

Divisions Affected – All

CABINET

19 November 2024

Epilepsy Services

Report of the Oxfordshire Joint Health Overview and Scrutiny Committee

RECOMMENDATION

1. The Cabinet is **RECOMMENDED** to —
 - a) note the recommendation of the Oxfordshire Joint Health and Overview Scrutiny Committee:

“For Oxfordshire County Council Cabinet members and senior officers responsible for education and residential care for children and adults with Learning Disabilities and/or autism (who are affected by patient safety concerns), and those responsible for public health; to consider the likely impacts of the valproate policy for the local authority commissioning arrangements and the provision of safe residential care and out of county placements. It is also recommended that the Cabinet member for Public Health and Director of Public Health to consider the epilepsy population as part of the Council’s programme to tackle public health inequalities.”
 - b) Having noted the recommendation above to consider and determine a suitable response to the Oxfordshire Joint Health and Overview Scrutiny Committee

REQUIREMENT TO RESPOND

2. The Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.

INTRODUCTION AND OVERVIEW

3. At its meeting on 12 September 2024, the Oxfordshire Joint Health and Overview Scrutiny Committee (HOSC) received reports providing an update on epilepsy services. Two reports were received, one main report from Oxford

University Hospitals NHS Foundation Trust, and another brief report from NHS England South-East. This section provides a brief overview of the recent activities of the Committee around epilepsy as well as around the valproate policy and the background to the recent scrutiny session on 12 September 2024; as well as why this is being brought to the attention of Cabinet at the same time as recommendations have been made to the local NHS and national policymakers.

4. The Committee had received written evidence at its previous public meeting on 16 January 2024 from:
 - SUDEP Action and Epilepsy Action correspondence.
 - Correspondence from Professor Marian Knight, University of Oxford.
5. The letter from Professor Knight, concerned the findings of MBRRACE national surveillance of pregnant mothers and their unborn with a near doubling of sudden deaths against a backdrop of the introduction of the Pregnancy Prevention Programme. The third sector raised a red flag about the likely local safety impacts on residents and impacts on all stakeholders of a new national framework that valproate must not be started in new patients (male or female) younger than 55 years, unless two specialists independently consider and document that there is no other effective or tolerated treatment. It alerted to this being a very dramatic shift in clinical practice https://assets.publishing.service.gov.uk/media/65ae8f33fd784b0010e0c688/January_DSU_PDF.pdf
6. The Committee wrote to Steve Brine MP, Chair of the Parliamentary Health Select Committee in January 2024, requesting national scrutiny of the MHRA alert, the proposed timescales for implementation, the lack of a national impact assessment, and the lack of resources to support the new requirements; and received a response that it was included on the list of potential scrutiny items for the Select Committee.
7. The Committee also liaised with the ICB with a view to an update about the ICB response to the alert and the required local action plan and consideration of the suggestion that delay is sought to implementation because of the severe pressures in the NHS and until adequate resources can be made available to local systems. This was based on an understanding of the likely local impacts.
8. In April 2024, the ICB updated the Committee that a task force comprising consultants, specialist nurses, medicines safety officers, and representatives from charities and patients with lived experience had worked on a local impact assessment. In April, the Committee received the ICB local impact assessment on the MHRA Pregnancy Prevention Update November 2023. The impact report that was shared with Committee members and the public outlined that there were unavoidable consequences, and current services were ill-equipped to handle the implementation. Specifically, it was anticipated that approximately 2855 outpatient appointments would be lost due to the new requirements and predicted increased mortality and greater co-morbidity including emergency situations.

