

Epilepsy and risk during the COVID-19 pandemic; health care workers v1.2

Page 1: Participant information and consent

Epilepsy and COVID 19 – assessing escalation and mitigation of risk

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, Arjune Sen, Nuffield Department of Clinical Neuroscience at the University of Oxford, Jane Hanna OBE & Sammy Ashby (SUDEP Action, Project and PPI leads), in collaboration with other key partners are investigating risk in people with epilepsy.

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.

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.

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

Professor Orrin Devinsky, Langone Medical Centre, New York, USA

Professor Chantal Depondt, Hôpital Erasme – ULB, Bruxelles, Belgium

Dr Patricia Dugan, Langone Medical Centre, New York, USA

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. Consent: I certify that I am 18 years of age or over * *Required*

Yes

2. Consent: I certify that I am a healthcare worker who helps in the management of people with epilepsy * *Required*

Yes

3. Consent: 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: Basic demographics

4. Have you completed this survey previously?

- Yes
- No

5. Which country are you based in? * *Required*

6. What are the first two characters of the post-code/zip code where you work? * *Required*

7. Please indicate the date you are completing this survey * *Required*

Dates need to be in the format 'DD/MM/YYYY', for example 27/03/1980.

 

(dd/mm/yyyy)

8. What is your gender?

- Female
- Male
- Non binary
- Prefer not to say

9. Please enter your age

- 18-29
- 30-39
- 40-49

50-60

>60

Page 3: Role of healthcare provider

10. Which of the following best describes your primary role? * Required

- Community Neurology Nurse
- Consultant Epileptologist
- Consultant Neurologist
- Epilepsy Specialist Nurse
- General Practitioner
- Learning disability Psychiatrist
- Learning disability Specialist Nurse
- Medical trainee
- Neurophysiologist
- Nursing trainee
- Psychiatrist
- Psychologist
- Other

10.a. If you selected Other, please specify:

10.b. What type of patients do you see? * Required

- Adults only
- Children only
- Both adults and children
- Other:

10.b.i. If you selected Other, please specify: Optional

Page 4: About you and COVID-19

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

- Yes
- No
- Possibly
- Prefer not to say

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

- Yes
- No
- Prefer not say

13. If yes to either of the above, how many days were you not able to work because of COVID-19?

14. If no to being infected, have concerns over developing COVID-19 affected your productivity to work? * *Required*

- Not at all
- A little
- Quite a bit
- A moderate amount
- A lot
- Prefer not to say

15. Have any of the following had any impact on you during the COVID-19 pandemic?

	<i>Optional</i>				
	No impact	Minimal impact	Some impact	Significant impact	Prefer not to say

Own co-morbidities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern about becoming infected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern about own household/family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern about people with epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of PPE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social distancing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health of self	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health of other colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

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:

Page 5: About your service for people with epilepsy and COVID--19

18. Prior to the COVID-19 pandemic did you do **ROUTINE** out-patient clinic consultations by telephone? * *Required*

18.a. If yes, what proportion of your routine out-patient clinic consultations were done this way

- <10%;
- 10-25%
- 26-50%
- 51-75%
- >75%

19. Prior to the COVID-19 pandemic did you do ROUTINE out-patient clinic consultations by video-call? * *Required*

- Yes
- No

19.a. If yes, what proportion of your routine out-patient clinic consultations were done this way

- <10%;
- 10-25%
- 26-50%
- 51-75%
- >75%

19.a.i. If yes, what platform did you use *Optional*

- Attend anywhere
- Skype
- Zoom
- other – please specify

19.a.ii. Other platform used: *Optional*

20. During the COVID-19 pandemic, when we presume there are no/very few face to face appointments, what proportion of your work is being done by telephone? * Required

- <10%
- 10-25%
- 25-50%
- 50-75%
- >75%

21. During the COVID-19 pandemic, when we presume there are no/very few face to face appointments, what proportion of your work is being done by video-call? * Required

- <10%
- 10-25%
- 25-50%
- 50-75%
- >75%

22. Are you using other methods to communicate with your patients e.g. email? * Required

- Yes
- No

22.a. If yes, please specify method and proportion of your work that is being done in this way

23. Are you seeing any out-patients face to face at all? * Required

Please select no more than 1 answer(s).

