Epilepsy and risk during the COVID-19 pandemic; people with epilepsy v2

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Ethics Approval Reference: R69353/RE001

General Information

The aim of this study is to try and better understand risk in people with epilepsy. We know that there are risks linked to having epilepsy, but by understanding them and putting steps in place to reduce them, people with epilepsy can live well and live safely.

This project aims to better understand what risks people with epilepsy are facing, and what support they have, helping them live well with the condition. Particularly during the current COVID-19 pandemic, we know these things may be changing for people with epilepsy, so we want to better understand the changes and challenges you face. By knowing what problems people with epilepsy and their health professionals face, we will better understand what can be done to help make things better.

We appreciate your interest in participating in this online survey. You have been invited to participate as you are over 18 years old and are either a person with epilepsy, someone who cares for a person with epilepsy (who may be a child or adult with epilepsy), or a healthcare professional who helps in the management of people with epilepsy. Please read through this information before agreeing to participate by ticking the ‘yes’ boxes below.

You may ask any questions before deciding to take part by contacting the research team (details below).

We, Dr Arjune Sen (NDCN, University of Oxford, clinical research lead), Jane Hanna

OBE & Sammy Ashby (SUDEP Action, Project and PPI leads), in collaboration with other key partners are investigating risk in people with epilepsy during the COVID-19 pandemic.

In the online survey, you will be asked some basic demographic details (for example your age, which town you live in). If you have epilepsy you will be asked about the kind of seizures that you have and how often they occur as well as some other questions about your health. You will then be asked about how you are informed about risk. If you are a health care worker, you will be asked about how you communicate risk to people with epilepsy. We will also be asking questions that directly relate to the COVID 19 pandemic and how the care of people with epilepsy may have been affected by this emergency.

The online survey takes between 10 to 20 minutes to complete. No background knowledge is required and you do not need to do any preparation beforehand

The information we collect is anonymous and we will not be able to identify you personally from your answers. We pool these anonymous answers to better understand epilepsy and the management of risk.

At the end of the survey you will be given the option of contacting the research team if you wish to be informed of other similar research projects by emailing info@sudep.org. There is no obligation for you to do this and should you contact us we will not be able to link you to your responses on the survey

Thank you for your support,

Arjune Sen, Consultant Neurologist, Head Oxford Epilepsy Research Group

Jane Hanna, CEO, SUDEP Action

Samantha Ashby, Patient and Public Involvement Lead, SUDEP Action

Jennifer Thorpe, Researcher, SUDEP Action & University of Oxford

Key collaborators:

Professor Danielle Andrade, Toronto Western Hospital, Canada
Dr Danny Costello, Cork University Hospital, Ireland
Professor Helen Cross, UCL Great Ormond Street Institute of Child Health, London, UK
Professor Norman Delanty, Beaumont Hospital, Dublin, Ireland

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Professor Nathalie Jette, The Mount Sinai Hospital, New York, USA
Professor Charles Newton, KEMRI-Wellcome Institute, Kenya and University of Oxford, UK
Professor Terry O'Brien, Monash University, Australia.
Dr Piero Perucca, Monash University, Melbourne, Australia
Professor Ley Sander, The National Hospital for Neurology and Neurosurgery, University College London, UK

Key questions for you to consider:

Do I have to take part?

Please note that your participation is voluntary. If you do decide to take part, you may withdraw at any point during the questionnaire for any reason before submitting your answers by closing the browser. If you close the survey before pressing 'submit' at the end of the survey, no responses are sent to us. If you submit your answers to us, these cannot be amended or withdrawn as the data are sent to us anonymously.

How will my data be used?

Your answers will be anonymous and we will take all reasonable measures to ensure that they remain confidential.

Your data will be stored in a password-protected file and may be used in academic publications. Your IP address will not be stored. We have included a 'Prefer not to say' option for questions should you prefer not to answer a particular question. Research data will be stored for a minimum of three years after publication or public release.

The data that we collect from you may be transferred to, stored and/or processed at a destination outside the UK and the European Economic Area ("EEA"). By submitting your data, you agree to this transfer, storing or processing.

Who will have access to my data?

JISC is the data controller with respect to your personal data and, as such, will determine how your personal data is used. Please see their privacy notice here [https://www.jisc.ac.uk/website/privacy-notice#]. JISC online surveys will share only anonymised data with the University of Oxford, for the purposes of research.

