



## The impact of COVID-19 on epilepsy care: Perspectives from UK healthcare workers



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### ABSTRACT

The COVID-19 pandemic has created an immense pressure on healthcare providers, resulting in a shift to remote consultations and the redeployment of healthcare workers (HCWs). We present survey data from the United Kingdom (UK) HCWs to outline how changes in healthcare provision impact clinicians' well-being and ability to provide adequate care. We designed an online survey to gather the experiences of HCWs providing care to people with epilepsy. We received seventy-nine responses from UK-based HCWs, of whom 43% reported an impact on their mental health. Changes to service delivery have resulted in 71% of clinicians performing > 75% of their consultations remotely. Diagnosing and treating epilepsy has changed, with a fifth of respondents being significantly less confident in diagnosing epilepsy. Ultimately, these results show that COVID-19 has had an overall negative impact on HCWs and their ability to provide epilepsy care. These results must be considered when reorganizing health services to ensure optimal outcomes for people with epilepsy.

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### Introduction

The COVID-19 pandemic has resulted in an unprecedented challenge for healthcare services, with a shift to remote consultations and the redeployment of healthcare workers (HCWs) to critical care and emergency services [1]. To understand how these changes have impacted people with epilepsy, carers and epilepsy healthcare professionals, we initiated the COVID and Epilepsy (COV-E) Study in March 2020 to capture the impact of the pandemic in real-time [2]. Here we present the views of HCWs based in the United Kingdom (UK), recorded between April 2020– May 2021. We focus on how HCWs have been personally affected, logistical changes in the delivery of care, and how these factors impact the ability to deliver optimal individual outcomes.

### Methods

#### Study design

We designed an online survey for HCWs, involved in the care of people with epilepsy in a clinical setting. The survey contains thirty-nine questions ([Supplementary material 1](#)) focussing on the following aspects of epilepsy care:

#### Demographic data of respondents

Participants answered questions on their age, sex, clinical role, and the postcode of their place of work.

#### Health and wellbeing of the respondents, family and colleagues

HCWs were asked if they had been infected with COVID-19 and if the pandemic had impacted their mental wellbeing and underlying comorbidities. Respondents were also questioned about concerns for their family and colleagues.

Abbreviations: HCW, Healthcare worker; UK, United Kingdom.

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### Delivery of services

Respondents were asked about the provision of in-person care, telephone consultations, and the availability of diagnostic tools and treatments. They were also questioned about how any changes may have impacted the delivery of care.

### Survey pilot and dissemination

The online survey was disseminated on social media platforms by SUDEP Action and other epilepsy advocacy organizations (see acknowledgments). The survey focused primarily on collecting quantitative data. Free-text options were provided to facilitate additional qualitative data collection.

The University of Oxford Ethics Committee (Reference: R69353/RE001) approved the study.

### Data analysis

Data analyses utilized descriptive statistics. Qualitative coding was used to analyze free-text data. Statistical comparisons were not made owing to the small sample size. The results presented are an overview of all responses submitted between the survey's launch in April 2020 to May 2021 and are not sensitive to specific points in time.

## Results

### Overview

Seventy-nine UK-based HCW responses were received from neurologists subspecializing in epilepsy ( $n = 7$ ), general neurologists ( $n = 18$ ), epilepsy specialist nurses ( $n = 36$ ), family physicians (General Practitioners  $n = 6$ ), learning disability clinicians ( $n = 5$ ), and medical trainees ( $n = 4$ ). Responses were also received from one nurse practitioner, one physiologist (EEG technician) and a pediatrician. Responses originated from all regions in the UK, except for the North East and East Midlands. The highest concentration of responses emerged from the South-East of England ( $n = 16$ , 20%). Fifty-one percent of responses were captured during the first wave of the pandemic ( $n = 40$ ), between May 5th to June 1st 2020.

### Health and wellbeing of clinicians

Sixty-two per cent ( $n = 49$ ) of HCWs did not feel that their pre-existing comorbidities had been impacted during the pandemic. Thirty-nine per cent stated their mental wellbeing had been slightly affected during the pandemic ( $n = 30$ ). A small minority reported significant impact (5%,  $n = 4$ ; Fig. 1). Concern about becoming infected was also mentioned, with 48% stating that these factors impacted their wellbeing ( $n = 38$ ).

