

Assessing the Global Escalation and Mitigation of Seizure Risk During the COVID-19 Pandemic - Results from the COV-E Study

Thorpe, J^{1,2}., Hallab, S³., Ding, D⁴., Andraus, M⁵., Dugan, P⁶., Perucca, P⁷., Costello, D⁸., French, J. A⁶., O'Brien, T. J⁷., Dupont, C⁹., Andrade, D¹⁰. M., Sengupta, R¹¹., Delanty, N¹²., Jette, N¹³., Newton, C^{1,14}., Brodie, M¹⁵., Devinsky, O⁶., Cross, H. J¹⁶., Sander, J. W^{17,18}., Ashby, S². & Hanna, J²., Sen, A¹.



¹NIHR Biomedical Research Centre, Nuffield Department of Clinical Neurosciences, John Radcliffe Hospital, Oxford. ²SUDEP Action, Oxfordshire, UK. ³Sorbonne Universités, Université Pierre et Marie Curie (UPMC), Paris, France. ⁴Fudan University Huashan Hospital, Shanghai, China. ⁵Hospital Universitário Clementino Fraga Filho, Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brasil. ⁶Department of Neurology, New York University, USA. ⁷Department of Neuroscience, Central Clinical School, The Alfred Hospital, Monash University, Melbourne, Australia. ⁸Cork University Hospital, Ireland. ⁹Hôpital Erasme – ULB, Bruxelles, Belgium. ¹⁰Toronto Western Hospital, Canada. ¹¹The Institute of Neurosciences, Kolkata, India. ¹²Beaumont Hospital, Dublin, Ireland. ¹³Department of Neurology, Icahn School of Medicine at Mount Sinai, New York, USA. ¹⁴KEMRI-Wellcome Institute, Kenya. ¹⁵Epilepsy Unit, West Glasgow Ambulatory Care Hospital-Yorkhill, Glasgow, UK. ¹⁶UCL Great Ormond Street Institute of Child Health, London, UK. ¹⁷UCL Queen Square Institute of Neurology, London, UK. ¹⁸Stichting Epilepsie Instellingen Nederland (SEIN), Heemstede, Netherlands.

Study Ethical Approval Reference: R69353/RE001

Background

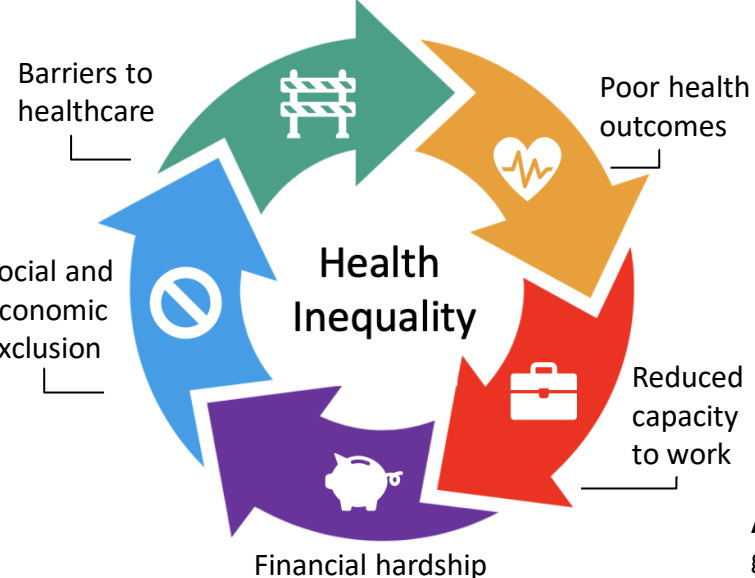
The disruption to health services and every-day routine during the COVID-19 pandemic could align with an increase in adverse health outcomes in people with epilepsy (PWE).

- ➔ **Disruption to health services may inhibit access to epilepsy care at the point of need.**
- ➔ **Isolation measures and decreased social interactions may lead to reduced access to social support and first aid.**
- ➔ **Changes to routine, income, stress and decreased physical activity could manifest in increased seizure activity.**

Inequality, epilepsy & COVID-19

The pandemic has sharply accentuated socio-economic inequality. Marginalized groups, including ethnic minorities, are at greater risk of COVID-19 infection and mortality.

Concurrently, these groups are more likely to experience adverse health outcomes in epilepsy.



Methods

To explore the impact of COVID-19 on people with epilepsy, we launched [three online surveys](#):

People with epilepsy, their caregivers and healthcare workers.