Your information may be shared with other parties that are interested in epilepsy and risk. Only anonymised and aggregated data will be shared. This may include other academic institutions, other charities that work in epilepsy, ministries of health and industry. These organisations may be outside your country of origin.

We would also like your permission to use your anonymised data in future studies, and to share data with other researchers (e.g. in online databases).

Responsible members of the University of Oxford and funders may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines, or as otherwise required by law.

The Principal Researcher is Arjune Sen who is attached to the Nuffield Department of Clinical Neurosciences.

This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee [reference number: R69353/RE001].

Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please speak to Arjune Sen; arjune.sen@ndcn.ox.ac.uk or contact SUDEP Action directly; info@sudep.org

We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

The Chair will seek to resolve the matter in a reasonably expeditious manner.

1. **Please note that you may only participate in this survey if you are 18 years of age or over.** I certify that I am 18 years of age or over. ✱ *Required*

○ Yes

2. **This study is for adults with epilepsy, people who care for people with epilepsy or healthcare workers who help in the management of people with epilepsy** This specific questionnaire is for people with epilepsy. I certify that I am an adult with epilepsy. ✱ *Required*

○ Yes

3. **If you have read the information above and agree to participate with the understanding that the data (including any personal data) you submit will be processed accordingly, please check the relevant box below to get started.** ✱ *Required*

○ Yes I agree to take part

Page 2: Introduction

Thank you for agreeing to share your information with us. By taking part in this research you are helping us to better understand how the current COVID-19 pandemic is impacting on people with epilepsy. Your input also helps us learn about any challenges or risks you may be facing and about your epilepsy self-management.

Please try to answer as many of the questions below as you can. There are some questions which have a free text box for you to answer in; we encourage you to share as much information as you can as this will help us spot patterns and trends in the data we receive.

If you completed this survey in spring/summer 2020, we invite you to repeat the survey, to outline how your experiences may have changed over time.

After submitting your responses, you’ll be able to access some extra information, free resources and places for support and advice. If you have any questions while completing the survey, please contact SUDEP Action (info@sudep.org or 01235 772850)

Page 3: About you

4. Have you completed this survey previously?

○ Yes
○ No

5. **Which country do you live in?** ✱ *Required*

☐

5.a. **What are the first four characters of your postcode/Zip Code?** ✱ *Required*

☐

5.b. **What is your gender?** *Optional*

○ Male
○ Female
○ Non-Binary
○ Prefer not to say
○ Other

5.b.i. Other (please specify if you wish)

☐

5.c. What is your age

○ 18-29

○ 30-39
○ 40-49
○ 50-59
○ >60
○ Prefer not to say

5.d. **Would you describe yourself as belonging to a minority ethnic group in your country?** ✱ *Required*

○ Yes
○ No
○ Unsure
○ Prefer not to say

5.d.i. **If yes, please describe which identity best describes you (optional)**

☐

Page 4: About your epilepsy

6. **What type of seizures do you have? Please tick all that apply:** ✱ *Required*

☐ Absence
☐ Atonic (drop attacks)
☐ Focal epilepsy, type unknown
☐ Focal seizure with loss of awareness (complex partial seizure)
☐ Focal seizure without loss of awareness (simple partial seizures)
☐ Generalised epilepsy, type unknown
☐ Myoclonic (brief muscle jerking
☐ Rare epilepsy subtype
☐ Tonic Clonic (Convulsion or ‘grand mal’)
☐ Does not have a specific diagnosis
☐ Not sure
☐ Other

6.a. Other : please specify

6.b. **Do you experience any of these seizures from sleep? (Nocturnal seizures or sleep seizures)** ✱ *Required*

☐ Yes
☐ No
☐ Unsure

6.b.i. If yes, please list the types of seizures you may have from sleep

6.c. **Approximately how many seizures have you had in the last 12 months? Please enter the number you have for each type of seizure. If unsure or if you do not have that type of seizure, enter n/a.**