- Yes
- No

23.a. If yes, please detail. An example may be to perform VNS titration

Page 6: Diagnosing and treating epilepsy during the COVID-19 pandemic

24. Are you as confident diagnosing epilepsy when working remotely as when seeing people face to face?

* Required

Please select no more than 1 answer(s).

- Significantly less confident
- A little less confident
- Just as confident
- More confident

24.a. Reasons for answer: * Required

25. What impact is the reduced availability of the following investigations having on your ability to help DIAGNOSE people with epilepsy?

* Required

	* Required			
	No change	Minimal impact	Some impact	Significant impact
Blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antibody tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ECG	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EEG	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brain imaging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neuropsychology assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neuropsychiatry assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25.a. If you wish to make any other comment on availability of investigations to help diagnose epilepsy, please make them here:

26. What impact is the reduced availability of the following investigations/treatments having on your ability to TREAT people with epilepsy?

* Required

	* Required			
	No change	Minimal impact	Some impact	Significant impact

Blood tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antibody tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECG	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EEG	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain imaging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuropsychology assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuropsychiatry assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resective epilepsy surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
VNS implantation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26.a. If you replied other, please give more details

26.b. If you wish to make any other comment on availability of investigations to help treat epilepsy, please make them here:

27. **Has your approach to PRESCRIBING anti-seizure medication altered in any way?** * Required

Please select no more than 1 answer(s).

- No change
- Minimal change
- Some change
- Significant change
- Prefer not to say

27.a. If there has been a change, please give reason(s):

27.b. **Has your approach to WITHDRAWING anti-seizure medication altered in any way?** * Required

Please select no more than 1 answer(s).

- No change
- Minimal change

- Some change
- Significant change
- Prefer not to say

27.b.i. If there has been a change, please give reason(s):

28. Is your impression that, overall, seizure frequency is altered during the COVID-19 pandemic? * Required

- I think that seizures are more frequent
- No change
- I think that seizures are less frequent
- Prefer not to say

28.a. Reasons for your answer

29. Do you think that working remotely has overall affected the care you can offer your patients? * Required

- It has had significant negative impact
- It has had some negative impact
- No change
- It has had some positive impact
- It has had significant positive impact
- Prefer not to say

29.a. If you think that there has been an impact, either positive, or negative, or both some positives and some negatives, please give details:

30. Overall do you think that the risk to people with epilepsy is increased during the COVID-19 pandemic in the following categories?

	<i>Optional</i>				
	No change	Minimal change	Some change	Significant change	Prefer not to say
Risk of seizure control worsening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of anti-seizure medications being unavailable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risks to mental health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of adverse psychosocial impact	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30.a. Any other comments?

Page 7: Epilepsy and risk during COVID-19:

31. During your clinical care would you/ do you, where applicable, discuss the following. Please click 'view as separate questions' if the table does not display easily:

	PRIOR TO COVID-19 * Required					DURING COVID-19 * Required				
	Never	Occasionally	Sometimes	Most of the time	Always	Never	Occasionally	Sometimes	Most of the time	Always
Alcohol consumption	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contraception	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing epilepsy with friends and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epilepsy and driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing epilepsy and working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Life changes (moving to a new house, jobs, study)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rescue medication e.g. buccal midazolam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health and stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memory difficulties	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Potential pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational drug usage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Safety aids and equipment (i.e. seizure alarms, seizure diaries)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety of others e.g. if young children at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety precautions and first aid (e.g. bathing, swimming)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stigma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31.a. Any other comments:

32. During the COVID-19 pandemic do you now also discuss:

	<i>* Required</i>				
	Never	Occasionally	Sometimes	Most of the time	Always
Anxieties related to COVID-19	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Government safety advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hand washing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions between anti-seizure medications and COVID-19 treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Management of fever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of people with epilepsy contracting COVID-19	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social distancing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

33. During your clinical care in people who have experienced a first seizure, where applicable, will you discuss the following. Please click 'view as separate questions' if the table does not display easily

	PRIOR TO COVID-19 * Required					DURING COVID-19 * Required				
	Never	Occasionally	Sometimes	Most of the time	Always	Never	Occasionally	Sometimes	Most of the time	Always
Alcohol consumption	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contraception	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing epilepsy with friends and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epilepsy and driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing epilepsy and working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Life changes (moving to a new house, jobs, study)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health and stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memory difficulties	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Potential pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational drug usage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety aids and equipment (i.e. seizure alarms, seizure diaries)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Safety of others e.g. if young children at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety precautions and first aid (e.g. bathing, swimming)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stigma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

33.a. Any other comments:

34. In people for whom English/ your country's national language is not their first language, what methods are you using to help with remote consultations? Choose all that apply * Required

- None
- Family or household member providing translation
- Using third party translation service (please provide details)

34.a. Other (please specify)

34.b. Is your approach to risk in people who do not speak English/ your country's national language as their first language any different to those for who English/ your country's national language is their first language and if so why? Examples may include - different cultural approach to risk; too difficult to explain remotely; waiting for face to face appointment

35. In people with epilepsy and intellectual disability, what methods are you using to help with remote consultations? Tick all that apply * Required

- No additional methods
- Speaking to family members
- Speaking to carers
- Contacting general practitioner
- Other, please specify
- Prefer not to say

35.a. Other (please specify)

35.a.i. Is your approach to risk in people with intellectual disability any different to those without learning disability and if so why? Examples may include - different approach to risk; too difficult to explain remotely; waiting for face to face appointment

36. In people with dissociative seizures (non-epileptic attacks), have you changed your management strategies? *

Required

- No change
- Minimal change
- Some change
- Significant change

36.a. If there has been a change, please provide details

37. Are you pro-actively contacting vulnerable people with epilepsy during the COVID-19 pandemic:

	* Required	
	Yes	No
Elderly (aged >70)	<input type="radio"/>	<input type="radio"/>
People with learning disability	<input type="radio"/>	<input type="radio"/>
Pregnant women with epilepsy	<input type="radio"/>	<input type="radio"/>



37.a. Other (please specify)

38. Are you aware of any cases of SUDEP during the COVID-19 pandemic? If so and you are happy to provide anonymous details of the case, please email separately to info@sudep.org

39. If there is anything else you would like to share with us about your epilepsy service or your delivery of epilepsy care during the COVID-19 pandemic, please note it here

Page 9: THANK YOU!

Thank you for taking part in this research – your support is helping us to help people with epilepsy 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 can also contact the Lead Researcher, Dr Arjune Sen via arjune.sen@ndcn.ox.ac.uk.

Below is also a list of free information, tools and resources for health professionals which you may find of interest in supporting your work with people with epilepsy:

- 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/
- Free epilepsy risks communication Checklist for health professionals (the SUDEP and Seizure Safety Checklist): <https://sudep.org/checklist>
- Epilepsy & Risk information (via SUDEP Action): <https://sudep.org/epilepsy-and-risk>
- Free leaflets on epilepsy risks: <https://sudep.org/leaflets-and-downloadable-information> (hard copies can be ordered for free direct from SUDEP Action)
- International Epilepsy organisations: <https://sudepactionday.org/get-involved/organisations/>
- 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 & their free resources for health professionals, please register to receive the SUDEP Action Health Professional Enews here: <https://sudep.org/contact-us>

Key for selection options

18 - Prior to the COVID-19 pandemic did you do ROUTINE out-patient clinic consultations by telephone?

Yes

No
