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.

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 (AEDs), 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 Delanty, O’Brien, T’Jette, Dupont, C’, Andrade, D’O., Sengupta, R’tt, Devinsky, O’, Cross, H, J’t, Sander, J, W’tt, Ashby, S’t, & Hanna, J’t, Sen, A’t.

Changes to Health
- 30% of respondents reported changes to their health during the pandemic (fig. 2)
- 29% required emergency care due to their epilepsy during the pandemic.

Changes to Health Services
- 29% of respondents found difficulties in accessing epilepsy services.

Communication on Risk
- Few people with epilepsy reported communication on seizure risks (fig. 3)
- 15% had discussed SUDEP in the 12 months prior to survey completion

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.

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
- 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.

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