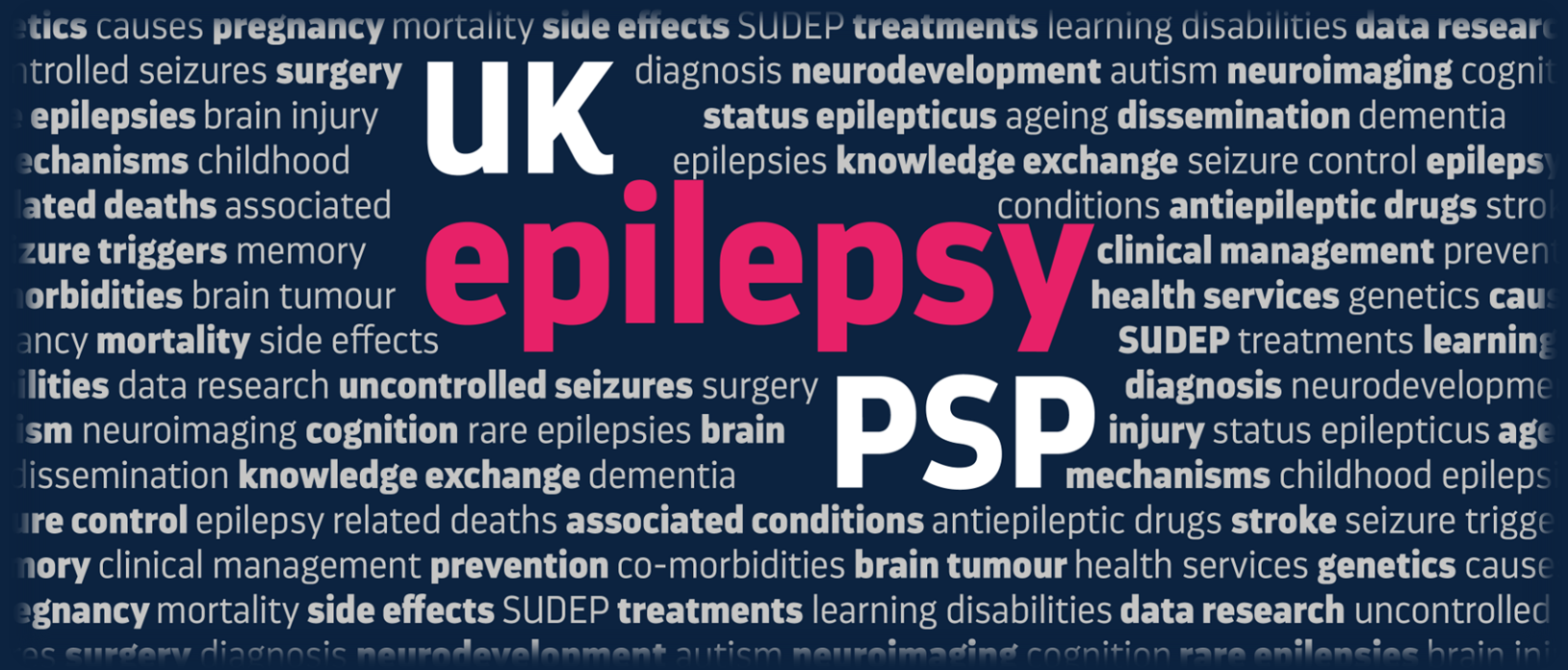


Top 10 Epilepsy Research Priorities

Powered by Epilepsy Research UK

EPILEPSY – WHAT'S AT STAKE?

LIVES

600,000 people in the **UK** and **65million worldwide** are currently living with epilepsy.

BILLIONS

In the UK, epilepsy costs the **National Health Service (NHS) £2 billion** every year.

INEQUALITIES IN RESEARCH FUNDING

*Despite epilepsy being one of the most prevalent neurological conditions, funding for epilepsy research is disproportionately less than other neurological conditions:

- £82.5 million in research into dementia (patient population 850,000)
- £34 million in research into Parkinson's disease (patient population 145,000)
- **£12.8 million in research into epilepsy (patient population)**

*Epilepsy Research UK 'A Life Interrupted' report Oct 2020

WHAT IS THE UK EPILEPSY PRIORITY SETTING PARTNERSHIP?

