**SUPPLEMENTARY**

**I. First survey PDF**

PDF attached separately – see email.

**II. Primary and their secondary categories used to process the priorities submitted by the epilepsy community in response to the first survey.**

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| **Primary category: Causes** |
| Hormones |
| Genetics |
| Acquired brain injury |
| Seizures |
| Rare epilepsies |
| Childhood epilepsies (including early onset) |
| SUDEP |
| Age-related epilepsy |
| Late onset epilepsy (adult) |
| Uncontrolled seizures/refractory epilepsy |
| Complex epilepsy |
| Absences |
| Lifestyle (as cause of epilepsy or seizures) |
| Idiopathic epilepsy (epilepsy of unknown cause) |
| Cause general |
| Brain tumour-associated epilepsy |
| Stroke-associated epilepsy |
| Pregnancy (cause) |
| Brain lesions |
| Stress |
| Status epilepticus (including in sleep) |
| Epilepsy-related brain networks |
| Memory loss (cause of) |
| Epilepsy in women |
| Sleep |
| Cognition impairment (cause of) |
| Vascular |
| **Primary category: Diagnosis** |
| Genetic testing |
| Early onset (childhood) |
| Neuroimaging |
| Early diagnosis |
| Accurate diagnosis |
| Diagnosis general |
| Rare epilepsies |
| Diagnostic tools |
| Acquired brain injury |
| Stroke-associated epilepsy |
| Targeted diagnosis |
| Personalised/precision |
| EEG (including video-EEG) |
| **Primary category: Prognosis** |
| Life expectancy |
| Hormones (impact of) |
| Quality of life |
| Seizure changes |
| Mental health |
| Seizure control |
| Memory |
| Rare epilepsies |
| Ageing |
| Cognition |
| Uncontrolled seizures/refractory epilepsy |
| General long-term impact of epilepsy (including treatment) |
| Prognosis general |
| Treatment |
| Neurodevelopment |
| Accurate prognosis |
| Acquired brain injury |
| Brain tumour-associated epilepsy |
| Status epilepticus (including in sleep) |
| Stroke-associated epilepsy |
| Epilepsy in women |
| Genetics |
| Seizure pattern |
| **Primary category: Prevention** |
| SUDEP |
| Epilepsy (prevention) |
| Seizures |
| Acquired brain injury |
| Prevention general |
| Status epilepticus (including in sleep) |
| Pregnancy mortality |
| Impact on neurodevelopment |
| Memory loss |
| Mental health (including suicide) |
| **Primary category: Treatment** |
| Personalised/precision |
| Status epilepticus (including in sleep) |
| Uncontrolled seizures/refractory epilepsy |
| Early treatment |
| AEDs in pregnancy  |
| Seizures |
| AEDs/ASMs |
| Non-pharmacological (including diet, exercise, etc.) |
| Efficacy  |
| Surgery |
| Side-effects (including mental health, memory, cognition) |
| Availability |
| Contraindications/drug combinations |
| Ketogenic diet |
| Cannabis-based therapy |
| Treatment general |
| Drug repurposing |
| Cause-focused treatment |
| Novel treatments (including delivery) |
| Comorbidities (treatment for) |
| Hormonal treatment |
| Rare epilepsies |
| Acquired brain injury |
| Stroke-associated epilepsy |
| Epilepsy in women |
| Neurofeedback therapy |
| Brain stimulation/stimulators (including vagus nerve stimulation (VNS)) |
| Safety |
| **Primary category: Management** |
| Rare epilepsies |
| Pregnancy  |
| Impact on mental health |
| Memory |
| Cognition |
| Treatment |
| Hormones |
| Seizures (including seizure detection) |
| Absences |
| Uncontrolled seizures/refractory epilepsy |
| Sleep |
| Personalised/precision |
| Epilepsy in women |
| Management general |
| Complex epilepsy |
| Acquired brain injury |
| Brain tumour-associated epilepsy |
| Stroke-associated epilepsy |
| Comorbidities (management of) |
| Stress |
| Status epilepticus (including in sleep) |
| **Primary category: Lifestyle** |
| Exercise  |
| General lifestyle |
| Diet/gut |
| Impact on lifestyle |
| Independence |
| Safety |
| **Primary category: Support** |
| Young adults |
| Personalised |
| Clinical  |
| Support general |
| Treatment |
| SUDEP |
| Pregnancy |
| Information |
| Absences |
| Families/friends/carers |
| People with epilepsy |
| Comorbidity |
| Employment |
| Support groups |
| Councilling |
| Mental health |
| Epilepsy in women |
| Occupational therapy |
| Uncontrolled seizures/refractory epilepsy |
| Diagnosis |
| Helplines |
| **Primary category: Comorbidity** |
| Neurodevelopmental disorders |
| Mood changes |
| Behavioural changes |
| Dementia |
| Mental health |
| Comorbidity general |
| Autoimmune |
| Migraines |
| PTSD |
| Cavernoma |
| Asthma |
| **Primary category: Knowledge dissemination** |
| SUDEP |
| Awareness |
| People affected by epilepsy |
| Information |
| Pregnancy & epilepsy |
| Rare epilepsies |
| Treatment |
| Knowledge dissemination general |
| Research |
| Case studies |
| Status epilepticus (including in sleep) |
| Genetics |
| **Primary category: Data** |
| AI/machine learning |
| Data research |
| Patient/clinical registries |
| Clinical registries |
| Clinical trials |
| Patient data |
| Research registries |
| Patient involvement in research |
| Data general |
| Research models |
| **Primary category: Health services** |
| Availability |
| Priority |
| Emergency care |
| Consistency |
| Training (including first aid) |
| Continuity |
| Health services general |
| Referrals |
| **Primary category: Epilepsy in childhood** |
| Early onset |
| Cognition |
| Side-effects |
| Mental health |
| Learning disability |
| Treatment |
| Diagnosis |
| Cause |
| Management |
| Rare epilepsies |
| Behaviour |
| Seizures |
| Sleep |
| Epilepsy in childhood general |
| Transition |
| Status epilepticus (including in sleep) |
| Support |
| Prevention |
| Infantile spasms |
| Neurodevelopment |
| **Primary category: Out of Scope** |
| Stigma |
| Social funding |
| Public policy |
| Research |
| Social research |
| Infrastructure |
| Employment |
| Education |
| Research funding |

