



PARTICIPANT INFORMATION SHEET

Study title: Research to design a course on seizure first aid for people with epilepsy and their family and friends

(REC reference no: 15/NW/0225)

1. Invitation paragraph

You are being asked to take part in a research study. Here is information to help you decide if you want to take part.

Please read it carefully. Ask us if there is anything you do not understand or if you want more information. You can take time to decide whether or not you want to take part.

2. The background to the study

Currently, 6 out of 7 hospital admissions for epilepsy are made on an emergency, rather than planned basis. Many of these visits have little long term benefit for patients as the seizures leading to them were uncomplicated and occurred in those in whom the diagnosis was already established. Moreover, these emergency visits do not typically lead to people with epilepsy receiving any additional ongoing support from the NHS.

One reason why people with epilepsy visit emergency departments for uncomplicated seizures is that they and their informal carers can lack confidence managing seizures. They can be unsure as to what the effects of seizures are, not know when medical attention is required, and can be fearful of death. As you will know, the NHS has not yet implemented routine education for people diagnosed with epilepsy and there is limited time within usual care appointments for this information to be provided.

Therefore, in partnership with the Epilepsy Society, our project aims to develop a short, group-based course on seizure first aid. It will be specifically designed for adults with established epilepsy who frequently make emergency visits and their family and friends. Once developed, we shall complete a pilot trial of the course.

3. How do you want people like me to be involved?

Rather than starting from scratch, the course that we will develop shall be based on a successful ½-day group course offered by the Epilepsy Society. Their course is titled 'Epilepsy awareness and seizure management'. People from a variety of backgrounds, including patients, carers, teachers and care home staff, pay to attend their course. It is delivered by an educational facilitator who has experience of working with people with epilepsy, such as a nurse.

The Society's course was not specifically developed to meet the needs of people with epilepsy who visit emergency departments. This group can be particularly challenged by epilepsy and may have lower educational levels. We therefore need to adapt the course, refining its content and format for the target population.

To help us do this, we are seeking advice on what changes are needed to the current course from representatives from the main groups and sectors supporting people with epilepsy. We shall also consult with patients and carers.

4. Why am I being invited to take part?

The groups we shall seek feedback from includes the ambulance service, neurologists, nurses, general practitioners, and emergency medicine doctors. We shall also speak with representatives from user groups and the commissioning sector. We believe your expertise makes you well placed to provide us with feedback on the course.

5. If I agreed to take part what would I have to do?

You would be sent the content and materials for the Epilepsy Society's current package and their guidelines on what constitutes appropriate first aid for seizures. Then ~2 weeks later you will be asked to provide feedback by means of an interview with our research worker. The interview would last about 60 minutes.

Depending on your preference, the interview will be conducted face-to-face, by telephone or by Skype. The things that we would like your feedback on will vary depending on your area of expertise. If you are medically trained, questions might include:

- "What did and didn't you like about the course's current content and delivery?"
- "What inaccuracies are there in the content of the current course?"
- "How do you suggest the programme could be more helpful?"
- "How do you think the intervention might be best rolled out within the NHS, if a future trial found it to be effective?"

6. Do I have to take part?

No. It is up to you. If you want to take part, you will be given this information sheet to keep, given the opportunity to have any questions answered and asked to sign a consent form.

If you decide to take part, you are free to change your mind at any time and you will not need to give a reason. No new information would be collected from you. However, any information that had already been collected would typically be kept by the study team.

7. Are there any benefits in taking part?

The information we get from the study may help us better support people with epilepsy in the future.

To recognise the time and effort involved in reviewing the course materials and in providing feedback you will receive a consultancy fee of £200.

8. Are there any risks in taking part?

There are no known disadvantages or risks of taking part.

9. Will my taking part be kept confidential?

Yes. Only the research team will be able to see the information. This includes the audio recording from your interview. Anything that we publish or pass on will have your name and address and any personal information removed so that you cannot be identified. All information will be stored on password protected computers at the University of Liverpool.

10. What if something goes wrong?

The University of Liverpool provides insurance cover just in case you experience a problem from taking part in the study. If you are worried about anything to do with the study, you should contact the research team. Their details are at the end of this sheet.

11. What will happen to the results of the study?

The results from this study will be used to identify what changes are needed to the Epilepsy Society's current course. They might also be published. You will not be identified in any report. If you would like to have a copy of any published results, you can ask for one by contacting the study team.

All information generated by this study, including the transcriptions from the interviews, will be held on password secured computers at the University of Liverpool offices. In line with the university's policy, data will be archived at the University of Liverpool for of at least 10 years, longer if judged to be of historical significance. After this period the data will be destroyed.

12. Who is funding and organising the study?

The study is funded by the National Institute for Health Research. The study is being done by the Institute of Psychology, Health and Society, The Whelan Building, University of Liverpool, L69 3GL. The lead researcher is Dr Adam Noble.

13. Who has reviewed the study?

This study has been reviewed and approved by National Research Ethics Service Committee North West - Liverpool East (Reference: 15/NW/0225).

14. Contact for further information:

Should you need further information about the study you can contact the research team at any time:

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You will be given a copy of this information sheet and a signed copy of your consent form to keep.