Training nurses in a competency framework to support adults with epilepsy and intellectual disability: the EpAID cluster RCT

Howard Ring,^{1,2,3}* James Howlett,⁴ Mark Pennington,⁵ Christopher Smith,¹ Marcus Redley,^{1,3,6} Caroline Murphy,⁷ Roxanne Hook,¹ Adam Platt,¹ Nakita Gilbert,¹ Elizabeth Jones,^{1,2} Joanna Kelly,⁷ Angela Pullen,^{8,9} Adrian Mander,⁴ Cam Donaldson,¹⁰ Simon Rowe,¹¹ James Wason⁷ and Fiona Irvine¹²

¹Department of Psychiatry, University of Cambridge, Cambridge, UK ²Cambridgeshire and Peterborough NHS Foundation Trust, Cambridge, UK ³National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England, Cambridge, UK ⁴Medical Research Council (MRC) Biostatistics Unit, Cambridge Institute of Public Health, Cambridge, UK ⁵King's Health Economics, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK ⁶Norwich Medical School, University of East Anglia, Norwich, UK

⁷King's Clinical Trials Unit, Institute of Psychiatry, King's College London, London, UK

⁸Epilepsy Action, Leeds, UK

⁹NHS Leeds West Clinical Commissioning Group, Leeds, UK

¹⁰Yunus Centre for Social Business and Health, Glasgow Caledonian University, Glasgow, UK

¹¹NHS Wakefield Clinical Commissioning Group, Wakefield, UK

¹²School of Health and Population Science, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK

*Corresponding author har28@cam.ac.uk

Declared competing interests of authors: During the preparation of this report Howard Ring was the chairperson of the Health Technology Assessment Mental, Psychological and Occupational Health Panel and he was a member of the Psychological and Community Therapies Panel during the project. Cam Donaldson was a member of the Medical Research Council Methodology Research Panel.

Published February 2018 DOI: 10.3310/hta22100

Plain English summary

The EpAID cluster RCT

Health Technology Assessment 2018; Vol. 22: No. 10 DOI: 10.3310/hta22100

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

Plain English summary

A dults with an intellectual disability (ID) have an intelligence quotient (IQ) of < 70 and serious limitations A in communication and the abilities required for many or all of the demands of everyday life. They also have an increased risk of epilepsy compared with the rest of the population. The epilepsy experienced by those with an ID tends to be more severe and more difficult to treat than epilepsy in those without an ID.

The aim of the Epilepsy And Intellectual Disability (EpAID) trial was to see whether or not making use of the recently developed Learning Disability Epilepsy Specialist Nurse Competency Framework could improve outcomes for adults with an ID and epilepsy compared with treatment as usual. A key aspect of this framework is that it was designed to be used by all ID nurses, not just the small number of epilepsy nurse specialists, and, therefore, if it is shown to be effective, it could be readily used across the NHS.

The trial took place in 17 community ID clinical teams across England, Scotland and Wales and involved 312 adults with an ID and epilepsy. Overall, the results of the trial indicated that, in terms of clinical outcomes, the competency framework was no better than treatment as usual. For those with a mild or moderate ID the results suggested that use of the framework may have been associated with a slight reduction in the severity of their seizures, as noticed by somebody providing care for them.

The EpAID clinical trial is the first controlled trial to test the possible benefits of a nurse-led intervention for epilepsy in adults with an ID. The economic analysis suggested that, in general, the competency framework intervention resulted in a small reduction in quality of life but saved money.

© Queen's Printer and Controller of HMSO 2018. This work was produced by Ring *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health 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.

Health Technology Assessment

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 4.236

Health Technology Assessment is indexed in MEDLINE, CINAHL, EMBASE, The Cochrane Library and the Clarivate Analytics Science Citation Index.

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 HTA archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hta. 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 Technology Assessment journal

Reports are published in *Health Technology Assessment* (HTA) if (1) they have resulted from work for the HTA programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

HTA programme

The HTA programme, part of the National Institute for Health Research (NIHR), was set up in 1993. It produces high-quality research information on the effectiveness, costs and broader impact of health technologies for those who use, manage and provide care in the NHS. 'Health technologies' are broadly defined as all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care.

The journal is indexed in NHS Evidence via its abstracts included in MEDLINE and its Technology Assessment Reports inform National Institute for Health and Care Excellence (NICE) guidance. HTA research is also an important source of evidence for National Screening Committee (NSC) policy decisions.

For more information about the HTA programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hta

This report

The research reported in this issue of the journal was funded by the HTA programme as project number 10/104/16. The contractual start date was in August 2013. The draft report began editorial review in March 2017 and was accepted for publication in September 2017. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft 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 HTA 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 HTA programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2018. This work was produced by Ring *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. 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).

Health Technology Assessment Editor-in-Chief

Professor Hywel Williams Director, HTA Programme, UK and Foundation Professor and Co-Director of the Centre of Evidence-Based Dermatology, University of Nottingham, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

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 Director of the NIHR Dissemination Centre, University of Southampton, UK

Ms Tara Lamont Scientific Advisor, NETSCC, 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 John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), 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 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 Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

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

Please visit the website for a list of members of the NIHR Journals Library Board: www.journalslibrary.nihr.ac.uk/about/editors

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