ages. This indicates that more men with epilepsy die younger.

The epilepsy deaths data also showed that a high number of people had co-morbidities. The most common co-morbidities were respiratory disease, malignant cancer and circulatory disease, indicating the complexity of epilepsy deaths.

In addition to the deaths data PHE also holds a large amount of data relating to hospital activity. Analysis of this data showed that in 2015/16 approximately 91% of admissions for Epilepsy were emergency admissions. The mean length of stay for epilepsy admissions is 3.6 days. The admission figures remained fairly stable between 2012/13 and 2015/16.

Admissions for individuals where epilepsy was not the primary diagnosis but mentioned epilepsy were 169,855 in 2015/16, these admissions have shown an increasing trend since 2012/13 when the figure was 152,380.

Neurology data produced by PHE can be found here: www.gov.uk/guidance/neurology-data-and-analysis-a-guide-for-health-professionals

⁴ <https://www.gov.uk/guidance/neurology-data-and-analysis-a-guide-for-health-professionals>

2.4 Tony Marson, The Walton Centre

Professor Tony Marson then presented on the national audit of seizure management in hospitals which was run in 2011 and 2013, with the third round currently being rolled out.

The two audits analysed 9000 Emergency Department attendances across 154 departments, and patients were classified into three groups:

- Those with known epilepsy (61%)
- Those who had had previous blackouts (17%)
- Those who presented with their first seizure (22%)

Key findings from both audits were that less than 50% of first seizures were referred to a seizure clinic and less than 50% of known epilepsy patients were under active follow up.

In 2013, 45.1% of patients with known epilepsy had attended the ED as a result of a seizure in the previous 12 months, and 62.9% had not been seen by an epilepsy specialist in the previous 12 months. This appears to show a pattern of people having multiple A&E attendances but not seeing epilepsy specialists. There was also indication from the data that people were not on the best combination of medication to prevent further seizures.

The audits also looked at investigations requested and onward referral. A high proportion, 41.4%, of all patients who presented in ED following a seizure were not being referred onto an epilepsy pathway, this indicates a disconnection between services or difficulties identifying patients with epilepsy in ED's.

Tony concluded with his interpretation that the greatest opportunity to improve quality of life for people with epilepsy in the short to medium term is to offer comprehensive services that allow access to currently available and proven technologies. But he acknowledged that changing the way that things are done in the NHS is difficult, therefore we need to engage the clinical community to identify problem, use data to identify solutions, make incremental changes and learn from them thereby creating a learning health system.

2.5 Angie Pullen, Epilepsy Action

We then heard from Angie Pullen, Epilepsy Action, on their 2017 survey looking at the state of NHS Epilepsy services. Information for this survey was obtained through the freedom of information requests submitted to trusts and the data collected has been used to produce a map of the services available nationally. Of the 244 trusts contacted 236 responded.

Angie took us through the key findings comparing results to when the survey had been run previously in 2012. The following improvements were identified:

- The number of trusts offering adults access to an epilepsy nurse increase from 54% to 68%.
- The number of trusts not offering young people access to transition services had decreased from 65% to 42%.

-
- The number of trusts saying that patients were offered care plans increased from 47% to 92%.
 - The number of children waiting less than 4 weeks for an EEG increased from 41% to 57%.

Despite these improvements there were also indicators that had decreased, these were:

- Providers able to offer a child an MRI within 4 weeks down from 50% to 40%
- Providers able to offer an adult an MRI within 4 weeks down from 50% to 35%
- Average wait for an EEG for an adult had increased from 4 to 6 weeks
- Providers able to offer a first adult appointment within 2 weeks had decreased from 20% to 8%.

The survey also looked at care planning and services for patients with epilepsy and learning disabilities. This highlighted that the majority of care plans are a letter to the GP that is copied to the patient and that some areas do not have the expertise in managing epilepsy and learning disabilities.

In response to these findings Epilepsy Action put forward the following suggestions for pathway design:

- Ensure timely access to first epilepsy appointments
- Ensure adequate diagnostic capacity, particularly MRI and EEG
- Improve access to neuropsychologists and neuropsychiatrists to identify learning and behavioural difficulties, improving quality of life and educational potential.
- Ensure that annual reviews are designed in
- Agree what constitutes an effective care plan to ensure they are helpful for both clinicians and patients
- Promote self-management in the epilepsy pathway and better support people with epilepsy to live the best quality of life possible.

2.6 Juliet Ashton and Ann Touray, Norfolk Community Health and Care and North and South Norfolk CCG's

Juliet and Ann told the story of how they have grown the Epilepsy Specialist Nursing service across Norfolk since 2016.

They explained that pre-2016 there was little engagement with the CCG's, epilepsy nursing was a small and niche service within the community trust and the team had very little capacity and were getting burnt out. There was poor (if any) joined up working between secondary, community and primary care.