AIM: TO IDENTIFY THE TOP 10 PRIORITIES FOR RESEARCH INTO EPILEPSY

- A once-in-a-generation opportunity for the entire epilepsy community to shape the future of research into epilepsy and drive greater research investment
- Rigorous James Lind Alliance methodology
- Collaborating with UK-wide epilepsy charities
- Supported by UK-wide and national partner organisations

Involving:

- People living with epilepsy, clinicians, families, carers, bereaved community
- Health and social care professionals
- People of all ages
- All four nations of the UK
- Minority & hard-to-reach groups

James Lind Alliance
Priority Setting Partnerships

EPILEPSY RESEARCH UK
epilepsy action
SUDEP Action SUDEP.ORG
ILAE BRITISH BRANCH
Young Epilepsy
epilepsy society

PARTNER ORGANISATIONS

We engaged with over 100 partner organisations who helped share the survey with their supporters and memberships...

and many more...

STEERING COMMITTEE

UK wide representation: epilepsy patient groups, people with lived experience of epilepsy, health care professionals

UK EPILEPSY PSP SCOPE

The health research priorities of people with epilepsy to include:

- **Causes:** to include prevention (including the impact of epilepsy on antenatal and maternal health), co-morbidities
- **Diagnosis:** to include access to health services
- **Treatments:** to include anti-epileptic drugs, surgery, treatment side effects, co-morbidities (including those as a consequence of treatment), and epilepsy that does not respond to treatment
- **Clinical management of epilepsy:** to include risk of epilepsy-related deaths (including Sudden Unexpected Death in Epilepsy – SUDEP), service access, neurodevelopment, co-morbidities, social and psychological factors, and emerging areas such as epilepsy in older people
- **Dissemination of research breakthroughs to influence epilepsy care, practice and policy:** to include medical education and pathways to improved care

The PSP excluded from its scope questions about:

- Social research
- Health & Social funding
- Non-UK based research
- Functional seizures

UK EPILEPSY PSP TIMELINE

Start

SURVEY 1

Nov- Feb:
Collecting the priorities of the entire epilepsy community

COMPLETE

DATA PROCESSING

Nov-April:
Processing the priorities and demographic data

COMPLETE

SUMMARY QUESTIONS

March-June:
Draft summary questions from the submitted priorities

COMPLETE

EVIDENCE CHECK

June-July:
Identify the longlist of 'unanswered' summary questions , excluding any 'answered' summary questions

COMPLETE

SURVEY 2

August:
Shortlisting survey

COMPLETE

PRIORITY SETTING WORKSHOP

September:
Top 10 priorities for research into epilepsy are decided

COMPLETE

End

LAUNCH & REPORTING

October 2022

UK EPILEPSY PSP FIRST SURVEY

The first survey received...

Total responses

2,014

Total priorities (approx.)

5,418

Launched: Thursday, 18th November 2021
Closed: Thursday 24th February 2022

SUMMARY QUESTIONS

From the 5,418 priorities submitted in the first survey...

110

...research summary questions were drafted

EVIDENCE CHECK

Aim

Determine whether the summary research questions are…

- ❑ Answered
- ❑ Partially answered
- ❑ Unanswered

…by the existing literature

Process

- ✓ Check Canadian Epilepsy PSP evidence database – updated & expanded from January 2020
- ✓ Check primary sources (eg Cochrane reviews, NICE guidelines, SIGN guidelines)
- ✓ Consult with Steering Group - confirm summary questions identified as **answered, unanswered** or **partially answered**

SUMMARY QUESTIONS

Following the evidence check...

