Using nationwide ‘big data’ from linked electronic health records to help improve outcomes in cardiovascular diseases: 33 studies using methods from epidemiology, informatics, economics and social science in the ClinicAl disease research using LInked Bespoke studies and Electronic health Records (CALIBER) programme

Harry Hemingway,1,2* Gene S Feder,3 Natalie K Fitzpatrick,1,2 Spiros Denaxas,1,2 Anoop D Shah1,2 and Adam D Timmis2,4,5

1Institute of Health Informatics, University College London, London, UK
2Farr Institute of Health Informatics Research, University College London, London, UK
3Centre for Academic Primary Care, School of Social and Community Medicine, University of Bristol, Bristol, UK
4Barts Health NHS Trust, London, UK
5Farr Institute of Health Informatics Research, Queen Mary University of London, London, UK

*Corresponding author

Declared competing interests of authors: none

Published January 2017
DOI: 10.3310/pgfar05040

Plain English summary

Big data to improve outcomes in cardiovascular diseases
Programme Grants for Applied Research 2017; Vol. 5: No. 4
DOI: 10.3310/pgfar05040

NIHR Journals Library www.journalslibrary.nihr.ac.uk
Plain English summary

How can we reduce death and suffering from heart disease by learning from the lifelong experience of UK citizens? Heart disease is the most common cause of early death in the UK, but we do not know how we can deliver benefits to patients by bringing together general practitioner and hospital records. We established a secure, anonymous research platform [ClinicAl disease research using Linked Bespoke studies and Electronic health Records (CALIBER)] and we used this to identify ways to improve quality of care and prospects for patients with heart disease. We studied millions of people initially free from heart disease and followed them up. We also studied people presenting with chest pain in the community or suffering from a heart attack. We compared treatment in the UK and Sweden, as both countries have similar health systems, although Sweden achieves better results for patients. We also tested a computerised tool that helps guide doctors to make decisions in chest pain clinics. We carried out a detailed study of hospital working practices to identify the types of care that give better results. Finally, we recruited >3000 patients being investigated for chest pain to help find out why diseases progress. Our findings could help doctors and policy-makers to make better decisions on care so that patients have better quality of life and longer life. In addition, the results will lead to better public health policy. Our findings clearly show that research using one of the NHS’ greatest assets – its data – is vital to innovate improvements in disease prevention, to make earlier diagnoses and to give the best treatments.
Programme Grants for Applied Research

ISSN 2050-4322 (Print)
ISSN 2050-4330 (Online)

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

Editorial contact: nihredit@southampton.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar. 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 Programme Grants for Applied Research journal
Reports are published in Programme Grants for Applied Research (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme
The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health Research (NIHR), was set up in 2006 to produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future. The Programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director.

The programme is a national response mode funding scheme that aims to provide evidence to improve health outcomes in England through promotion of health, prevention of ill health, and optimal disease management (including safety and quality), with particular emphasis on conditions causing significant disease burden.

For more information about the PGfAR programme please visit the website: http://www.nihr.ac.uk/funding/programme-grants-for-applied-research.htm

This report
The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0407-10314. The contractual start date was in January 2009. The final report began editorial review in March 2015 and was accepted for publication in April 2016. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR 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, CCF, NETSCC, PGfAR or the Department of Health. 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 PGfAR programme or the Department of Health.

© Queen’s Printer and Controller of HMSO 2017. This work was produced by Hemingway 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).
Programme Grants for Applied Research Editor-in-Chief

Professor Paul Little  Professor of Primary Care Research, University of Southampton, 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 Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

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

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

Professor Matthias Beck  Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke  Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Senior Scientific Advisor, Wessex Institute, UK

Ms Tara Lamont  Scientific Advisor, NETSCC, UK

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

Professor Geoffrey Meads  Professor of Health Sciences Research, Health and Wellbeing Research Group, 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: nihredit@southampton.ac.uk