genetics causes pregnancy mortality side effects SUDEP treatments learning disabilities data research uncontrolled seizures surgery diagnosis neurodevelopment autism neuroimaging cognition dissemination dementia seizure control epilepsy antiepileptic drugs memory clinical co-morbidities brain genetics causes pregnancy stroke seizure triggers management prevention tumour health services effects SUDEP treatments co-morbidities brain genetics causes pregnancy mortality side learning disabilities data research uncontrolled diagnosis neurodevelopment autism rare epilepsies brain injury status epilepticus knowledge exchange dementia mechanisms childhood epilepsies seizure control epilepsy related deaths associated conditions antiepileptic drugs stroke seizure triggers memory clinical management prevention co-morbidities brain tumour health services

YOUR QUESTIONS ANSWERED



SURVEY - UK EPILEPSY PRIORITY SETTING PARTNERSHIP

The UK Epilepsy Priority Setting Partnership is a national survey collating the views of the entire UK epilepsy community. We are seeking the input of all those working in epilepsy and all those affected by epilepsy including, friends, families and carers. This is a unique opportunity for you to have your say in driving and shaping the future of research

By participating in the survey, you are agreeing to have your priorities included in the UK Epilepsy Priority Setting Partnership. All submissions will be

| Epilepsy affects everyone differently – we want to know what YOU consider to be the top priorities for epilepsy research. | |
|---|-------------|
| YOUR PRIORITY 1 (Required) ((So Need inspiration? Browse the word cloud above for ideas.) | |
| | |
| | |
| O of 280 max characters | |
| YOUR PRIORITY 2 | |
| | |
| | |
| 0 of 280 max characters | |
| YOUR PRIORITY 3 | |
| | |
| | |
| 0 of 280 max characters | |
| ABOUT YOU | |
| We are asking for this information to ensure we have responses from across the entire epilepsy community. Your data is both necessary and ber success of this Priority Setting Partnership. | neficial to |
| Q1. Which of the following best describes you? Please select all that apply. | |
| Preson with epilepsy | |
| ☐ Healthcare professional | |
| An organisation representing the interests of people affected by epilepsy Friend or family member of company with epilepsy. | |
| Friend or family member of someone with epilepsy Caregiver or former caregiver of someone with epilepsy | |
| ☐ Bereaved friend or family member of someone with epilepsy. | |
| □ Prefer not to say □ Other | |
| If you selected 'Other' to Q1, please specify | |
| | |
| 0 of 120 max characters Q2. Patients and carers, if you know the type of epilepsy you or the person you care for has, please specify below. | |
| | |
| 0 of 50 max characters | |
| □ Don't know □ Prefer not to say | |
| Q3. Healthcare professionals, which of the following best describes you? | |
| Please select all that apply. | |
| □ Adult neurologist □ Paediatric neurologist | |
| □ Epilepsy Specialist Nurse | |
| □ General Practitioner (GP) | |
| □ Neuropsychologist/psychologist | |
| □ Neurosurgeon □ Paediatrician | |
| □ Neurophysiologist | |
| □ Learning Disability Nurse Specialist □ Social worker | |
| Occupational or physical therapist | |
| □ Dietician | |
| □ Physician assistant □ Pharmacist | |
| □ Speech therapist | |
| □ Prefer not to say □ Other | |
| If you selected 'Other' to Q3, please specify | |
| | |
| 0 of 120 max characters | 4 DAS DT |
| Q4. We want to ensure that we are reaching people from across the UK. Where do you live? Please provide the first half of your postcode eg, EC: LL50 | 1, PA3, B13 |
| 0 of 4 max characters | |
| □ Prefer not to say | |
| Q5. Gender | |
| □ Female | |
| □ Male □ Prefer not to say | |
| □ Prefer to self-describe | |
| If you selected 'Prefer to self-describe' to Q5, please specify | |
| 0 of 60 max characters | |
| Q6. Ethnicity | |
| □ Asian/Asian British | |
| □ Black/African/Caribbean/Black British □ Mixed/Multiple Ethnicity | |
| □ Other | |
| □ White □ Prefer not to say | |
| Q7. Age | |
| 0-15 | |
| □ 16-25 □ 26-35 | |
| □ 36-45 | |
| □ 46-55 | |
| □ 56-65 □ 66-75 | |
| □ 76-85 | |
| Over 86 | |
| □ Prefer not to say Q8. Where did you hear about the survey? | |
| | |
| Please select all that apply. | |

 $\ \square$ Patient Organisation

If you selected 'Patient Organisation' to Q8, please specifyWe ask that you specify the Patient Organisation so that we can provide our partners with feedback

If you selected 'Other' to Q8, please specify

Once all responses have been collated, a long list of the identified research priorities not currently addressed by research will be created. If you would like to be involved in the shortlisting process or just kept up to date with the next steps of the UK Epilepsy PSP, please provide your title, name and email address Title

First name

Email:

Last name

WHAT HAPPENS NEXT?

Please contact Anna, Research & Involvement Officer, at ukepilepsypsp@eruk.org.uk to request any of the following:

• The survey in a different language

The survey in a different format (eg, paper copy or braille)
 If you prefer to dictate your answers to the survey over the phone – a member of the Epilepsy Research UK team will assist