# Seizure first aid training for people with epilepsy attending emergency departments and their significant others: the SAFE intervention and feasibility RCT

Adam Noble,<sup>1\*</sup> Sarah Nevitt,<sup>2</sup> Emily Holmes,<sup>3</sup> Leone Ridsdale,<sup>4</sup> Myfanwy Morgan,<sup>5</sup> Catrin Tudur-Smith,<sup>2</sup> Dyfrig Hughes,<sup>3</sup> Steve Goodacre,<sup>6</sup> Tony Marson<sup>7</sup> and Darlene Snape<sup>1</sup>

**Declared competing interests of authors:** none

Published October 2020 DOI: 10.3310/hsdr08390

## **Plain English summary**

The SAFE intervention and feasibility RCT Health Services and Delivery Research 2020; Vol. 8: No. 39 DOI: 10.3310/hsdr08390

NIHR Journals Library www.journalslibrary.nihr.ac.uk

<sup>&</sup>lt;sup>1</sup>Department of Health Services Research, University of Liverpool, Liverpool, UK

<sup>&</sup>lt;sup>2</sup>Department of Biostatistics, University of Liverpool, Liverpool, UK

<sup>&</sup>lt;sup>3</sup>Centre for Health Economics and Medicine Evaluation, Bangor University, Bangor, UK

<sup>&</sup>lt;sup>4</sup>Department of Basic and Clinical Neuroscience, King's College London, London, UK

<sup>&</sup>lt;sup>5</sup>Institute of Pharmaceutical Science, King's College London, London, UK

<sup>&</sup>lt;sup>6</sup>School of Health and Related Research, University of Sheffield, Sheffield, UK

<sup>&</sup>lt;sup>7</sup>Department of Molecular and Clinical Pharmacology, University of Liverpool, Liverpool, UK

<sup>\*</sup>Corresponding author adam.noble@liv.ac.uk

# **Plain English summary**

imited knowledge of how to manage seizures leads some individuals with epilepsy to visit emergency departments following seizures despite not needing medical attention. Such visits are expensive for the NHS and can be inconvenient for patients.

Part A of this project aimed to develop a self-management course for patients frequently visiting emergency departments for epilepsy, as well as for their significant others, such as family and friends. Having developed the course, a large trial was needed to find out if it would be beneficial. Before doing that we needed to answer the following question: 'can such a trial be done?'. Part B of this project aimed to answer this by conducting a 'pilot randomised controlled trial'. A pilot is like a practice run.

In part A, nine health-care professionals and 23 service users helped us to develop the course, which we called Seizure first Aid training For Epilepsy (SAFE). They considered it acceptable and NHS feasible.

In part B, 53 patients diagnosed with epilepsy (and 38 significant others) were recruited from three emergency departments. Patients were randomly assigned to either an invitation to attend SAFE (with or without their significant other) or usual treatment only. All participants took their medication as usual. Participants were asked to complete questionnaires on their use of emergency departments and confidence managing seizures 3, 6 and 12 months later.

The pilot trial found that emergency departments could not easily identify people to invite, and fewer people agreed to take part than expected (12.5% rather than at least 20%). Those who did take part tended to participate for the full length of the trial, and information on their use of emergency departments 12 months later was obtained in over 90% of cases. Nearly all participants said that they would take part in such a trial again.

Even though parts A and B were carried out successfully, it was difficult to identify potential participants and fewer people agreed to participate than we expected, so a large trial, as currently designed, is not feasible.

## **Health Services and Delivery Research**

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

#### Criteria for inclusion in the Health Services and Delivery Research journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

#### **HS&DR** programme

The HS&DR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HS&DR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-services-and-delivery-research.htm

#### This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 14/19/09. The contractual start date was in June 2015. The final report began editorial review in September 2019 and was accepted for publication in April 2020. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2020. This work was produced by Noble et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

## Editor-in-Chief of Health Services and Delivery Research and NIHR Journals Library

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

### **NIHR Journals Library Editors**

**Professor John Powell** Chair of HTA and EME Editorial Board and Editor-in-Chief of HTA and EME journals. Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Senior Clinical Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

**Professor Andrée Le May** Chair of NIHR Journals Library Editorial Group (HS&DR, PGFAR, PHR journals) and Editor-in-Chief of HS&DR, PGFAR, PHR journals

**Professor Matthias Beck** Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson Consultant Advisor, Wessex Institute, University of Southampton, UK

Ms Tara Lamont Senior Scientific Adviser (Evidence Use), Wessex Institute, University of Southampton, UK

Dr Catriona McDaid Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Professor of Wellbeing Research, University of Winchester, UK

Professor John Norrie Chair in Medical Statistics, University of Edinburgh, UK

**Professor James Raftery** Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

**Professor Helen Snooks** Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

**Professor Jim Thornton** Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk