

UK Epilepsy Priority Setting Partnership Survey Launch: Social Media Toolkit

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.

The survey will officially launch on **Thursday 18th November 2021**. The inequalities in research funding of epilepsy have meant progress has been slow. If we want to drive more investment, we must do as other health conditions have done, and provide clearly evidenced priorities to effect change. Your priorities will enable us to:

- **Carry out clinical research that matters most to people affected by epilepsy**
- **Fund research-based on evidenced priorities**
- **Drive collaborations with associated condition charities**
- **Generate the evidence needed to influence government and institutional funders to give us our fair share**

As a member of the UK Epilepsy PSP Steering Group, we would appreciate your help in getting the word out there that the survey is officially launching on the 18th November and is now open for feedback.

To assist you, we've prepared some suggested social media posts that you can use along with various images.

UK Epilepsy Priority Setting Partnership : Key information

Survey dates: Open from Thursday 18th November 2021 until Thursday 17th February 2022

Website landing page: www.epilepsyresearch.org.uk/uk-epilepsy-psp

Landing page Bitly: <https://bit.ly/uk-epilepsy-psp>

Survey: <https://epilepsyresearch.org.uk/uk-epilepsy-psp-survey/>

Survey page Bitly: <https://bit.ly/uk-epilepsy-psp-survey>

How to complete the survey:

Online at: <https://epilepsyresearch.org.uk/uk-epilepsy-psp-survey/>

If you require the survey in a different format, 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

Social Media Guidance

- Include the link to the survey:
<https://epilepsyresearch.org.uk/uk-epilepsy-psy-survey/>
- Include the hashtag **#UKepilepsyPSP** where possible
- Encourage followers to share with 'please RT'
- Tag participating organisations (handles provided below)
- Use the advert banners (provided below) as images alongside social media posts

Twitter Handles	Potential hashtags
You may wish to tag these when using images as appropriate, feel free to use others to spread the word	
@EpilepsyRUK @LindAlliance @epilepsyaction @youngpilepsy @SudepAction @epilepysociety @ILAEBRITISH @ESNA_epilepsy	#UKepilepsyPSP #StrongerTogether

Suggested social media posts

- The UK Epilepsy Priority Setting Partnership is a national survey gathering the views of the entire epilepsy community... and it opens TODAY! Find out more and have your say here: <https://bit.ly/uk-epilepsy-psy> #UKepilepsyPSP
- The UK Epilepsy Priority Setting Partnership is a unique opportunity for you to help drive positive change for everyone affected by epilepsy and shape the future of research. Find out more and have your voice heard here: <https://bit.ly/uk-epilepsy-psy> #UKepilepsyPSP
- Take part in the first-ever UK Epilepsy Priority Setting Partnership and help set the research agenda for the next 10 years. Your opinion matters – get it heard here today: <https://bit.ly/uk-epilepsy-psy-survey> #UKepilepsyPSP
- **[your charity]** has joined the other leading UK epilepsy charities for a landmark UK Epilepsy Priority Setting Partnership. You can help drive positive change for everyone affected by epilepsy by sharing your research priorities here: <https://bit.ly/uk-epilepsy-psy-survey> #UKepilepsyPSP #StrongerTogether
- What 3 priorities for epilepsy would you like research to focus on? The UK Epilepsy Priority Setting Partnership wants to hear YOUR opinion. Learn more about the #UKepilepsyPSP and have your say here: <https://bit.ly/uk-epilepsy-psy>
- You can influence the future of epilepsy research in the UK. If you've been affected by epilepsy, tell us the questions you want answered by research in the UK Epilepsy Priority Setting Partnership survey here: <https://bit.ly/uk-epilepsy-psy-survey> #UKepilepsyPSP

- I've just shared my research priorities as part of the UK Epilepsy Priority Setting Partnership to help drive positive change for people affected by epilepsy. To take part, please complete this short survey here: <https://bit.ly/uk-epilepsy-psp-survey>
#UKepilepsyPSP

Suggested longer social media posts

- **[your charity]** is a partner of the UK Epilepsy Priority Setting Partnership, which will support research to accelerate our understanding of **[primary focus of your charity]**. This national survey will collate the views of the entire epilepsy community – doctors, nurses, epilepsy charities, people living with epilepsy and their families, friends and carers. Join us to drive positive change for everyone affected by epilepsy – find out more and take the survey today: <https://bit.ly/uk-epilepsy-psp>
#UKepilepsyPSP
#StrongerTogether
- **[your charity]** has joined the other leading UK epilepsy charities for a landmark UK Epilepsy Priority Setting Partnership. The information we gather will help identify and prioritise areas of healthcare that can be improved by research and result in higher quality studies and increased investment. This is a unique opportunity for you to help drive positive change for everyone affected by epilepsy and shape the future of research.
What 3 priorities for epilepsy would you like to see addressed by research? The #UKepilepsyPSP wants to hear YOUR opinion. Find out more and have your voice heard here: <https://bit.ly/uk-epilepsy-psp>
#StrongerTogether