Ann explained how they had to identify 'the hook' to generate interest in developing this service and that hook was the de-prescribing of Buccal Midazolam. This was identified as a potential QIPP saving for North Norfolk CCG and from that they were able to develop a business case for increasing the number of community epilepsy nurses. The business case was able to demonstrate

how this would improve patient experience and access hence driving up quality, provide the opportunity to develop pathway working and implement new innovations, to reduce inappropriate prescribing on buccal midazolam and increase the number of patients being seen through increased awareness of the service, and finally implement a prevention programme through patient self-management education and sharing of expertise with ambulance staff, GP's and integrated care co-ordinators.

The service commenced in February 2017, the team now consists of 4 Epilepsy nurses and one administrator. They have a caseload of 1020 patients and undertake 339 patient contacts per month. They have increased the number of community bases they work out of from 6 to 22 which means that patients are now receiving care closer to home, there is improved equity of access for patients and this has led to reduced DNA rates and improved satisfaction from patients. They have also saved neurologist time through reducing follow up appointments, and time spent liaising with GPs on medication changes. They also provide advice and guidance to GPs ahead of the need for neurologist input.

Juliet and Ann believe that one of the key ingredients in their success was taking the time to get to know one another and working collaboratively to solve the problems faced.

2.7 Patient Representatives

On the day we also heard from a number of Epilepsy Action volunteers on their experience of living with epilepsy. They have all had different experiences of epilepsy services, however to maintain their anonymity the key themes have been summarised below.

What went well?

- When good relationships developed with professionals e.g. GP always asking how things were and Consultant explaining things clearly to both parent and child
- Support and care offered by paediatric services

Poor experience:

- Transition from paediatric to adult services – particularly communication between services and managing expectations and relationships with the family.
- A "breakdown of trust" and feeling like everything was a "battle" was described in relation to transition experiences.
- Lack of emotional or mental health support, particularly after initial diagnosis. A feeling of "just being left to get on with it" was described.
- Ensuring that appropriate advice and guidance is given around contraception for women of child bearing age.

2.8 Sarah Vibert, The Neurological Alliance

The final presentation of the day was from Sarah Vibert, Chief executive of the Neurological Alliance. Sarah presented the findings from their 2016 patient survey. This is a survey run biennially by the Alliance, and the overarching theme from the 2016 survey was that in every area patient experience had deteriorated in comparison to 2014.

In the 2016 survey they had 542 responses from people with epilepsy, 291 of those had a co-morbid health condition and 93% were on epilepsy medication.

Compared to the wider population of people with neurological conditions Epilepsy patients generally saw their GP fewer times before getting a diagnosis and only 9% compared to 19% for all neuro patients waited more than 12 months to see a specialist. However, this is a pretty low baseline and there is still plenty of room for improvement.

In terms of ratings of care 15% of epilepsy respondents rated their care as excellent and 43% said that they experienced delays in getting the care that they needed.

In 2016 44% of epilepsy patients said that they have had an unplanned admission and 29% have had more than one. This is compared to only 26% of all neuro patients having had an unplanned admission which indicates this is a major issue for epilepsy. In addition to this 26% of epilepsy patients who have been admitted were dissatisfied with their care, citing lack of information, communication and availability of neurologists as the main issues.

Other key themes were that only 26 (4.7%) respondents said that they receive self-management support and 34% were dissatisfied with the information they received about their condition.

3. Summary of discussions

Throughout the day there were also three workshops, based on the RightCare methodology, where delegates were asked to discuss the following questions:

Workshop 1:

- What does the Right Care data tell us about – potential?
- What are the national challenges facing this population group or service delivery?
- What are the blocks? Why are we not 'doing good' already?

Workshop 2:

- What are the higher value interventions which if fully and consistently implemented, would have the biggest impact on outcomes for people with the condition and therefore improve value (better outcomes for the best cost) along the pathway?
- What are the lower or negative value interventions or activities which the system should stop delivering, change or target more effectively?
- What are the system enablers which will enable the interventions/activities to be delivered most effectively?

Workshop 3:

- What are the main sources of evidence for the intervention?
- What guidance, tools and practice examples are there which should form part of the resource set to support better planning and implementation of the high-level pathway?
- What are the target outcomes which would be achieved by implementing the intervention?
- What are the measures by which we would know whether the intervention had been implemented and the target outcomes had been achieved?