57

...summary questions moved forward for prioritisation

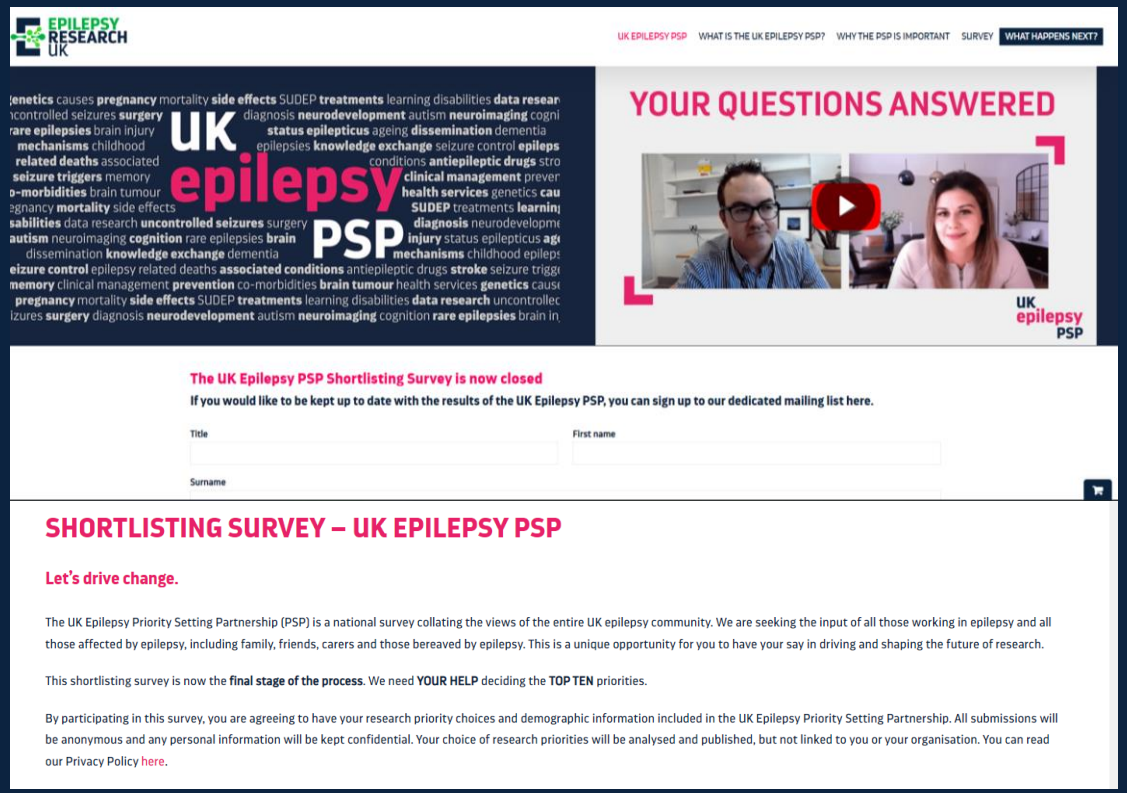
UK EPILEPSY PSP SHORTLISTING SURVEY

The second, interim survey received…

Total responses

2,798

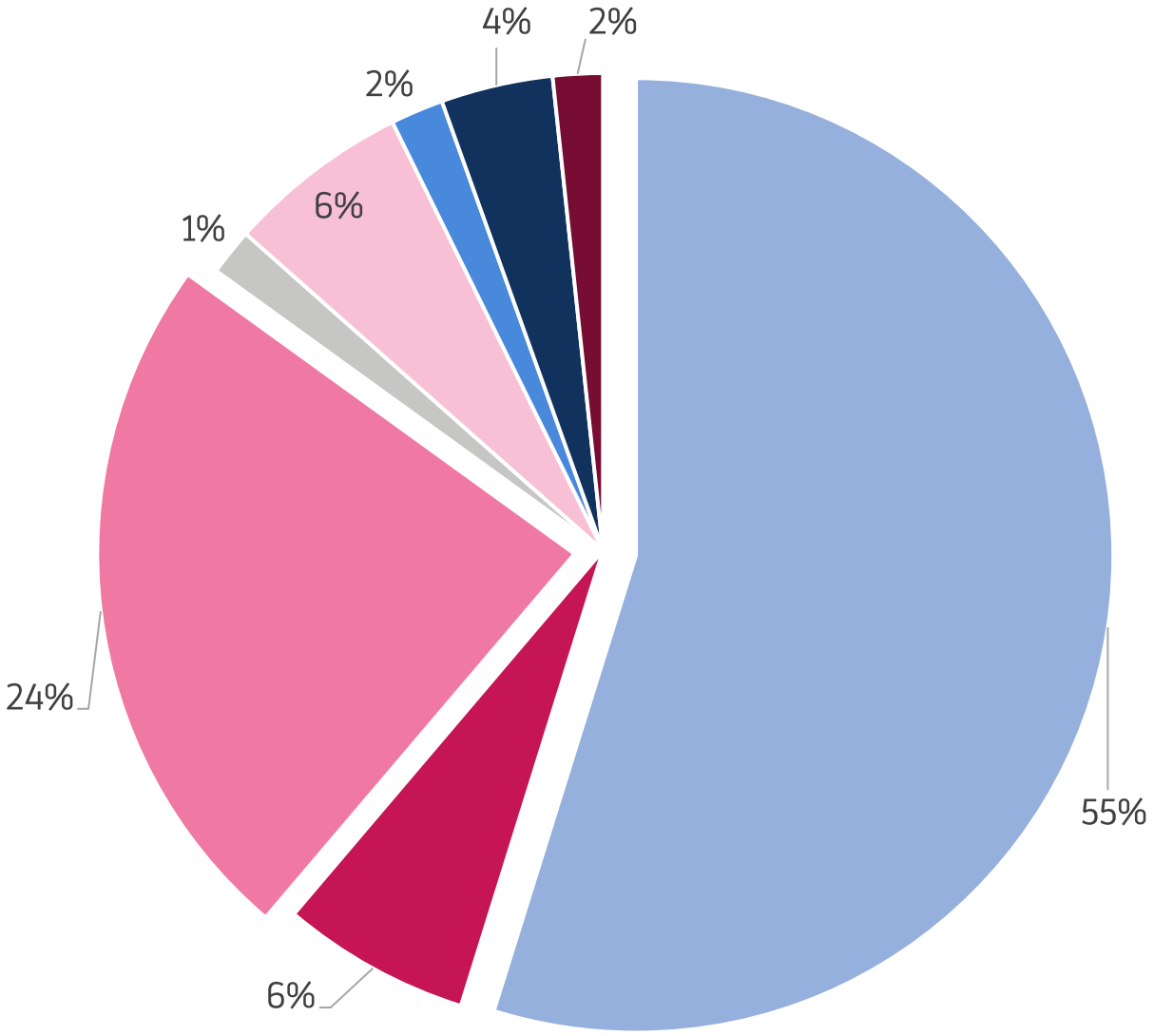
Launched: Wednesday 3rd August 2022
Closed: Monday 5th September 2022



Demographics

Q1: Which of the following best describes you?

REQUIRED: Please select ONE option that best applies.



Group	Response no.	% of response
Person with epilepsy	1560	54.81
Healthcare professional	182	6.39
Organisation representatives	45	1.58
Parent of someone with epilepsy	676	23.75
Family member or friend of someone with epilepsy	176	6.18
Caregiver or former caregiver of someone with epilepsy	51	1.79
Bereaved family member or friend of someone who had epilepsy	108	3.79
Other	48	1.69

Examples from 'Other':

- Had epilepsy
- Member of public
- Health services data specialist

These 'Other' responses have been assigned to one of the main groups.

Total No. of Participants: 2798

SUMMARY QUESTIONS

From the 57 summary research questions longlisted...