**III. List of the 57 questions unanswered or partially answered questions included in the shortlisting survey**

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| Qu Number | QUESTION |
| 1 | How can existing anti-seizure medicines (ASM) be improved (e.g. to be more effective or have fewer side effects), and how can new ASMs be developed?  |
| 2 | What are the causes and contributing factors of epilepsy-related deaths, including Sudden Unexpected Death in Epilepsy (SUDEP), and how can these deaths be prevented? How can those bereaved by epilepsy be best supported?  |
| 3 | What causes drug-resistant (refractory) epilepsy, and how can it be best treated?  |
| 4 | What impact do epilepsy, seizures and anti-seizure medication (ASMs) have on brain health - including cognition, learning, behaviour and mental health? |
| 5 | How can people with epilepsy achieve long-term seizure control? |
| 6 | What causes epilepsy in children and in adults? Can knowing this help with prediction and/or prevention? |
| 7 | What is the relationship between sleep, epilepsy and nocturnal seizures? |
| 8 | What is the relationship between epilepsy, epilepsy treatment and memory? |
| 9 | How does epilepsy and epilepsy treatment impact neurodevelopment, and can this be managed or prevented? |
| 10 | How do hormonal changes in women throughout the lifespan (e.g. puberty, pregnancy, menopause) impact epilepsy, and how can this impact be addressed?  |
| 11 | How can non-drug lifestyle factors (such as physical activity, weight management and dietary changes) help people manage their epilepsy?  |
| 12 | What is the relationship between the immune system, infection, inflammation and epilepsy? |
| 13 | How can tools, devices and biological markers be used to accurately predict and prevent seizures and the onset of epilepsy? |
| 14 | What are the genetic causes/markers of epilepsy, and how can genetic screening be used to diagnose or predict the onset of epilepsy? Could this testing be used prior to the first seizure? |
| 15 | How can targeted, personalised medicine, such as gene therapy, be used to treat and/or prevent epilepsy?  |
| 16 | What diagnostic tools and markers can be used to achieve an earlier diagnosis of epilepsy? |
| 17 | What are the causes and contributing factors that trigger seizures in people with epilepsy, and how do these differ among the epilepsies? |
| 18 | Can we improve epilepsy outcomes by focusing directly on conditions that co-occur with epilepsy? |
| 19 | What impact does a lack of understanding about epilepsy within the health service have on people with epilepsy?  |
| 20 | What causes people with well-controlled epilepsy to have breakthrough seizures? |
| 21 | A prognosis maps the likely course of a medical condition. What is the prognosis and long-term impact of epilepsy and epilepsy treatments, and can this be accurately predicted? |
| 22 | What is the long-term neurodevelopmental impact of epilepsy and anti-seizure medications (ASMs) on child development during pregnancy? How can pregnancy safe treatments be developed? |
| 23 | How can we advance epilepsy surgery to improve outcomes?  |
| 24 | How could national epilepsy patient registries be used to optomise management, treatments and future research into epilepsy?  |
| 25 | What are the causes of rare epilepsies, and how can they be best diagnosed and treated? |
| 26 | Why does remission from epilepsy occur across the lifespan, and how can it be predicted? When is it safe to withdraw anti-seizure medications (ASMs) following epilepsy or seizure remission? |