9. The Committee wrote to Victoria Atkins MP, the then Secretary of State for Health (copied to the Chair of the Parliamentary Health Select Committee), to bring the local ICB impact assessment to her attention and to request that until the likely impacts and risks of phase 1 of the policy are assessed and safety addressed, that they allow the local NHS to delay implementation. The Committee received a response from the Department of Health that due to the General Election, this would have to be brought to attention after this had happened.
10. The Committee felt it crucial to receive an update on the current state of epilepsy services, and national and local contexts in which this service operates.
11. Between the January update and the Scrutiny item on 12 September, the MHRA issued a second update extending the Pregnancy Prevention Programme to another anti-seizure medication Topiramate <https://www.gov.uk/drug-safety-update/topiramate-topamax-introduction-of-new-safety-measures-including-a-pregnancy-prevention-programme>. In September there was an announcement of a third update, this time adding requirements for boys and men additional to those that were announced in January and applying the September update to all boys and men regardless of age <https://www.gov.uk/drug-safety-update/valproate-use-in-men-as-a-precaution-men-and-their-partners-should-use-effective-contraception>
12. This item was scrutinised by HOSC given that it has a constitutional remit over all aspects of health as a whole; and this includes the availability or accessibility of epilepsy services, as well as the national and local impacts of the Pregnancy Prevention Programme valproate policy. Upon commissioning this item, some of the points the Committee sought to investigate involved the following:
 - The effects of epilepsy as a condition on patients and families; and the health inequalities implications surrounding this.
 - Whether there are any high-risk groups that have been identified within Oxfordshire.
 - Insights into the Oxfordshire epilepsy workforce, including full-time equivalent neurologists and specialists; and on trends of demands on clinical time and where these pressures stem from.
 - Whether there are any community-based epilepsy services in Oxfordshire (and if there are any GPs with a specialist interest in epilepsy across the County).
 - Details of any training on epilepsy for GPs and community-based professionals.
 - Data on waiting times and any trends against recommended NICE good practice including first seizure clinic; follow-up appointments; new

tertiary patients; as well as waiting times for the ketogenic diet for children with severe epilepsy.

- Insights into the new regulation on Valproate and Topirimate. What the impact on patients will be of the accelerated Valproate regulation.
 - Given that the MHRA also announced that the Prevent programme will apply to Topirimate; what data outcomes are required locally for reporting nationally, and is any other data collected locally on outcomes of patients with epilepsy?
 - Details around the steps taken thus far to progress the Oxford University Hospitals NHS Foundation Trust proposal to consider specialist clinics (including epilepsy) for Wantage Community Hospital. One outcome of coproduction and engagement was that epilepsy was included in the long list this year that was shared with the public in July.
 - Who is leading on patient safety and at what levels of governance locally has consideration and assurance been given of the patient safety of people with epilepsy and their families including the adequacy of resource, funding, workforce and training for the Oxfordshire epilepsy service (in light of population-health needs and the added work and nature of the MHRA regulations on Valproate and Topirimate, and the context of medicines shortages).
 - The support being provided to tackle sudden death in epilepsy, suicide and other epilepsy-related premature mortality in Oxfordshire.
 - Whether there are any plans to continue to develop and to improve epilepsy services moving forward, and if there is any planned coproduction with the voluntary sector in Oxfordshire and patients with epilepsy and their families.
13. A summary of the 12 September scrutiny session, key observations and considerations follow that the Committee urges the Cabinet and senior officers to give consideration to in respect of the impacts on Oxfordshire residents and local authority services. This is because it became clear from HOSC scrutiny that there were especially severe local impacts due to poor provision of the epilepsy service and because of unfunded and unbalanced national mandatory policies. It was considered important this was brought to the attention of Cabinet and senior officers who are responsible for commissioning and provider arrangements for children and adults of people with epilepsy with learning disability or autism; and because of public health responsibilities relating to this population that is experiencing serious and worsening health inequalities.
14. These observations also informed a separate set of recommendations that have been issued to the BOB Integrated Care Board, Oxford University Hospitals NHS Foundation Trust, and NHS England South East region (The committee

has also written with recommendations to Karin Smyth MP, health minister and to Layla Moran MP, Chair of the Parliamentary Health and Social Care Committee).