Concern about family members was recorded by 61% of respondents ( $n = 48$ ). Concern about colleagues' mental health was expressed in higher numbers, with 50% citing that the pandemic had impacted their colleague's mental health ( $n = 40$ ), and 10% expressing that it had a significant impact ( $n = 8$ ).

### Changes to service delivery

Before the pandemic, 29% of respondents would routinely use telephone consultations ( $n = 23$ ). Only 6% reported using video calls routinely ( $n = 5$ ). HCWs reported that most consultations were held remotely during the pandemic, with 71% of respondents performing > 75% of their work by telephone ( $n = 56$ ). Thirty-nine percent of respondents had no face-to-face consultations during

the pandemic ( $n = 31$ ). Few respondents routinely utilized video consultations, with just 9% using video calls for over a quarter of their consultations ( $n = 7$ ).

When questioned on the broad impact of remote working, half of the respondents specified that the circumstances negatively impacted their ability to deliver care. Qualitative data identified difficulties in trust-building as a significant factor, alongside the nuances being lost when the individual is not in a face-to-face consultation ( $n = 11$ ).

### Impact on diagnosing epilepsy

HCWs were asked about their confidence in diagnosing epilepsy when working remotely. Nineteen per cent reported being significantly less confident ( $n = 15$ ), with a further 59% being slightly less confident ( $n = 47$ ). Qualitative data attributed the decline in confidence to more significant difficulties in communicating complex symptoms over the phone. The ability to build trust and establish rapport was also thought to be limited when exclusively communicating via telephone.

When questioned about limitations in investigations, most respondents reported that limits in EEG provision, brain imaging and neuropsychology/psychiatry assessments impacted their ability to diagnose epileptic seizures confidently (Fig. 2). Meanwhile, a lack of other investigations, such as blood tests, immunological screens and ECGs, impacted less on diagnostic capabilities.

### Impact on treating epilepsy

Limitations in treatment modalities had less impact (Fig. 2). Nineteen per cent expressed that there had been a significant impact on vagal nerve stimulation implantation capabilities ( $n = 15$ ), and 16% noted a similar effect on resective epilepsy surgery ( $n = 13$ ).

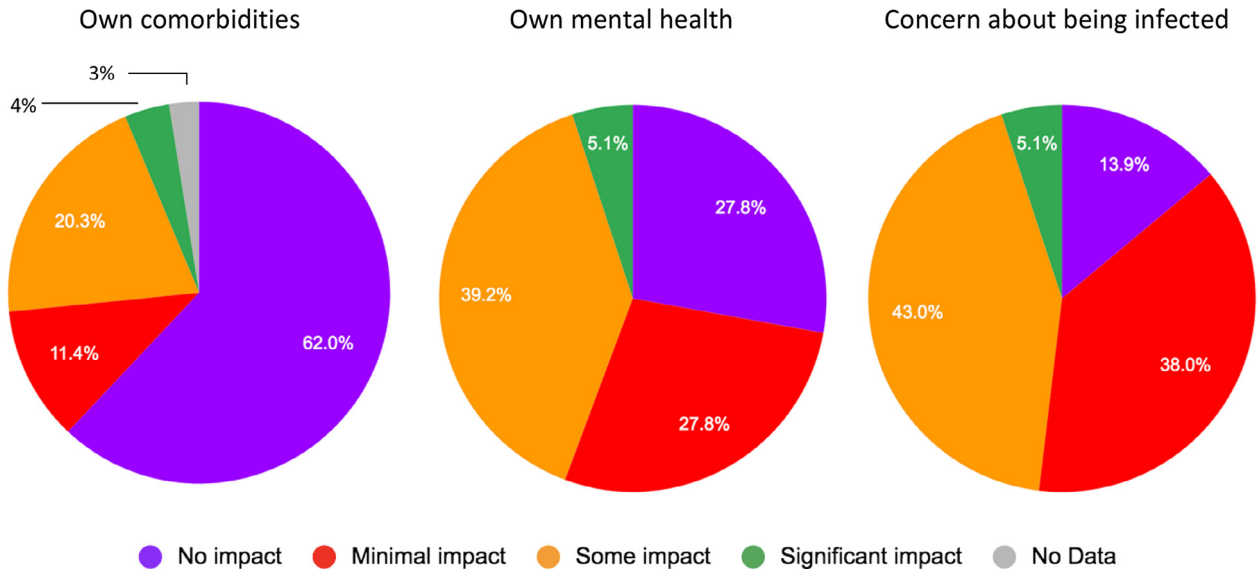
Most respondents reported no change in their prescribing of ASM (57%,  $n = 45$ ), with the remaining respondents reporting some modification (29%,  $n = 23$ ) or minimal change (11%,  $n = 9$ ). Respondents did not comment on switching of ASMs. Routine discussion on rescue medication was, though, conducted by 35% of respondents during the pandemic ( $n = 28$ ), a 6% rise from before the pandemic (29%,  $n = 23$ ). Three respondents described an increase in rescue medication prescriptions to reduce hospitalisations.