| 27 | How does pregnancy affect the health of women with epilepsy, and how can the risk of epilepsy-related deaths during pregnancy be reduced? |
| 28 | How can cannabinoid-based therapies be used to treat epilepsy, and what are the associated risks and benefits? |
| 29 | How can quality of life be improved for people with epilepsy, their families and carers?  |
| 30 | Why does status epilepticus (SE) occur, and how can it be treated and prevented? |
| 31 | How can we prevent or best manage acquired epilepsy (e.g. epilepsy following brain injury, stroke or brain tumour)? |
| 32 | Why do different types of epilepsy and seizures vary in terms of presentation, side effects and effectiveness of treatments, and how do they vary over time? |
| 33 | Why does seizure frequency differ between people with the same type of epilepsy? |
| 34 | "Why does the effectiveness of anti-seizure medications (ASMs) and treatments differ among people with epilepsy, and how can ASM effectiveness be predicted? " |
| 35 | What is the relationship between diet, gut health and epilepsy, and can this relationship be used to improve epilepsy management? |
| 36 | How does epilepsy affect fertility in people with epilepsy? |
| 37 | What are the brain changes, on a cellular and network level, that lead to the development of epilepsy? |
| 38 | How can anti-seizure medication (ASM) trials be optimised to identify the best possible treatments for people with epilepsy, including through drug repurposing? |
| 39 | How does stress cause epilepsy and/or seizures? How can this be best managed? |
| 40 | How does ageing impact epilepsy, including its incidence, severity, presentation and treatment?  |
| 41 | How can we diagnose epilepsy sooner and more accurately to determine its type and cause? |
| 42 | How can brain stimulation, such as vagus nerve stimulation (VNS), be used to treat epilepsy and prevent epilepsy-related deaths? |
| 43 | How can big data analysis, through artificial intelligence (AI) and machine learning, aid the diagnosis and management of epilepsy? |
| 44 | How can neuroimaging be used to predict the onset of seizures and support the management of epilepsy? |
| 45 | What is the relationship between dementia and epilepsy?  |
| 46 | How can people with epilepsy improve research through their involvement in every stage of the research process? |
| 47 | How can the ketogenic diet (KD) be used to treat epilepsy, and what is the long-term impact of KD? |
| 48 | What causes absence seizures, and how can they be prevented? |
| 49 | How can collaboration within health care sectors (e.g. general practice, epilepsy specialist care, psychiatry) be improved to advance the management of epilepsy?  |
| 50 | What is the relationship between migraine and epilepsy?  |
| 51 | What is the optimum timepoint in the condition for people with epilepsy to undergo surgery? |
| 52 | How and why do variations between the type or brand of the same antiseizure medication (ASM) cause differences in outcomes for people with epilepsy? |
| 53 | What is the relationship between post-traumatic stress disorder (PTSD) and epilepsy?  |
| 54 | What causes seizures that affect awareness and behaviour, and what impact do seizure-induced sensory disturbances have on people with epilepsy?  |
| 55 | What modes of delivery for anti-seizure medicine promote adherence in children and young people with epilepsy? |
| 56 | What is the best form of psychological support for children and young people with epilepsy? |
| 57 | What is the relationship between heart disease and epilepsy? |