25

...were shortlisted for discussion at the UK Epilepsy PSP Workshop

UK EPILEPSY PSP WORKSHOP

Ra	Il	Question (abbreviated)	G1	G2	G3	C
1	O	What are the causes of epilepsy-related deaths, including SUDEP, and how can these be prevented?	5	1	2	8
2	Y	What underlying mechanisms cause epilepsy in children and in adults?	3	5	7	15
3	L	How does epilepsy and epilepsy treatment impact neurodevelopment, and can this be managed or prevented?	2	9	6	17
4	C	How can existing anti-seizure medicines (ASM) or emerging therapies be improved; how can new ASMs be developed?	12	4	3	19
5	T	What impact do epilepsy, seizures and anti-seizure medication (ASMs) have on brain health?	1	14	4	19
6	H	How can tools, devices and biological markers be used to accurately predict and prevent seizures and onset of epilepsy?	13	2	5	20
7	S	What causes drug-resistant (refractory) epilepsy, and how can it be best treated?	4	17	1	22
8	F	How can quality of life be improved for people with epilepsy, families and carers, including those bereaved by epilepsy?	9	3	12	24
9	G	How can targeted, personalised medicine, such as gene therapy, be used to treat and/or prevent epilepsy?	7	7	13	27
10	K	How do hormonal changes in women throughout the lifespan impact epilepsy, and how can this impact be addressed?	6	10	11	27
11	A	How can big data analysis, through AI and machine learning, aid the diagnosis and management of epilepsy?	8	12	10	30
12	X	What is the relationship between sleep, epilepsy and nocturnal seizures?	11	18	8	37
13	E	How can people with epilepsy achieve long-term seizure control in people with well-controlled epilepsy?	15	8	16	39
14	I	How can we advance epilepsy surgery to improve outcomes?	16	11	14	41
15	Q	What are the genetic causes/markers of epilepsy, and how can genetic screening be used to diagnose or predict?	14	15	15	44
16	J	How could national epilepsy patient registries be used to optimise management, treatments and future research ?	10	13	22	45
17	B	How can collaboration within health care sectors be improved to advance the management of epilepsy?	21	6	21	48
18	P	What are the causes that trigger seizures in people with epilepsy, and how do these differ among the epilepsies?	17	16	18	51
19	D	How can non-drug lifestyle factors help people manage their epilepsy?	23	21	9	53
20	V	What is the relationship between ageing and epilepsy, and conditions associated with ageing such as dementia?	20	19	20	59
21	N	What are the best forms of psychological interventions for children and young people with epilepsy?	18	20	23	61
22	U	What impact does a lack of understanding about epilepsy within the health service have on people with epilepsy?	22	22	19	63
23	W	What is the relationship between diet, gut health and epilepsy?	25	23	17	65
24	R	What causes absence seizures, and how can they be prevented?	19	25	25	69
25	M	How does stress cause epilepsy and/or seizures? How can this be best managed?	24	24	24	72

WORKSHOP CONCLUSION – THE TOP 10

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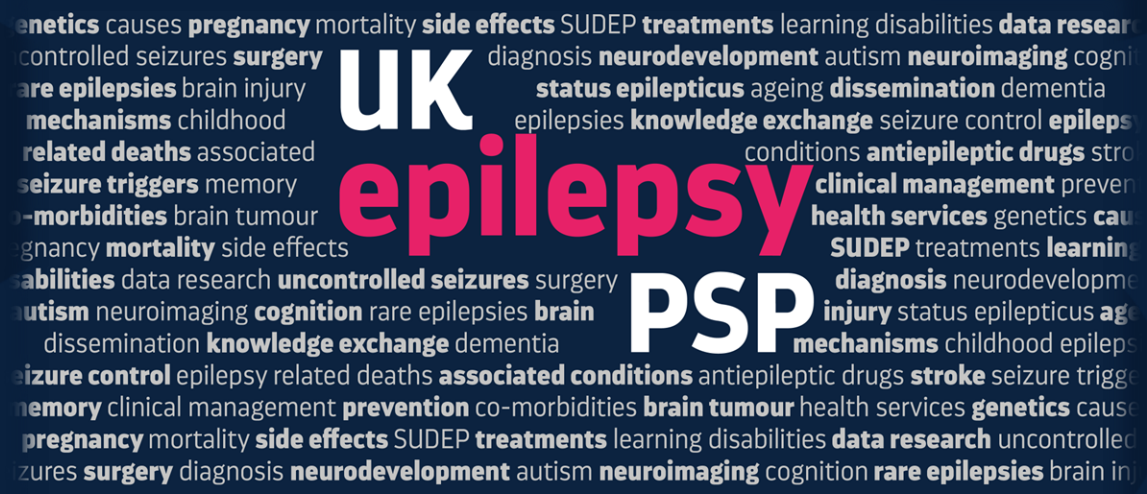
LAUNCH & REPORTING

October 2022

We are here

FINAL RANKING



TOP 10

10

How can big data analysis, through artificial intelligence (AI) and machine learning, aid the diagnosis and management of epilepsy?