	0	1	1 to 5	5 to 10	10 to 20	20 to 50	More than 50	N/A
Absence	○	○	○	○	○	○	○	○
Atonic (drop attacks)	○	○	○	○	○	○	○	○
Focal epilepsy, type unknown	○	○	○	○	○	○	○	○
Focal seizure with loss of awareness (complex partial seizure)	○	○	○	○	○	○	○	○
Focal seizure without loss of awareness (simple partial seizures)	○	○	○	○	○	○	○	○
Generalised epilepsy, type unknown	○	○	○	○	○	○	○	○
Myoclonic (brief muscle jerking)	○	○	○	○	○	○	○	○
Rare epilepsy subtype	○	○	○	○	○	○	○	○
Tonic Clonic (Convulsion or ‘grand mal’)	○	○	○	○	○	○	○	○
Does not have a specific diagnosis	○	○	○	○	○	○	○	○
Other seizure type/Unknown/unspecified seizure type	○	○	○	○	○	○	○	○

6.c.i. Please add any additional comments if you wish:

☐

7. **Do you have any other health conditions? Please tick all that apply:** ✱ *Required*

☐ Diabetes

☐ Heart condition

☐ Hypertension/high blood pressure

☐ Intellectual disability

☐ Memory difficulties

☐ Mental health difficulties

☐ Non-epileptic attacks/ dissociative seizures

☐ Respiratory/ lung condition

☐ Prefer not to say

☐ None of the above

☐ Other

7.a. Other (please specify)

Page 5: About the care of your epilepsy

8. **Who is the main health professional who manages (looks after) your epilepsy? e.g. the person who decides which epilepsy medication you take, for example.** ✱ *Required*

- ○ Community Neurology Nurse
- ○ Consultant Epileptologist
- ○ Consultant Neurologist
- ○ Epilepsy Specialist Nurse
- ○ General Practitioner
- ○ Learning disability Psychiatrist
- ○ Learning disability Specialist Nurse
- ○ Psychiatrist
- ○ Psychologist
- ○ Other

8.a. Other (please specify):

☐

8.b. **How many times per year do you usually see/consult a health professional about your epilepsy?** ✱ *Required*

- ○ <1
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6+

9. **Do you take medication for your Epilepsy?** ✱ *Required*

○ Yes
○ No

9.a. If you know which medications you take, please provide details below (optional):

☐

9.b. **If you do take anti-seizure medication, which statement best describes you?**

○ I always remember to take my medication, on time, as prescribed
○ I am sometimes forgetful about taking it
○ I often have trouble taking my medication
○ I don’t see why I should take it
○ None of the above
○ Not applicable

9.c. **Have you had any injuries or needed emergency care (e.g. via a paramedic, ambulance service, at A&E or a minor injuries unit) because of your epilepsy in the last 12 months?** ✱ *Required*

○ Yes
○ No

9.c.i. If yes please provide details below (optional):

☐

10. **Has the person in charge of your medical care discussed the following in the last 12**

months? (Tick all that apply): ✱ *Required*

☐ AED (seizure medication) side effects
☐ Rescue medication e.g. buccal midazolam
☐ Alcohol
☐ Contraception
☐ Discussing epilepsy with friends and family
☐ Epilepsy and driving
☐ Life changes (moving to a new house, jobs, study)
☐ Managing epilepsy and working
☐ Mental health and stress
☐ Pregnancy
☐ Recreational drugs
☐ Safety aids and equipment (i.e. seizure alarms, seizure diaries)
☐ Safety precautions and first aid (i.e. swimming)
☐ Sleep
☐ Stigma
☐ SUDEP
☐ None of the above

Page 6: COVID-19/Coronavirus impact on people with epilepsy

11. **Have you personally been infected with COVID-19:**

○ Yes
○ Possibly
○ No
○ Prefer not to say

12. **Have you had to self-isolate because of a household-member having symptoms of COVID-19?**

○ Yes
○ No
○ Prefer not to say

13. Whether you have been infected personally or not, have recent coronavirus/COVID-19 measures caused any changes to your health ✱ *Required*

○ Yes
○ No
○ Unsure

13.a. If yes, what changes have you noticed? (Tick all that apply):

☐ Changes in the number, type or length of seizures
☐ Disrupted sleep patterns
☐ Increased alcohol consumption

☐ Increased mental strain, stress, worry, anxiety, or depression
☐ Increased recreational drug consumption
☐ Other
☐ Not applicable

13.b. Other (please specify):

☐

13.c. Has COVID-19/coronavirus-related disruption made it difficult for you to take medication on time? ✱ *Required*

○ Yes
○ No
○ Not applicable

13.c.i. If yes, what are the reasons for this? (tick all that apply):

