Parallel Session 1:
Epilepsy
Wed 6 May, 14:45 - 15:45
Hall 1

1. Validation of the Scottish Epilepsy Deaths Study Score (SEDSS) Using Routinely Collected Data in Wales: **Srishti Tripathi**
2. Compliance with MHRA Valproate Pregnancy Prevention Guidelines: A Retrospective Audit in a UK Neurology Service: **Julian Kurz**
3. Systematic review of under- and over-reporting of seizures in epilepsy: prevalence, mechanisms and clinical implications: **Naveen Kumar**
4. The association between deprivation and incident epilepsy in Wales; A population-level study of 2.4-million people: **Kathryn Bush**
5. An international cohort study of valproate and infertility in men with epilepsy or bipolar disorder: **Gashirai Mbizvo**
6. Vulnerability factors for non-epileptic seizures in patients with epilepsy – a retrospective cross-sectional study: **Benjamin Sacks**

Validation of the Scottish Epilepsy Deaths Study Score (SEDSS) Using Routinely Collected Data in Wales

Tripathi S[2], Daniels H[1], Lacey A[1], Mbizvo G[3,4,5], Duncan S[6], Pickrell O[1,7], Chin R[6,8]

[1]Swansea University Medical School, [2]Queen's University, [3]Liverpool Interdisciplinary Neuroscience Centre, University of Liverpool, [4]Pharmacology and Therapeutics, Institute of Systems, Molecular and Integrative Biology, University of Liverpool, [5]The Walton Centre NHS Foundation Trust, [6]Muir Maxwell Epilepsy Centre, Institute for Neuroscience and Cardiovascular Research, The University of Edinburgh, [7]Morriston Hospital, Swansea Bay University Health Board, [8]Neurosciences Unit, Royal Hospital for Children and Young People

Background: The Scottish Epilepsy Deaths Study Score (SEDSS) was developed to identify individuals at increased risk of epilepsy-related death. We externally validated SEDSS within the Welsh Population using the Secure Anonymised Information Linkage databank.

Methods: A retrospective cohort study of adults (≥18 years) with epilepsy living in Wales 2015–2019. Epilepsy-related deaths were defined as deaths with epilepsy recorded on death certificates. SEDSS were calculated for all individuals at the beginning of each study year and used to categorise low, medium, high and very-high risk groups based on individual SEDSS. We used logistic regression to compare odds-ratios (OR) for epilepsy-related death in each of the SEDSS risk groups.

Results: We found 423 epilepsy-related deaths after analysing 114,716 epilepsy person-years. Increasing SEDSS risk categories associated with increasing risk of epilepsy-related death. Odds ratios (95% CI) for epilepsy-related deaths (compared to the reference category (SEDSS=0)) for low, medium, high and very high-risk categories were 4.5(1.6–10.0); 1.3(1.0–1.7); 3.2(2.4–4.3) and 7.6(5.6–10.4) respectively.

Conclusion: SEDSS demonstrates predictive value in identifying individuals at higher risk of epilepsy-related death within the Welsh population. SEDSS performed particularly well for the high and very high-risk categories and may help prioritise targeted preventative interventions

Compliance with MHRA Valproate Pregnancy Prevention Guidelines: A Retrospective Audit in a UK Neurology Service

Kurz J[1], Hasan T[2], Sharma S[1], Munasinghe V[1], Chauhan V[2]

[1]Northern Care Alliance NHS Foundation Trust, [2]Department of Neurology, Manchester Centre for Clinical Neurosciences, Northern Care Alliance NHS Foundation Trust, [3]The University of Manchester, Faculty of Biology Medicine and Health

Background/Aims: Valproate is an effective antiepileptic drug associated with significant teratogenic risk. The Medicines and Healthcare products Regulatory Agency (MHRA) mandates its regular review via Annual Risk Acknowledgement Forms (ARAF). This audit assessed compliance with MHRA guidelines among patients prescribed valproate within the Northern Care Alliance Trust.