Surveys were translated into [11 languages](#).

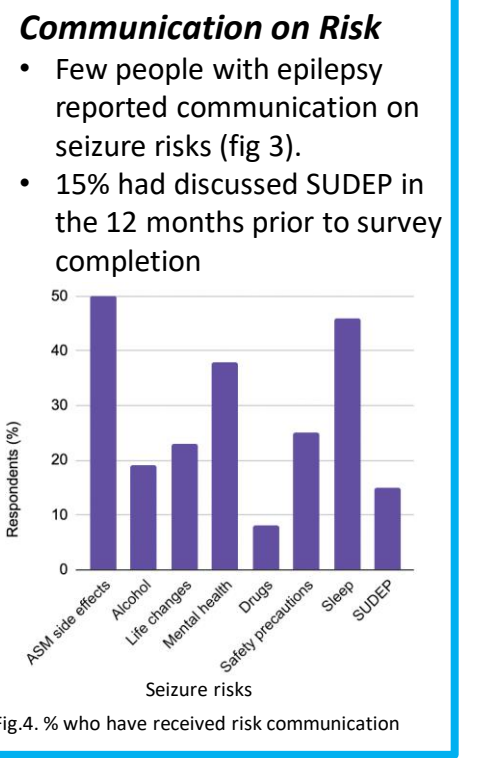
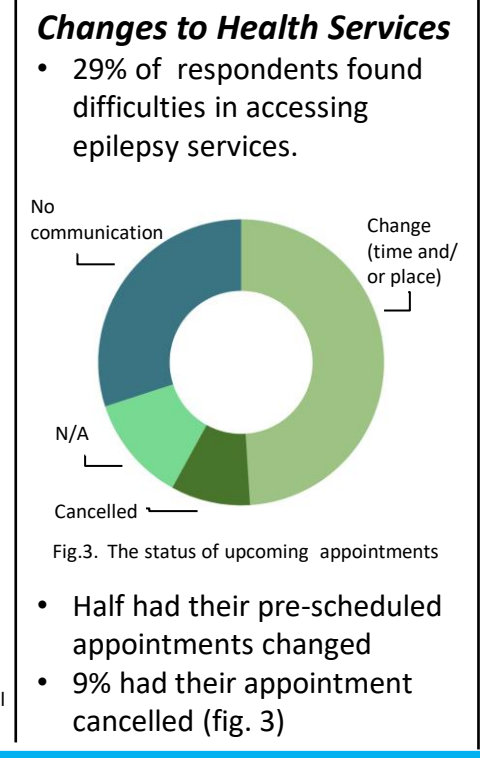
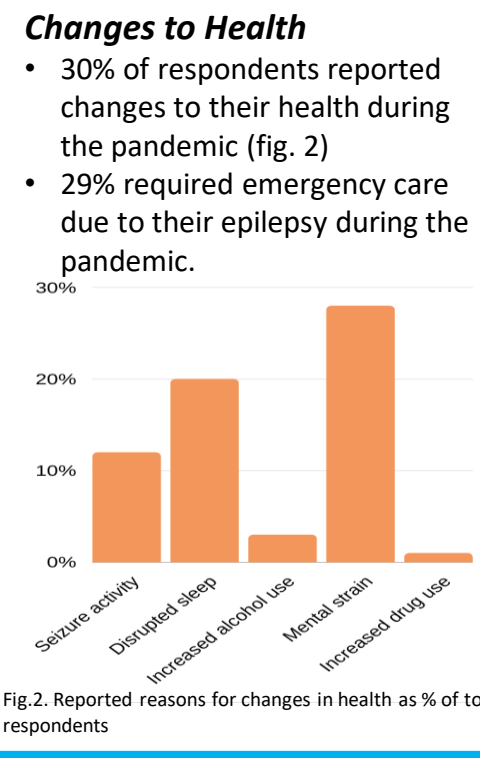
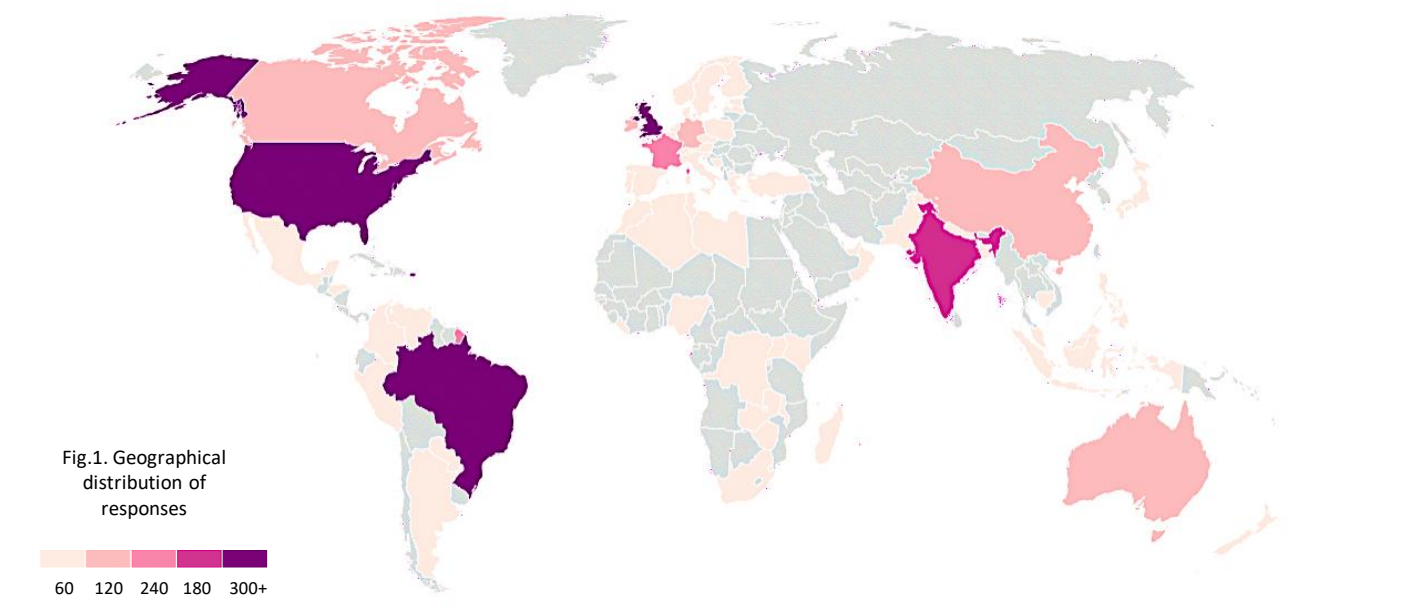
Participants had to be over 18 years and all data are anonymous.

The survey explored:

- ✔ **Demographics:** Age, sex, ethnicity and postcode information, vaccination status
- ✔ **Health background:** Epilepsy type, seizure type(s), medications (ASMs), care provider, health service use, emergency visits, injuries, and comorbidities.
- ✔ **Risk factors for epilepsy morbidity and mortality:** changes in behavior and circumstances during the pandemic, including mental health sleep patterns and changes to seizures.
- ✔ **Access to healthcare:** experience obtaining prescriptions, changes to appointments, communication with physicians and satisfaction of care received.

Results

As of 13th July 2021 we have received 3,152 responses from 71 countries (fig. 1). 60% were submitted by PWE; 27% by caregivers of PWE and 14% by HCW.



Discussion

[People with epilepsy have experienced a decline in health and well-being during the COVID-19 pandemic.](#) Issues highlighted include:

Changes in seizure activity	Declining mental health	Sleep disruption
Isolation and solitary living	Disturbances to healthcare	Insufficient risk communication

These stressors could increase seizure activity and may increase an individual's risk of premature death from Sudden Unexpected Death in Epilepsy (SUDEP), suicide or injuries.

In the absence of comprehensive and consistent epilepsy services, physicians are impeded in their ability to identify rising risk profile in patients, whilst also limiting their capacity to intervene.



Conclusion

The ongoing COVID-19 pandemic has negatively impacted people with epilepsy and their access to health services. As the pandemic persists, the following actions are crucial:

- Promoting health literacy and **providing robust communication on risk** to support self-management of modifiable risk factors.
- **Delivering care that is personalized** to an individual's health, socio-economic background and environment, to ensure that no one is left behind.

These efforts can contribute towards reducing the risk of declining health and **epilepsy-related mortality**.

Acknowledgements: This research was funded by SUDEP Action charity 1164250 (England & Wales) and supported by the Oxford NIHR Biomedical Research Centre. We are grateful to the following organisations for promoting this work, allowing for global reach: BAND Foundation, CURE, Dravet Syndrome UK, Epilepsy Action, Epilepsy Connections, Epilepsy Foundation America, Epilepsy Research UK, Epilepsy Society, Epilepsy Sparks, IBE, ILAE, Matthew's Friends and the Neurological Alliance.