Quote

“A new study is long overdue, the outcomes of which would benefit people living with epilepsy by providing the evidence of need and priorities to support research development. We know that PSPs can lead to increased funding from NIHR, which is so urgently needed for epilepsy, given the shocking inequalities in research funding.”

Dr Rhys Thomas, UK Epilepsy PSP Lead

Supporting Social Media Banners/Images (More available in dropbox)

Image 1

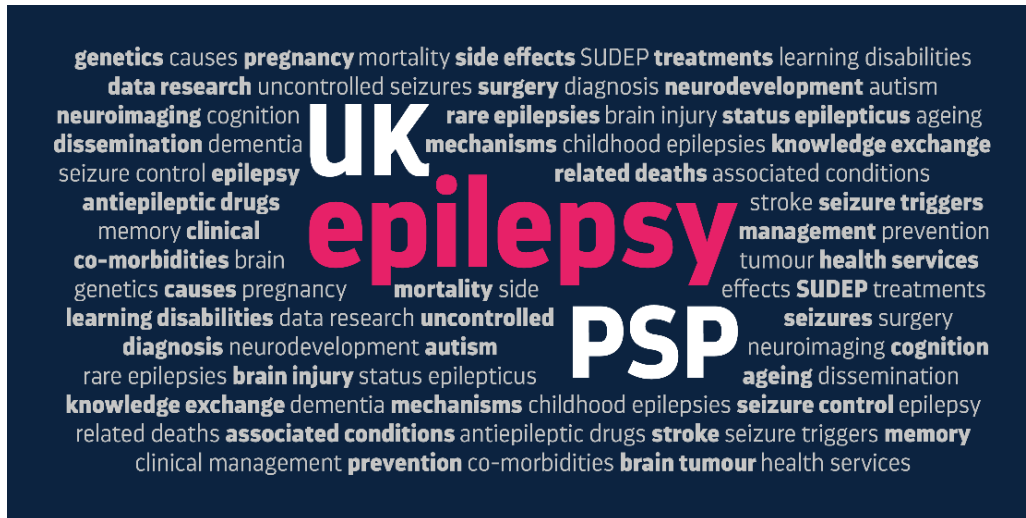


Image 2



Image 3



UK
epilepsy
PSP

Image 4

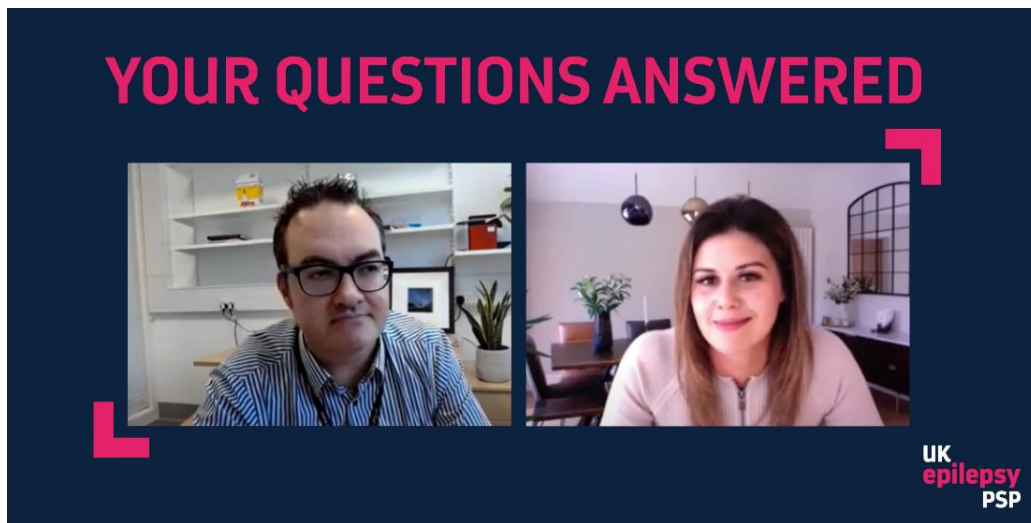


Image 5



Image 6