Methods: Patients were identified from our Internal Epilepsy Dashboard as of 21 February 2025. Electronic patient records (EPR) were reviewed for annual evidence of ARAF completion and contraceptive status over the preceding 8 years.

Results: Among 298 female patients (mean age 38 years), 83% had documented counselling on valproate-associated risks within the last 12 months. Over 8 years, evidence of at least one ARAF was present in 85% of patients, with 57% having a double-signed ARAF; only 1 patient had this performed annually. There was no scanned evidence of an ARAF completed in 26% of patients. Only 56% were using contraception; non-use was primarily attributed to severe learning disabilities (62%) or patient choice (24%).

Conclusions:Despite counselling women on valproate's risks, annual ARAF compliance is suboptimal. Enhanced digital systems for ARAF completion are required to improve outcomes and to aid structured contraception counselling. A significant proportion of patients decline contraception, despite knowing risks.

Systematic review of under- and over-reporting of seizures in epilepsy: prevalence, mechanisms and clinical implications

Kumar N[1], Pizarro J[2], Kandasamy R[3], Walker M[2,4], Yogarajah M[5]

[1]Department of Neurology, King's College Hospital, [2]Chalfont Centre for Epilepsy, Chalfont St Peter, [3]Department of Clinical Neurophysiology, The National Hospital for Neurology & Neurosurgery, [4]Department of Clinical and Experimental Epilepsy, UCL Queen Square Institute of Neurology, [5]Institute of Neurology, Queen Square

Introduction: Seizure frequency guides clinical decisions, driving advice, and trial endpoints, yet commonly patients both under- and over-report. Under-reporting may reflect impaired awareness/recall, but this cannot explain over-reporting. This review aims to quantify misreporting and discuss possible mechanisms. We hypothesised that disrupted interoception biases both missed and false-positive seizure judgements.

Methods: Following PRISMA (2020) standards, we searched Medline, Embase, and PsycINFO (1990–present) for articles comparing patient-reported to EEG-determined seizure frequency. Article screening/data extraction were completed in duplicate. Proposed mechanisms were synthesised within a predictive-processing framework, using published interoception data in epilepsy and pilot diary–EEG-interoceptive concordance analyses.

Results: Twenty-eight studies were included. 60% (24%-85.8%) of seizures were unreported and 58% (23%-87%) were over-reported. Under-reporting was highest for nocturnal and impaired-awareness seizures, while over-reporting was commonest with absence-type seizures. Interoception data indicate people with epilepsy show reduced interoceptive accuracy but increased bodily sensibility, risking both missed ictal cues and misattribution of events. In telemetry-linked analyses, poorer interoception was associated with lower reporting accuracy (U=41, one-tailed p=0.028).

Conclusion: Seizure misreporting is highly prevalent and bi-directional. Altered interoception may contribute to unrecognised or misattributed seizures, providing a parsimonious mechanism for seizure misreporting, and highlighting potential markers to identify patients at risk of diary inaccuracy.

The association between deprivation and incident epilepsy in Wales; A population-level study of 2.4-million people

Bush K[1], Fonferko-Shadrach B[2], Strafford H[2], Ramsay S[1], Kingston A[1], Thomas R[1], Pickrell O[2]

[1]Newcastle University, [2]Swansea University

There is an association between socioeconomic deprivation and epilepsy in the United Kingdom, with the highest rates observed in the most deprived areas. These unjust and preventable differences represent health-inequalities. We aim to further understand the association between deprivation and incident epilepsy by classifying cases by aetiology.

This cohort study follows 2.4million individuals, with Welsh GP registration on the 2011 census date. Conducted within the Secure Anonymised Information Linkage (SAIL) Databank, between 2011–2024, using health, death, census (household-deprivation scores) and area-level demographic data (Welsh Index of Multiple Deprivation deciles). Epilepsy cases are classified by aetiology: Genetic/mitochondrial/chromosomal, syndromes, non-preventable and preventable. Cox-proportional hazard (CPH) ratios calculate incident epilepsy risk.