SUMMARY

15. The Committee would like to express thanks to Professor Arjune Sen (Consultant Neurologist, OUH), Jackie Roberts (Lead Learning Disability Epilepsy Specialist Nurse, OUH), Rohini Rattihalli (Consultant Paediatric Medicine, OUH), Marcus Neale (Epilepsy Specialist Nurse, OUH), Rustam Rea (Consultant, OUH), Jane Adcock (Consultant Neurologist, OUH), Janice Craig (Medicines Optimisation Lead Pharmacist, NICE Medicines and Prescribing Associate, BOB ICB), Rachael Corser (Chief Nurse, BOB ICB) and Sarah Fishburn (Senior Clinical Quality Improvement Manager, NHS England) for attending the meeting and answering questions from the Committee on the topic of epilepsy services.
16. Kristi McDonald, a registered speaker, shared her personal experience with epilepsy and the impact of the new Pregnancy Prevention regulations on her life. She highlighted the severe neglect and ignorance faced by epilepsy patients. She described the complexities of living with epilepsy, the mental health impacts, and the recent tightening of policies on sodium valproate and topiramate. She criticised the policy for stripping away informed consent and shared decision-making and breaching human rights, sharing examples of how the policy had harmed other patients.
17. The Committee then asked Professor Sen to introduce the epilepsy team and provide an overview of epilepsy and the service. The Consultant Neurologist explained that everyone experiences abnormal electrical discharges in the brain and that 1 in ten will experience a seizure in their lifetime requiring investigation. Epilepsy is a neurological disorder characterized by a network of electrical discharges which leads to recurrent seizures. It is a largely hidden disability. Each individual is likely to have some known triggers to seizures and the worsening of risk factors can be flagged and mitigated. The epilepsies often carry significant associated co-morbidities and when not well managed a large socio-economic impact.
18. There were significant and escalating demands on the service, including severe shortages of specialist nurses and neurologists and long waiting times for patients. OUH serves a local population of 762,500 (and additional tertiary 2 million catchment) with waiting lists that are not safe for patients. NICE recommends a two-week waiting time for a first seizure, but at OUH this is a 9 month wait (tertiary referral one year). Children with epilepsy not controlled by medication who could benefit from the Ketogenic diet are waiting 3 years. New referrals to the epilepsy nurse service had tripled and requests from GPs for written guidance and letters had increased ten-fold in 3 years.
19. Access to treatment and anti-seizure medications has become extremely challenging. There were shortages of anti-seizure medications with some

patients in Oxfordshire having to travel a long distance two weeks before their medicine was due so as not to run out of a source of supply.

20. Most concerning was the vast impact from the Medicines and Healthcare products Regulatory Agency (MHRA) regulations on the service, including the need for additional patient appointments and two clinical signatures (including a review of all patients who are seizure-free with a view to switching of medication from Valproate or Topiramate anti-seizure medications). The numbers of prescriptions are closely monitored. Clinicians confirmed the ICB local impact assessment report which had found an inequality of access to medication by girls and women and the likely harms. The consultant paediatrician spoke of the harrowing experience of a sister and a brother both living with epilepsy but with the sister experiencing physical and mental health crisis because of lack of access to Valproate <https://www.channel4.com/news/fears-over-dangerous-change-in-prescription-rules-for-epilepsy-drug>.
21. The Oxfordshire epilepsy clinical team were now undertaking excessive working during periods of leave, early mornings and late evenings because of these national demands and the welfare of the team was affected. There were immediate impacts and there was the enduring impact direct and indirect on patient safety and on recruitment and retention. The programme was also now extended to boys and men for the first time effecting 1045 boys and men in Oxfordshire and neither this or the extension of the programme to Topiramate had yet been factored in to any consideration of what was needed to sustain the service. The Oxfordshire epilepsy service was not in a position to implement safely.
22. There were only 2 full-time equivalent neurologists in the service. Whilst NICE recommends 9 epilepsy specialist nurses per 500,000 the Oxford service only has 3.6. The Committee received evidence that there was extremely poor provision for the Oxfordshire epilepsy service compared with other OUH services for similar 'cliff-edge' long-term conditions and that it also fared very badly in comparison with similar services elsewhere like Sheffield. The Committee asked why the Oxfordshire epilepsy team was significantly under-resourced compared to other areas with similar populations, and what the historical context and funding situation behind this disparity were. The Epilepsy Specialist Nurse and the consultants reflected on the historical inequalities between epilepsy and neurology and other conditions and the postcode lottery across the UK since the late 1990s and the increasing complexities around epilepsy service commissioning. Despite prioritising patient care, the nurse highlighted the difficulties in sustaining services due to insufficient resources, staffing, and funding; especially when national programmes like the Pregnancy Prevention Programme did not come with national funding.
23. The Committee asked about the potential for improving services and NHS performance on epilepsy. The Epilepsy Specialist Nurse discussed the setup of a satellite clinic in Brackley, which reduced travel times for patients significantly. The epilepsy team had worked in co-production with a population in South Oxfordshire to produce an outline plan of how a community-based clinic in