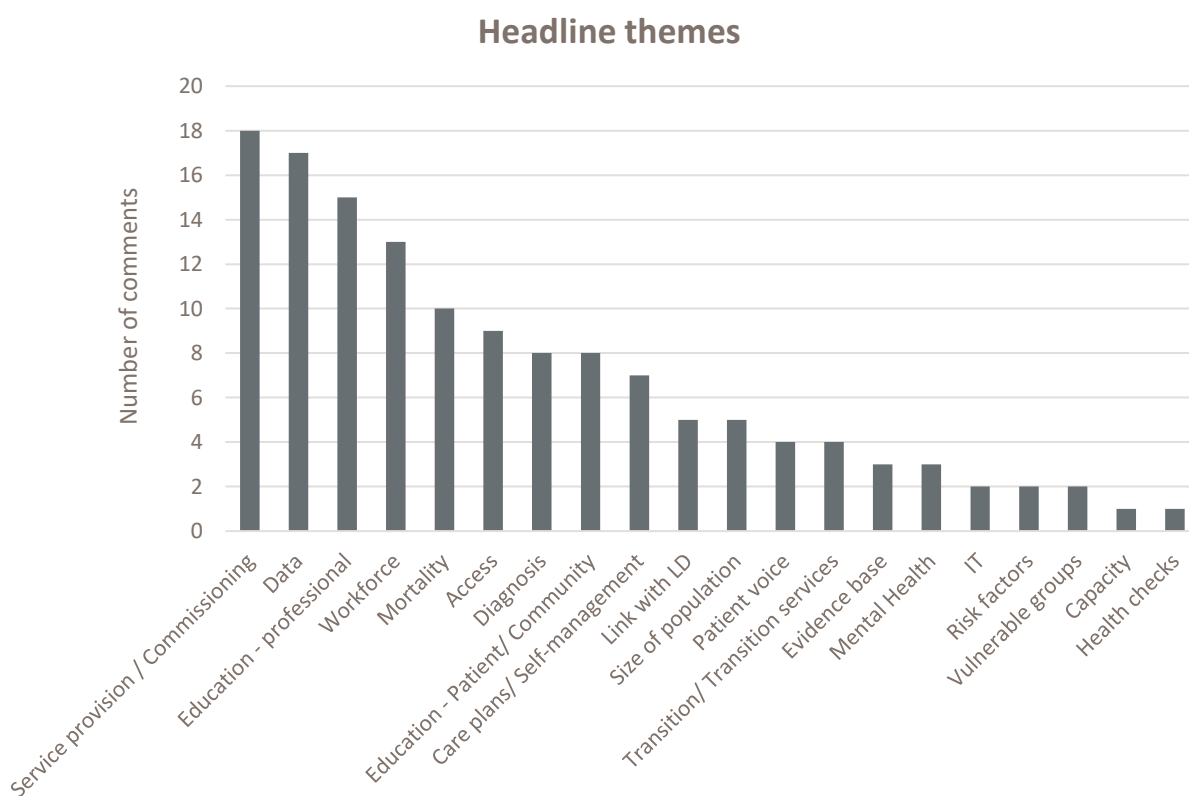
The notes from these workshops are being consolidated and analysed by the RightCare team and will form the starting point for the development of the epilepsy pathway. Initial findings are shared here to illustrate the discussions from the day, please note that this is not the final output and there will be further analysis and discussion with stakeholders.

3.1 National challenges

National challenge themes that emerged on the day can be seen in Graph 1. These themes have been used to derive the following potential service improvement priorities:

1. Identification and segmentation of epilepsy population
2. Mortality – taking a risk management approach
3. Coordination of care in primary and community care
4. Access to specialist epilepsy services
5. Mental health support in the community
6. Population and whole system approach to education
7. Support of people with Learning Disabilities
8. Medicines optimisation
9. Personalised care using a risk management approach

Graph 1. National Challenge Themes



3.2 Higher value interventions

Comments relating to higher value interventions are summarised in the table below according to headline theme:

Theme	Summary of comments
Access	<p>Access to counselling and self-management services.</p> <p>Meaningful appointment times negotiated with patients.</p> <p>Precision medicine and access to other interventions e.g. surgery.</p> <p>Timely access to someone with knowledge of epilepsy.</p> <p>Ensure annual review, particularly for people with poor seizure control.</p>
Care Plans / self-management	<p>Care planning in a format that is appropriate for the patient and in terminology that they understand.</p> <p>An emergency plan so that patients / carers / professionals know who to contact in emergency situations.</p> <p>A pregnancy toolkit that fits with the care plan.</p> <p>Tailored education and support for self-management.</p>
Data	<p>Information sharing.</p> <p>National epilepsy registry with a standard minimum dataset.</p>
Education – Patient / Community	<p>Family / carers to receive training on how to look after / support patients.</p> <p>Public education to raise awareness of epilepsy as a condition.</p> <p>Train teachers to recognise potential epilepsy signs in children to support earlier diagnosis.</p>
Education - Professional	<p>Equip LD services with epilepsy knowledge.</p> <p>Equip staff with the ability to counsel patients around diagnosis and seizure management.</p> <p>Seizure and safety checklists.</p> <p>Supporting paramedics on when / when not to take a patient to A&E.</p>
Patient voice	<p>Epilepsy champions at a local level informing local pathway design.</p>
Service provision / Commissioning	<p>Ability to access electronic patient care records across the NHS.</p> <p>Improved continuity of care by joining up services.</p> <p>Specialist nurses and advice lines.</p> <p>Telehealth for review or triage of more stable patients.</p>

