Eye donation from palliative and hospice care contexts: the EDiPPPP mixed-methods study

Tracy Long-Sutehall,¹ Mike Bracher,¹
Sarah Mollart² and Jane Wale³

¹School of Health Sciences, University of Southampton, Southampton, UK
²West Suffolk Hospital NHS Foundation Trust, Suffolk, UK
³Milton Keynes University Hospital NHS Foundation Trust, Eaglestone, UK

*Corresponding author  T.Long@soton.ac.uk

The authors would like to acknowledge the contribution of our colleague Dr. Banyana C. Madi-Segwagwe Research Fellow for the EDiPPPP study who died unexpectedly shortly after completion of the study.

Disclosure of interests of authors

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/KJWA6741.

Primary conflicts of interest: None declared.

Published November 2023
DOI: 10.3310/KJWA6741

Plain language summary

Eye donation from palliative and hospice care contexts: the EDiPPPP mixed-methods study

Health and Social Care Delivery Research 2023; Vol. 11: No. 20
DOI: 10.3310/KJWA6741

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

The Royal National Institute of Blind people report that over 2 million people in the United Kingdom are living with sight loss. This number is predicted to double to nearly 4 million by 2050. Conditions that lead to sight loss and impaired vision can be treated if eye tissue is available through, for example corneal transplantation, reconstructive surgery and research into eye diseases. However, the problem is that there is not enough eye tissue available to meet current need.

Patients under the care of hospice care services and hospital palliative care services who, due to a cancer diagnosis, are unable to donate other organs or tissues, may be able to donate their eyes.

To explore potential for eye donation in these settings, we looked at the clinical notes from patients who died in the previous 2 years to see if they could potentially have been a donor. We also interviewed patients and carers seeking their views regarding 'if', 'when' and 'how' a conversation about eye donation should take place within end-of-life care planning. We also asked healthcare professionals (via interviews and a national survey) about their views regarding eye donation being part of end-of-life planning, and what they saw as the key barriers to this becoming a routine practice.

We found that many patients are eligible for eye donation, but very few are asked about this option, and that patients indicated they wanted this option raised with them so that they could make decisions about donation. A review of patient notes, healthcare professional interviews and survey responses indicate that eye donation is not part of the current routine clinical practice.

Our work presents a clear case for a change to current practice so that patients who wish to donate are offered this opportunity as a part of routine end-of-life care, and that changes in the current practice require specific training initiatives and institutional support.
Criteria for Inclusion in the Health and Social Care Delivery Research journal

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

HSDR programme

The HSDR 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 HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm.

This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number HSDR 17/49/42. The contractual start date was in January 2019. The final report began editorial review in August 2022 and was accepted for publication in April 2023. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR 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 and Care 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, the HSDR 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, the HSDR programme or the Department of Health and Social Care.

Copyright © 2023 Long-Sutehall et al. This work was produced by Long-Sutehall et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaptation in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).
NIHR Journals Library Editor-in-Chief

Dr Cat Chatfield  Director of Health Services Research UK

NIHR Journals Library Editors

Professor Andrée Le May  Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Dr Peter Davidson  Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, 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  Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Ms Tara Lamont  Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid  Reader in Trials, 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  Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery  Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Rob Riemsma  Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Helen Roberts  Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, 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

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

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