Oxfordshire could benefit patients and staff during 2025 but would need workforce capacity to progress this. Progressing this plan was now negatively impacted by the requirement of two clinical signatures and additional appointments mandated nationally.

24. The Committee asked about the rise in demand for services for patients with learning disabilities and epilepsy. The Lead Learning Disability Epilepsy Specialist Nurse had been working closely with Oxford Health and Oxford University Hospitals to streamline services for patients in Oxfordshire. There were two learning disability teams, each with experienced Band 6 and Band 7 nurses. These teams primarily supported individuals with epilepsy and other health conditions, ensuring medication compliance and addressing potential risks like SUDEP. A significant focus of her concern was on the challenge of transition from childrens' to adult services, with more action needed to facilitate smooth transitions through transition clinics.
25. The Consultant Paediatrician spoke about the complexities of managing epilepsy in children, particularly those with learning disabilities and particularly with the confusion and complexity of communications with parents concerning the Pregnancy Prevention Programme. She discussed the need for personalised risk-benefit assessments for patients and the lack of a national framework to guide these decisions at the same time that there was a mandatory national framework for protection of a future unborn population.
26. There were widespread and shared concerns across all witnesses about the accelerations to the Pregnancy Prevention Programme including the governance processes at the MHRA. The Committee received evidence from one of the epilepsy clinical leads for NICE who spoke about the robust governance processes required at NICE when making recommendations about clinical practice and about medicines. NICE required a public and transparent evidence-based process from the start which involved third sector patient and clinical stakeholders and public consultation over a prolonged period. The Committee heard from the clinical team and from patients that this hadn't happened with the MHRA Pregnancy Prevention Programme Updates and that when there was stakeholder engagement it was on implementation including materials for updates. The feedback from patient organisations was ignored on most and certainly on critical aspects. These included that the aggregated regulation and national materials were mandatory without regard for different and especially vulnerable populations e.g. for children, the LGBTQ community and people with learning disability and epilepsy.
27. Kristi McDonald said that the national regulations and patient materials were unbalanced and felt hostile to living patients with a worsening of stigma and discrimination. The national framework and materials were not inclusive of patient preferences and there was no right of appeal. The MHRA national framework and NHS ignored essential information and existing safety empowerment tools valued by herself and other patients and recommended by MBRRACE and NHS RightCare Epilepsy Toolkit. The clinical team was clear professional organisations had complained too. The processes did not however allow for public transparency on stakeholder feedback. The Committee noted

evidence from a patient that in a recent MHRA private briefing session accountability was explained as ministerial and across the whole health ecosystem but that accountability for individualised decisions made under the policy rested with clinicians. The Committee heard about widespread international concern that the UK Pregnancy Prevention Programme was now extreme with insufficient evidence and without a national framework to ensure proportionality with patient safety needs and the preferences of the individual.