3.3 Lower or negative value interventions

Comments relating to lower or negative value interventions that should be stopped are summarised in the table below according to headline theme:

Theme	Summary of comments
Data	Duplication of information e.g. patients repeating history / plan to different professionals. Not sharing of information.
Education – Professional	Over reliance on secondary care. Seizures at home presenting in A&E. 20% of patients on sub-optimal medication.
Service provision / Commissioning	CT scans in A&E. Over imaging or repetition of diagnostic investigations when unnecessary. Non-standardised referrals Stop treating everyone as urgent, triaging should help determine how quickly someone needs to be seen.

4. Next steps

Actions agreed following the day were:

- RightCare to develop an optimal pathway for Epilepsy based on our discussions today and further input from attendees/stakeholders. They are looking to pull together a multidisciplinary group to ensure that everyone's views are heard. For more information or if you would like to be involved please contact Vittoria Polito.
- NNAG will be looking to set up an Epilepsy sub group to take some of the actions and improvements identified forward. For more information on how to be involved in this please contact the Neurological Alliance.

The following were also highlighted as key projects coming up in the next few months:

- NICE are in the process of updating their guidance on Epilepsy, there is a scoping workshop on Monday 26th November 2018 in London. Contact NICE if you would like to be involved.
- NICE are also producing a guideline on Cannabis based products for medicinal use, this is due to be published in 2019 and is in the scoping stage. Please contact NICE for more information.
- Dr Adam Noble, University of Liverpool will be starting a research project looking at alternative care pathways for ambulances and maximising the chances of the change being economical and beneficial for patients and the NHS. For more information or if you would like to be involved please contact Adam.
- Jane Kachika and Rohit Shankar NHSE learning disability programme are leading work to develop integrated care for people with epilepsy and learning disabilities and seeking feedback from local areas willing to test their draft guidance and tools to improve their services. Please contact them directly if you would like to be involved.
- The Neurological Alliance and MS Society are setting up a working group to look at care planning for people with neurological conditions. Please contact the Neurological Alliance if you would like to find out more.

5. Appendices

Appendix 1 - Attendees

Name	Job Title and organisation
Adam Noble	University of Liverpool
Adrian Williams	Chair CRG and NNAG
Alexander Thompson	RightCare
Andrew Platt	RightCare
Angie Pullen	Epilepsy Action
Ann Touray	CCG Commissioner – North Norfolk
Antonia Drummond	NHS England
Clair Cobbold	Epilepsy Action Volunteer
Doug McCorry	Neurologist
Erin Davies	Epilepsy Action Volunteer
Holger Allroggen	Neurologist
Jackie Roberts	ESNA
Jacquie Kemp	National Programme of Care Senior Manager
Oli Williams	Liva Nova
Jane Hanna	Chief Exec – SUDEP Action
Jane Kachika	LD Nurse, NHSE Program Manager for Pathway
John Forsey	Liva Nova
Jon Dickson	GPwSI and researcher
Julie Riley	Walton Vanguard
Juliet Ashton	ESN Norfolk
Katie Dowden	Public Health England, Public Health Intelligence Analyst
Linda Mayhew	Epilepsy Action Volunteer
Lucy Hawkins	Senior Consultant, The Strategy Unit
Maggie Tristram	ESN Oxford
Manny Bagary	Consultant Neuropsychiatrist, ILAE
Melissa Maguire	Neurologist
Michael Jackson	Head of Health Intelligence, Public Health England
Naheed Rana	RightCare
Nichole Taske	NICE
Nicola Adamson	Commissioner – NHS England

Nigel Bennett	Epilepsy Action Volunteer
Paul Eldridge	Neurosurgeon
Paul May	President of the SBNS
Peter Cavanagh	RightCare
Priya Oomahdat	Head of Neuroscience Transformation Programme
Rachel Turner	Epilepsy Action Volunteer
Rhys Thomas	Neurologist
Richard Selway	Neurosurgeon
Rob Thomas	National Policy Lead UCB
Rohit Shanker	Consultant in Adult Developmental Neuropsychiatry, Exeter Medical School
Rosemarie Pardington	Director of Integrated Care, Young Epilepsy
Sam McIntyre	Emergency Medicine
Sammy Ashby	Director of Policy & Development, SUDEP Action
Sarah Vibert	Chief Executive Neurological Alliance
Tony Marson	The Walton Centre
Vittoria Polito	Pathways Lead, Right Care

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