We observed 17,455 incident epilepsy cases; Age/sex/rural-urban CPH adjusted hazard ratios (AHR) for incident epilepsy in the most deprived households versus least were: AHR:3.04 (95%(Confidence interval)CI:2.38-3.90). By aetiology, the highest epilepsy risk in the most deprived households versus least were: genetic-epilepsies: AHR:15.00(95%CI:10.69-21.07) and preventable-epilepsies AHR:6.55(95%CI:4.65-9.21).

We describe significant socioeconomic inequalities in incident epilepsy, using household-deprivation measures predating epilepsy. The highest risk is for genetic epilepsies and epilepsies with preventable aetiologies. We hypothesise the high genetic risk reflects reverse-causation. Focus upon strategies reducing preventable aetiologies may reduce both epilepsy incidence and inequalities.

An international cohort study of valproate and infertility in men with epilepsy or bipolar disorder

Mbizvo G[1], Duncan S[2], Nancarrow L[1], Sagarino T[3], Watkins L[4], Mbizvo M[5], Lip G[1], Marson T[1]

[1]The University of Liverpool, [2]Muir Maxwell Epilepsy Centre, Centre for Clinical Brain Sciences, The University of Edinburgh, [3]TriNetX LLC, [4]University of South Wales, 5Reproductive Health Programme, Population Council

Valproate is highly effective at treating epilepsy and bipolar disorder. It faces prescribing restrictions in men due to concerns it causes testicular dysfunction and infertility. These mostly stem from animal models – the human evidence is limited and conflicting.

We report the largest ever retrospective cohort study of infertility in men with epilepsy or bipolar disorder, using real-world healthcare data from TriNetX. 91,917 of the men are exposed to valproate, and 535,803 unexposed. Cohorts are propensity score matched for a comprehensive set of baseline covariates, and survival analysis is undertaken using Cox-proportional hazards models.

No significant difference is seen between valproate-exposed and unexposed men across lifetime risks of infertility, testicular hypofunction, testicular atrophy, and a composite of low sperm concentration, motility, vitality, normal forms, and semen volume ($p > 0.05$).

Our findings do not support an association between valproate and infertility in men with epilepsy or bipolar disorder in real-world settings.

Vulnerability factors for non-epileptic seizures in patients with epilepsy – a retrospective cross-sectional study

Sacks B[1], Chow B[2], Koreki A[2], Kandasamy R[1], Yogarajah M[1]

[1]National Hospital for Neurology & Neurosurgery, Queen Square, London, United Kingdom, [2]University College London, Queen Square Institute of Neurology, Department of Epilepsy

Background: Non-epileptic seizures occur in 5-20% of people with epilepsy, a prevalence substantially higher than the general population. The reasons for this co-occurrence remain unclear and may relate to psychiatric comorbidity, medication exposure, or disease-specific vulnerability factors.

Methods: We compared patients with a confirmed dual diagnosis of epilepsy and NES (n=103) to a control group with epilepsy alone (n=91) at the National Hospital for Neurology & Neurosurgery and Chalfont Centre for Epilepsy. Demographic and clinical characteristics were described, and differences in anti-seizure medication were assessed using propensity score matching and binary logistic regression.

Results: In the dual diagnosis group, mean age at onset was 12.5 years for epilepsy and 31.5 years for NES. Females were significantly over-represented in the dual diagnosis group (76% vs 55%, p = 0.006). Rates of psychiatric comorbidity were high but not significantly different between groups (83.5% vs 79.6%, p = 0.458). No significant anti-seizure medication associations were identified, although lacosamide showed a non-significant trend towards the dual diagnosis group.

Discussion: In this interim analysis, dual diagnosis was associated with female sex but not with psychiatric comorbidity, seizure semiology or anti-seizure medication. Our ongoing work aims to further characterise this cohort and identify potential vulnerability factors.