28. The Committee asked the Medicines Optimisation Lead Pharmacist and the Senior Clinical Quality Improvement Manager at NHS England about the impact of the accelerated mandatory MHRA policies. The NHSE manager explained she had been specially seconded and was spending most of her time on it because of the impacts and complexities. The development of strong teamwork across the region and the ICB and all stakeholders had been encouraging with shared understanding of negative local impacts and development of local mitigations where these were possible. There had been whole system escalation to the NHS and MHRA because the increase in clinical and administrative workload across specialist and community NHS providers from the national mandatory requirements had not been funded and because of widespread and shared concerns across the South-East Region about undermining of basic NHS principles of informed consent, shared and balanced decision-making, evidence-based decision-making, transparency and impact on medication choices, family planning, patient safety and health inequalities.
29. The NHSE said they had met with families across the South-East that had been denied Valproate and had received evidence of patient harms from stakeholders. Access to the MHRA was difficult but they had now been informed that MHRA focused on drug safety, stating that while they regulate medication, it is the NHS's responsibility to implement these regulations and deal with impacts. The risk to the local NHS identified by the ICB local impact statement on severe local impacts on waiting lists, the service and residents was on the divisional risk register and was highlighted regularly at national meetings. At a recent national meeting the focus was on reduction of prescribing and absence of any balancing metric including outcomes for patients. The NHSE gave evidence they had written to all professional regulators and had requested clarity on accountability. The GMC had responded that regarding clinicians they would take account of exercise of the duty of candour and raising of concerns at an institutional level.

KEY POINTS OF OBSERVATION:

30. Below are some key points/themes of observation that the Committee has in relation to epilepsy services. These points of observation relate to some of the themes of discussion during the meeting on 12 September, and have also been used to shape the recommendation being made by the Committee to Cabinet.
31. The Committee recognised that all people experience abnormal electrical brain discharges and that 1 in 10 people will experience a seizure in their lifetime that will need investigation, but that with someone diagnosed with epilepsy it is a network of electrical discharges. Seizures can range from brief lapses of

attention called absence seizures to full convulsive or generalised seizures. The place and the time of day or night are important. Each person may experience different triggers for their epilepsy and will have a different exposure to safety issues.

32. Whilst there are over forty different types of epilepsy 70% of people can be seizure-free if properly diagnosed and treated. Yet the World Health Organisation report had highlighted epilepsy as a public health emergency in 2021 [Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology](#). The World Health Organization (WHO) has identified a significant treatment gap in epilepsy care, particularly in low- and middle-income countries, where up to 75% of people with epilepsy may not receive the treatment they need¹.
33. Public Health England found deaths in neurology with an increasing trend pre-pandemic when all other causes fell. Deaths in epilepsy were premature and three times more likely in deprived areas and a recent systematic review in the Lancet found this was the case for mid and high deprivation areas. https://assets.publishing.service.gov.uk/media/5a941945e5274a5b87c2fe47/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf
<https://www.sciencedirect.com/science/article/pii/S2468266724001324>
34. The report by Economist impact in 2024 found neurology clinics struggling more than other NHS services with waiting lists raising by 76% between 2021 and 2023 [Neurology crisis costing UK £96bn – Economist report \(epilepsy.org.uk\)](#) showing that the availability of such specialists is seriously limited, even in high-income places and the Committee found that the Oxford epilepsy service was especially poorly served when contrasted with other similar services across the UK and with Western Europe where there was a ratio of 1 neurologist per 12,000 population.
35. The Committee recognises epilepsy as a treatable ‘cliff-edge condition’ affecting 1 per cent of the population that often presents as an emergency (or sudden fatality for at least 21 people a week ([EB | Epilepsy & Behavior | Prevent 21: SUDEP Summit | ScienceDirect.com by Elsevier](#))). Deaths can result from Sudden Unexpected Death in Epilepsy (SUDEP) or from accident or status or suicide. The Committee heard evidence from lived experience that empowerment of people living with the condition and their families is a priority, but that awareness and support for people having access to good practice safety communication tools from the third sector was not happening. This meant that people living with epilepsy and health and care professionals were not being helped to appreciate individualised worsening of risk factors for Sudden Unexpected Death in Epilepsy (where an otherwise healthy person with epilepsy would die suddenly, often in their sleep), or risks of injuries, accidents and/or deteriorating mental health drowning or suicide so that there could be a plan to mitigate.