☐ Changes in everyday routine
☐ Delays in prescription deliveries
☐ Difficulties in collecting a prescription
☐ Difficulties in ordering a prescription
☐ Stress or worry causing forgetfulness
☐ Unsure
☐ Not applicable

13.c.i.a. Other (please specify):

☐

13.d. Are you living with anyone during current isolation/ lockdown measures? ✱

Required

○ Yes
○ No
○ Other

13.d.i. If other please specify:

☐

13.d.ii. If yes, are you living with someone who is aware of your epilepsy and able to provide first-aid? ✱ *Required*

○ Yes
○ No
○ Unsure
○ Other

13.d.ii.a. If other please specify:

☐

Page 7: COVID-19/Coronavirus impact on healthcare for people with epilepsy

14. Have you found it difficult getting help for your epilepsy from health services during the current pandemic? ✱ *Required*

○ Yes
○ No

14.a. If you answered yes, tick the services you have had difficulties with (please tick all that apply):

☐ Neurology services
☐ General hospital services
☐ General Practice
☐ Out-of-hours services
☐ Emergency services/accident and emergency (A&E)
☐ Ambulance services
☐ Learning disability services
☐ Pharmacy services
☐ Telephone advice services
☐ Other, please specify (optional):
☐ Not applicable

14.b. If you would like to share further information, please explain any problems you have had (optional):

15. Have you had planned medical appointments that have been changed? ✱ *Required*

○ Yes, my appointment has been changed
○ No, my scheduled appointment was cancelled
○ No, I haven’t had any communication about pre-scheduled appointments
○ Not applicable
○ Other

15.a. Other (please specify)

☐

15.b. If you answered yes, how has your appointment changed? *Optional*

☐ It is an in-person appointment later in the year
☐ It is an in-person appointment, but at a different healthcare facility
☐ It is an in-person appointment, but with a different health worker
☐ The appointment will be over telephone at the same time as planned
☐ The appointment will be over telephone at a different time to the original appointment
☐ The appointment will be over videocall at the same time as planned
☐ The appointment will be over videocall at a different time to the original appointment

15.b.i. Other (please specify):

☐

15.c. Are you satisfied with these changes?

○ Yes

○ No
○ Unsure

15.c.i. If you are not satisfied or unsure, please explain the reasons for your answer (optional):

16. **If you do not have any planned medical appointments, have you been contacted about changes in health care services due to COVID-19/coronavirus? (tick all that apply):** ✱ *Required*

☐ Yes, from my GP
☐ Yes, from my epilepsy specialist
☐ Yes from my learning disability specialist
☐ No, I have not heard from them
☐ Not applicable

16.a. Other, please specify (optional):

17. Have you been offered a COVID-19 vaccination?

○ Yes, and I am waiting to receive my first dose
○ Yes, and I have received one dose
○ Yes, and I have received two doses

○ Yes, but I will not accept it

○ No, I have not yet been offered a COVID-19 vaccination

○ Other

17.a. If other, please specify:

☐

17.b. If you have been vaccinated, please indicate the month you received each dose:

☐

18. If you have additional comments or concerns about your epilepsy during the COVID-19/coronavirus outbreak, please tell us your thoughts (optional)

☐

Page 8: THANK YOU!

Thank you for taking part in this research – your support is helping us to help people with epilepsy with risk in the UK and in countries around the world.

If you have any questions or concerns after filling in this survey, please do get in contact with us via SUDEP Action and we'll do our best to help: info@sudep.org or 01235 772850.
You may also want to speak to your doctor or nurse, if you are concerned about your epilepsy or physical or mental well-being at this time.

Below is also a list of free information, tools and resources which you may also want to take a look at, especially if you have questions or would like to learn more about epilepsy risks and how to positively manage them:

- WHO: https://www.who.int/emergencies/diseases/novel-coronavirus-2019
- ILAE: https://www.ilae.org/patient-care/covid-19-and-epilepsy/covid-19-and-epilepsy
- EPNS: https://www.epns.info/covid-19-and-neurological-disorders/
- NHS: www.nhs.uk/conditions/coronavirus-covid-19/
- Epilepsy & Risk information (via SUDEP Action): www.sudep.org or https://sudep.org/epilepsy-and-risk
- To find out more about this research project, other research into epilepsy risks and be kept up to date with the work of SUDEP Action, please register to receive the SUDEP Action Enews here: https://sudep.org/contact-us