What causes drug-resistant (refractory) epilepsy, and how can it be best treated?

8

How can quality of life be improved for people with epilepsy, their families and carers, including those bereaved by epilepsy?

7

How do hormonal changes in women throughout the lifespan (eg puberty, pregnancy, menopause) impact epilepsy, and how can this impact be addressed?

6

How can tools, devices and biological markers be used to accurately predict and prevent seizures and the onset of epilepsy?

5

How can targeted, personalised medicine, such as gene therapy, be used to treat and/or prevent epilepsy?

4

How does epilepsy and epilepsy treatment impact neurodevelopment, and can this be managed or prevented?

3

What impact do epilepsy, seizures and anti-seizure medication (ASMs) have on brain health - including cognition, memory, learning, behaviour and mental health?

2

What underlying mechanisms cause epilepsy in children and in adults?

1

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?

COMPARISON - CANADIAN EPILEPSY PSP TOP 10

Canadian Epilepsy PSP Top 10

1. Can genetic markers be used to diagnose and treat epilepsy and seizure disorders?
2. What are the impacts of long-term use of anti-seizure drugs, the causes of side-effects of these treatments and how we can prevent the side effects?
3. What are the long-term impacts of seizures on a person's brain, and overall health and development?
4. How can the risk of SUDEP (Sudden Unexpected Death in Epilepsy) be reduced in people with epilepsy?
5. What is the most effective testing protocol for determining causes of seizures and/or a diagnosis of epilepsy or other seizure disorders and reduce time to diagnosis?
6. What are the brain changes, on a cellular level, that lead to seizure development?
7. How effective is surgical treatment for adults and children who experience seizures/epilepsy?
8. What causes memory problems associated with seizures? Can these memory problems improve over time and what are the best treatment options for memory loss in people who experience seizures?
9. Aside from anti-seizure drugs and some brain lesions, what causes behavioural changes in people who experience seizures? What is the best way to treat behavioral issues?
10. What is the efficacy (ie the effectiveness of reducing seizures) of adding a second antiseizure medication compared to changing to a different antiseizure medication? How can we determine which combination of anti-seizure drugs are effective?

UK Epilepsy PSP Top 10

1. 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?
2. What underlying mechanisms cause epilepsy in children and in adults?
3. What impact do epilepsy, seizures and anti-seizure medication (ASMs) have on brain health - including cognition, memory, learning, behaviour and mental health?
4. How does epilepsy and epilepsy treatment impact neurodevelopment, and can this be managed or prevented?
5. How can targeted, personalised medicine, such as gene therapy, be used to treat and/or prevent epilepsy?
6. How can tools, devices and biological markers be used to accurately predict and prevent seizures and the onset of epilepsy?
7. How do hormonal changes in women throughout the lifespan (eg puberty, pregnancy, menopause) impact epilepsy, and how can this impact be addressed?
8. How can quality of life be improved for people with epilepsy, their families and carers, including those bereaved by epilepsy?
9. What causes drug-resistant (refractory) epilepsy, and how can it be best treated?
10. How can big data analysis, through artificial intelligence (AI) and machine learning, aid the diagnosis and management of epilepsy?