¹ [New WHO brief sets out actions needed to improve lives of people with epilepsy](#)

36. The impact of epilepsy extends beyond the seizures themselves. Children and adults also face absence from school, loss of driving licence, loss of employment and emergencies due to physical and mental health crisis. Stigmatisation, discrimination, mental health issues such as anxiety and depression are well established. Children experience severe inequalities <https://www.rcpch.ac.uk/resources/epilepsy12-round-3-methodology-datasets> and in 2024 epilepsy was included in Core20PLUS5 as a priority for tackling health inequalities in children <https://www.england.nhs.uk/wp-content/uploads/2022/11/core20plus5-cyp-infographic-v2.pdf>
37. 53% of people with epilepsy are economically inactive far worse than for autism, severe learning disabilities and mental health conditions; and this is not related to skills or qualifications <https://www.epilepsy.org.uk/news/high-rate-of-economic-inactivity-in-epilepsy>
38. The Midlands region has prioritised epilepsy and in people with learning disability and autism. 1 in 5 people with learning disability or autism have epilepsy. This population dies ten years younger than people with a learning disability or autism with another co-morbidity and has taken action <https://www.england.nhs.uk/midlands/2023/11/15/nhs-england-funded-project-aims-to-reduce-the-epilepsy-risks-faced-by-people-with-learning-disabilities/>, <https://sudep.org/epilepsy-safety/learning-disability-resources/>. The need for a focus on prevention in the community and avoidance of A and E and costly inpatient settings for people with learning disability and autism is at the core of the Oxfordshire charity supporting campaigners with learning disability with their 'Don't lock me up' and 'We can't wait' campaigns <https://mylifemychoice.org.uk/campaigns/>. The Committee heard that children and adults with a learning disability are likely to find the MHRA accelerated regulations on the Pregnancy Prevention Programme confusing and given this group is at high risk from their epilepsy the impacts need consideration and management because they are significant.
39. A recent national confidential enquiry into adult patients presenting to A and E found a gap in risk check, communication and follow up action for the many thousands of adults with epilepsy who present to and who are then discharged back into the community [NCEPOD - Epilepsy: \(2022\)](#). 1% of A and E attendances are for epilepsy, 30% of patients did not receive any advice. For patients who had not seen a specialist in the previous 12 months the referral rate was only 35%, a lower rate than those who had. 23% were on no medication for their seizures and 44% only on one medication <https://www.nashstudy.org.uk/> Adults also face loss of driving licence, loss of employment and emergencies due to both physical and mental health crisis.
40. Access to the right medication at the right time needs urgently to be improved as the impact of not accessing this can be catastrophic. Medication needs to be personalised as it can take some years for patients to have their epilepsy stabilised. National guidance on switching across different versions of the same drug is clear that for one category of medication there should be maintenance of supply and for another category the need for supply should be based on clinical judgement and consultation with patient and/or carer, taking into account factors such as seizure frequency and treatment history and

patient/carer-related factors <https://www.gov.uk/drug-safety-update/antiepileptic-drugs-updated-advice-on-switching-between-different-manufacturers-products>. However the Committee found there is no national framework to guide the switching or non-commencement of Valproate or Topirimate in children and adults who have seizures that are likely to respond most effectively to Valproate or Topirimate.