When questioned on approaches to withdrawing ASM, 43% reported no change ( $n = 34$ ), 32% reported some change ( $n = 25$ ), with 12% stating significant change ( $n = 10$ ). Qualitative data infer that clinicians are more cautious withdrawing unless side effects are exhibited, expressing concerns about limitations in the emergency services if increased seizure activity were to occur ( $n = 11$ ).

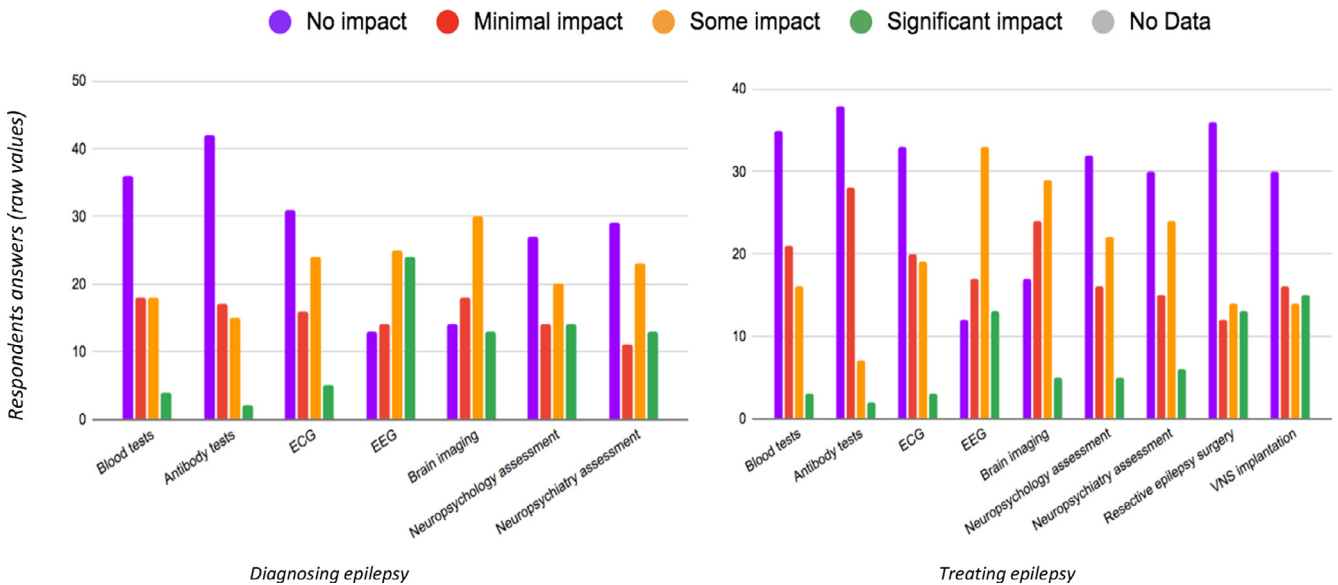
## Discussion

The data collected in this study demonstrate the immense challenges faced by clinicians during the height of the COVID-19 pandemic, particularly during the first wave. As services reconstitute, policymakers and clinicians now face difficult decisions grappling with issues of staff burn out, attendance backlogs, and increased morbidity in the population of people with epilepsy [2,3]. This is layered within the context of pre-existing shortages in neurology specialists, delays in service delivery and rising mortality in epilepsy [4–6].