NEXT STEPS – DISSEMINATION AND ACTION >>>

PUBLISH TOP 10 RESEARCH PRIORITIES

October 2022

Launch: ILAE British Branch Conference October 2022

PROMOTE PRIORITIES WITH RESEARCH & EPILEPSY COMMUNITY

- ILAE & AES Conferences
- Research publications
- Roundtable discussions: unpacking the Top 10
- Partner organisations

ACTION PRIORITIES THROUGH COLLABORATION

- Collaboration workshops
- Task force development

INFLUENCE FUTURE RESEARCH INTO EPILEPSY

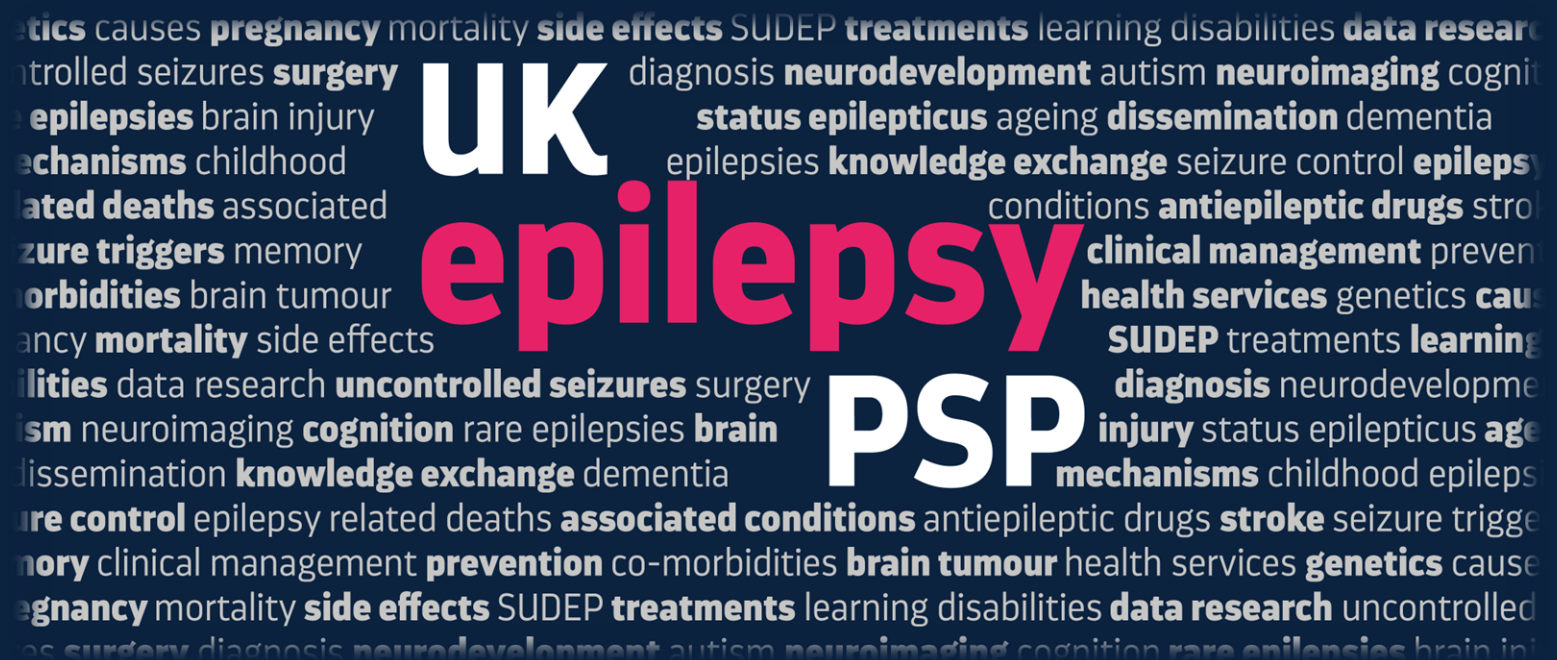
- Research strategy
- Evidence for increased investment

POWERED BY EPILEPSY RESEARCH UK

UK EPILEPSY PSP PROGRAMME TEAM

Epilepsy Research UK- Research & Involvement Team
Anna Norton, Caoimhe Twohig-Bennett

EASTBIO Professional Internship Programme, University of Edinburgh
Jack Armstrong, Adam Kovac



THANK YOU

Questions?

UKepilepsyPSP@eruk.org.uk

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