41. Based on the written and verbal evidence given to the committee, there was strong evidence supporting that the patient safety risks and shortfalls in epilepsy workforce are worsening because of the national Pregnancy Prevention Programme which has accelerated with three updates since 2024 restricting access to anti-seizure medications Valproate (January and September) and Topirimate (June). In addition to the summary of evidence we noted:
- a. Valproate taken whilst pregnant is one of medications that carries a high teratogenic potential with a 11% risk of congenital malformations and a 30-40% risk of neurodevelopmental disorders.
 - b. A systematic review in June 2024 of 923 studies was amongst other scientific papers this year which found reassuring evidence that paternal exposure to anti-seizure medication at conception is unlikely to pose any major risk of adverse outcomes for the unborn and there was insufficient evidence for regulatory action <https://jnp.bmj.com/content/early/2024/08/17/jnp-2024-334077.abstract>; [Paternal Valproate Treatment and Risk of Childhood Neurodevelopmental Disorders: Precautionary Regulatory Measures Are Insufficiently Substantiated - Garey - 2024 - Birth Defects Research - Wiley Online Library](#).
 - c. Valproate also happens to be the most potent medication to treat generalised epilepsies should girls and women have preferences to be safe from SUDEP and other harms and able to lead their best lives [The SANAD study of effectiveness of valproate, lamotrigine, or topiramate for generalised and unclassifiable epilepsy: an unblinded randomised controlled trial - The Lancet](#); <https://pubmed.ncbi.nlm.nih.gov/31831600/>.
 - d. A study in Brain 2024 is noted which found the risk of emergency attendance, hospital admission, injuries, burns and new on-set depression was 1 to 7% higher for patients withdrawn from valproate than in those remaining ON valproate <https://academic.oup.com/brain/article/147/10/3426/7657740>; and a paper in the Journal of Neurology in June 2024 estimated that 21,000–28000 people in the UK will be exposed to the potential hazards of breakthrough seizures. <https://link.springer.com/article/10.1007/s00415-024-12436>
 - e. The evidence from lived experience at HOSC is also supported by a thematic examination of the voices of 19 people with epilepsy and their lived experience of the direct damage of avoiding valproate or

42. There was unanimous recognition from HOSC of the need for urgent action in support of Oxfordshire residents living with epilepsy and their families, and to mitigate the serious health inequalities identified and to request the Cabinet and senior officers to consider the local impacts from the perspective of the local authority with a view to supporting visibility, inclusion and improvement:

Below are two more specific observations that the Committee has, which have shaped recommendations being made to the NHS, as well as the recommendation being made to cabinet:

A. Securing more resource for epilepsy services:

This all underscores the need for inclusion of epilepsy in work programmes of the NHS and local authorities as part of tackling inequalities in commissioning and provision of care and support for people to live their best lives. Improved awareness across the system would help tackle the invisibility of this population that has always had limited access to services and which have worsened further as a result of escalating demands and national policies on medicines. More resources to train healthcare and residential providers in epilepsy care and to even explore the potential establishment of comprehensive care centres with view to:

Improved outcomes- Early and accurate diagnosis would mean 7 out of 10 people would be seizure free on the right medication and could be managed well in the community. This would mean increased capacity to support treatment and care of people needing interventions to reduce the frequency and severity of seizures. This, in turn, enhances the overall quality of life for individuals with epilepsy and their families.

Reducing the treatment gap and health inequalities have been identified nationally and by the WHO- By ensuring that more individuals have access to the necessary medications and care, we can move towards equitable healthcare for all people with epilepsy, regardless of their geographic location or socioeconomic status.

Reducing mental health burden- Epilepsy often coexists with mental health conditions, making integrated care essential. Allocating resources to provide mental health support within an epilepsy service better integrated into primary care and the community can address the psychological and emotional needs of patients, leading to better overall health outcomes.

Economic benefits- Enabling individuals with epilepsy to lead productive lives, will increase workforce participation and reduce school absences. Securing more resources for epilepsy services can also contribute to reducing the stigma associated with the condition. Targeted public awareness campaigns and education programs with schools, workplaces, citizen advice centres and the public can change societal attitudes and promote understanding and

acceptance of epilepsy and support so that epilepsy is recognised as a disability and one that will only require minimal reasonable adjustment. This, in turn, can lead to more inclusive communities and workplaces. Proper support for children and adults with learning disability with epilepsy and autism or both to access the intervention they need for their epilepsy and their wider educational needs in the community close to their family will reduce the need for expensive out of county placements or special need schools. Effective epilepsy management can reduce healthcare costs associated with emergency care and hospitalizations. 1 in 5 people with learning disability and/or autism has epilepsy and the co-morbidities of epilepsy include mental health and for the older population stroke. Identifying risk in A and E and developing community-based prevention would decrease admissions, which can be lengthy for the most vulnerable group within this population. Therefore, the importance of securing further resources for epilepsy services cannot be overstated. From improving patient outcomes and reducing the treatment gap to fostering societal acceptance and economic benefits, the advantages are manifold. By prioritising epilepsy care and investing in the necessary resources, we can enhance the lives of millions of individuals living with epilepsy and build a more inclusive and compassionate society.