More mainstreamed use of telemedicine has been recognised as a helpful resource in increasing capacity building, allowing a greater number of people to be reviewed [7–9]. The flexibility offered in delivering teleconsultations may be seen favourably by some clinicians. As our study shows, however, difficulties in



**Fig. 1.** The extent to which respondents have been personally affected, including the impact on comorbidities that were present prior to the pandemic, mental health and concerns about being infected with COVID-19. In total, 24% of respondents reported that the COVID-19 pandemic had a notable impact on their pre-existing comorbidities (cumulative statistic inclusive of ‘some impact’ and ‘significant impact’ categories). Nearly half of the respondents reported concern over being infected (48%) and their mental wellbeing (44%).



**Fig. 2.** Impact of COVID-19 on epilepsy diagnosis and treatment tools, including chemical pathology, immunological tests, ECGs, EEGs, imaging, neuropsychology and psychiatry, resective epilepsy surgery and VNS. When diagnosing epilepsy, most respondents reported that access to EEGs and brain imaging had been impacted negatively during the COVID-19 pandemic. In contrast, only a small minority of respondents reported that access to blood tests and antibody tests had an impact in diagnosing and treating epilepsy.

diagnosing, prescribing and trust-building curtail the advantages of telephone consultations.

Video consultations may overcome certain barriers and have proven effective in other areas of medical practice [10]. Given the slow uptake of these technologies in a UK context, which seems to vary between primary, secondary and tertiary care, more research into the long-term usage and effectiveness of video platforms may be required. Individual-centred alternatives or adjustments will always be needed for those who cannot regularly access, or effectively operate video-technologies [10,11].

Recognizing the rising clinical uncertainty when diagnosing epilepsy and withdrawing ASM, our data suggest that clinicians

must be allowed the opportunity to consult with individuals under their care through the safest possible means, including access to secure video-consultations and in-person care. This may also reduce work-related stress for clinicians. People with epilepsy at the highest risk, including those needing further investigatory work, invasive treatments, and improved seizure management, should be prioritized for close monitoring and face-to-face care [8,12].

In the UK, the ability to see people promptly in a face-to-face consultation is improved compared to when most of the survey data were captured. The enduring effect of the pandemic is likely, though, to have had a cumulative adverse impact on clinicians'

mental and physical health of clinicians, which will continue to escalate if left unaddressed. Ongoing data collection aims to address this critical concern.

### Limitations

Participant self-selection could introduce bias of an unknown magnitude meaning our findings cannot represent all HCWs. Owing to the small sample size, our analysis has not explored differences in experiences between healthcare worker roles. Qualitative data may be skewed to portray negative experiences as those who look favorably toward mainstream healthcare protocols may feel less motivated to justify their position. The question on HCW comorbidities did not include a not-applicable option. Therefore, an undetermined proportion of those who have reported “no impact” may not experience any comorbidities (Fig. 1).

### Conclusions

This study shows that remote delivery of care poses certain risks to the well-being of people with epilepsy and their clinicians. People with epilepsy may face a greater risk of seizures, adverse health outcomes and increased risk of premature mortality during the COVID-19 pandemic [7–9]. Risk mitigation will remain vital whether care for people with epilepsy is delivered in person or remotely and requires continued monitoring and evaluation. Our results provide critical insights into the state of epilepsy care during 2020–21. We hope that these results can guide future directions in care provision, ensuring that the safety and wellbeing of people with epilepsy and their clinicians are promoted in a post-pandemic world.

### Ethical statement

Ethical approval for this study has been granted by University of Oxford Ethics Committee (Reference: R69353/RE001).

### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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### Appendix

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#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ebr.2021.100487>.

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