**IV. Top 25 questions ranked by each stakeholder group in the shortlisting survey. Top 14 from each of the four groups were taken forward to the UK Epilepsy PSP Workshop for final ranking.**
**The four groups represented in the table are: P = People with epilepsy; HCP = Healthcare professionals; CFM = Family members, friends or carers of someone with epilepsy and those bereaved by epilepsy; ECR = Epilepsy or associated condition charity and organisation representatives.**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Question** | **P** | **HCP** | **CFM** | **ECR** |
| What impact do epilepsy, seizures and anti-seizure medication (ASMs) have on brain health - including cognition, memory, learning, behaviour and mental health? | 1 | 1 | 1 | 3 |
| How does stress cause epilepsy and/or seizures? How can this be best managed? | 3 | 27\* | 8 | 32\* |
| How do hormonal changes in women throughout the lifespan (e.g. puberty, pregnancy, menopause) impact epilepsy, and how can this impact be addressed? | 4 | 8\* | 12 | 1 |
| How can existing anti-seizure medicines (ASMs) or emerging therapies (e.g. cannabinoid-based therapies, m-TOR inhibitors, etc.) be improved (e.g. to be more effective or have fewer side effects), and how can new ASMs be developed? | 5 | 5\* | 2 | 5\* |
| How can people with epilepsy achieve long-term seizure control, including minimising the risk of breakthrough seizures in people with well-controlled epilepsy? | 6 | 10 | 3 | 9\* |
| What is the relationship between sleep, epilepsy and nocturnal seizures? | 7 | 20\* | 6 | 9\* |
| What impact does a lack of understanding about epilepsy within the health service have on people with epilepsy? | 8 | 31\* | 22 | 14\* |
| What is the relationship between ageing and epilepsy, and conditions frequently associated with ageing such as dementia? | 9 | 42\* | 41\* | 24\* |
| What are the causes and contributing factors of epilepsy-related deaths, including Sudden Unexpected Death in Epilepsy (SUDEP), and how can these deaths be prevented? | 17 | 2 | 4 | 2 |
| What causes drug-resistant (refractory) epilepsy, and how can it be best treated? | 21 | 3 | 10\* | 7\* |
| How does epilepsy and epilepsy treatment impact neurodevelopment, and can this be managed or prevented? | 29 | 4 | 10\* | 7\* |
| How can quality of life be improved for people with epilepsy, their families and carers, including those bereaved by epilepsy? | 14 | 5\* | 5 | 14\* |
| What are the best forms of psychological interventions for children and young people with epilepsy? | 40\* | 7 | 17 | 19\* |
| How can collaboration within health care sectors (e.g. general practice, epilepsy specialist care, psychiatry, pregnancy/maternity care) be improved to advance the management of epilepsy? | 23\* | 8\* | 16 | 5\* |
| What is the relationship between diet, gut health and epilepsy, and can this relationship be used to improve epilepsy management? | 15 | 23\* | 9 | 21\* |
| How can tools, devices and biological markers be used to accurately predict and prevent seizures and the onset of epilepsy? | 43\* | 12 | 24 | 4 |
| How can non-drug lifestyle factors (such as physical activity, weight management and dietary changes) help people manage their epilepsy? | 16 | 20\* | 18 | 9\* |
| How could national epilepsy patient registries be used to optimise management, treatments and future research into epilepsy? | 48 | 17 | 41\* | 9\* |
| How can big data analysis, through artificial intelligence (AI) and machine learning, aid the diagnosis and management of epilepsy? | 55 | 23\* | 49 | 9\* |
| What are the causes and contributing factors that trigger seizures in people with epilepsy, and how do these differ among the epilepsies? | 11 | 36\* | 20\* | 24\* |
| How can we advance epilepsy surgery to improve outcomes? | 33 | 11 | 30 | 24\* |
| What causes absence seizures, and how can they be prevented?  | 12 | 52\* | 23 | 40\* |
| What are the genetic causes/markers of epilepsy, and how can genetic screening be used to diagnose or predict the onset of epilepsy? Could this testing be used prior to the first seizure? | 22 | 14 | 20\* | 16\* |
| What underlying mechanisms cause epilepsy in children and in adults? | 26 | 27\* | 14 | 29\* |
| How can targeted, personalised medicine, such as gene therapy, be used to treat and/or prevent epilepsy? | 32 | 13 | 13 | 24\* |