B. Prioritising patient safety:

Managing epilepsy involves not only addressing the medical aspects but also ensuring patient safety, which is paramount for both those affected and their families.

For the general population with epilepsy, it is critical that cultural assumptions and myths are tackled. It is vital for there to be signposting to awareness of empowerment information and tools to support engagement with the public sector, especially the NHS, local authorities, schools, and with employers, and to support self-care and support with risk assessments and reasonable adjustments where these are needed, or a safe home environment. There are very few things that just because you have epilepsy you cannot do e.g. working at heights, around unguarded machinery or near open unsupervised water.

For people with learning disability or autism and epilepsy it is also important that cultural assumptions and myths are tackled and treatment and care is individualised and based on accurate information about epilepsy:

SEND and schools: mental health and SEND staff awareness of third sector support for families and for schools.

Commissioning and providing of residential care: awareness of good practice guidelines

Annual Learning Disability Check to include use of existing digitalised patient safety check.

Safe Environment: Modification of the home environment to reduce hazards, such as installing a shower instead of a bath, adjustments in the kitchen and

advice on high-risk activities e.g. climbing a ladder. Consideration of interventions such as information on range of night monitors.

Additionally, according to a study published in the journal of Epilepsy and Behaviour, epilepsy can have profound impacts on mental and emotional health².

The committee also heard from lived experience about how existing anxieties about seizures and social stigma and discrimination had worsened with recent national policy and how the emotional toll on families was significant. Anti-epileptic drugs (AEDs) are a cornerstone of epilepsy treatment. Access to the right medicine at the right time and adherence to prescribed medication regimens is vital for controlling seizures. Steps to enhance medication safety could include:

- Education health and care professionals: Improved awareness across professionals who work in community based or emergency settings who may be alongside people with epilepsy of the importance of ensuring the patient is at the centre of decision-making, and of SUDEP and other epilepsy risks, and the positive impacts of care that includes the patient benefiting from the right medication in a timely way and other interventions and support if needed. Consideration of multi-disciplinary support including peer group support, counselling and therapy to help mitigate psychological impacts.
- Education for patients and families: Educating the patient, family, and community about epilepsy can reduce stigma and foster a more supportive environment. Signposting to information and empowerment tools to support self-advocacy, self-care and open communication with healthcare providers about any issues or changes in seizure patterns. Signposting to support networks available to access peer group support and practice advice.

RECOMMENDATION:

43. In light of the evidence received by the Committee, as well as the key observations highlighted above, the JHOSC issues the following recommendation to Oxfordshire County Council's Cabinet:

For Oxfordshire County Council Cabinet members and senior officers responsible for education and residential care for children and adults with Learning Disabilities and/or autism (who are affected by patient safety concerns), and those responsible for public health; to consider the likely impacts of the valproate policy for the local authority commissioning arrangements and the provision of safe residential care and out of county placements. It is also recommended that the Cabinet member for Public Health and Director of Public Health to consider the epilepsy population as part of the Council's programme to tackle public health inequalities.

² [EB | Epilepsy & Behavior | Journal | ScienceDirect.com by Elsevier](#)

LEGAL IMPLICATIONS

44. Under Part 6.2 (13) (a) of the Constitution Scrutiny has the following power: 'Once a Scrutiny Committee has completed its deliberations on any matter a formal report may be prepared on behalf of the Committee and when agreed by them the Proper Officer will normally refer it to the Cabinet for consideration.
45. Under Part 4.2 of the Constitution, the Cabinet Procedure Rules, s 2 (3) iv) the Cabinet will consider any reports from Scrutiny Committees.
46. The Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the Committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.
47. ”

Anita Bradley
Director of Law and Governance

Annex: 1 Scrutiny Response Pro Forma

Background papers: None

Other Documents: None

Contact Officer: Dr Omid Nouri
Scrutiny Officer (Health)
omid.nouri@oxfordshire.gov.uk
Tel: 07729081160

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