

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

Scientific 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

Scientific summary

Background

Globally, the estimated number of visually impaired people is reported by the World Health Organization (WHO) to be 285 million, with 39 million individuals recorded as blind, and 246 million as having low vision. According to Pascolini and Mariotti, over 10 million of those reported as blind have bilateral corneal blindness, which could be restored with a corneal transplant. However, these individuals do not have access to sight-saving and sight-restoring transplantation surgery owing to a shortfall in supply of tissue (cornea and sclera) that is only available via eye donation (ED).

According to the Royal National Institute of Blind (RNIB), over 2 million people in the UK have sight loss caused by conditions such as keratoconus and Fuchs' corneal dystrophy, which can be treated if eye tissue is available (e.g. by corneal transplantation and reconstructive surgery). Eye tissue is also needed for research into a wide variety of diseases, for example, endothelial failure post cataract surgery. The RNIB reports that approximately 5000 corneal transplants are required annually in the UK to address disease and injury resulting in sight loss, with costs to the UK economy (through unpaid carer burden and reduced employment rates) reported as £4.34 billion annually. Critically, this organisation predicts that by 2050, the number of people with sight loss will double to nearly 4 million in the UK mainly owing to an aging population. It is, therefore, imperative that the tissue needed to intervene in these conditions and to support research into the causes and treatment of eye disease is available.

The National Health Services Blood and Transplant (NHSBT) Tissue and Eye Services (TES) Bank in Speke, Liverpool (who supply most eyes for UK surgery) aim to achieve a weekly stock of 350 eyes so that they can provide 70 eyes every working day for treatment or research. From April 2021 to March 2022, donation of eyes from all sources (solid organ donation, tissue donation) generated 4555 eyes from 2286 donors equating to only 13 eyes per day and 88 eyes available per week. Significantly, the actual number of people waiting for a corneal transplant is difficult to confirm, as there is no centralised waiting list for patients who need a corneal transplant (unlike solid organ donation). A further pressure on the nationally reported donation rate of 4555 eyes is that approximately 30% will be discarded due to infection/viruses, with supply further compromised by a 28-day limit to storage requiring disposal of tissue thereafter.

Therefore, as the current supply of eye tissue is insufficient to meet the demand, new routes of supply are needed. As hospice care (HC) and hospital-based palliative care (HPC) services have been reported as potential donation sources, the ED from palliative and hospice care contexts: investigating potential, practice, preference and perceptions (EDiPPPP) study investigated the potential of these locations to meet the current supply deficits.

Research questions and study objectives

Research Question (RQ1a): Potential – What is the potential for ED in HPC services and HC services?

RQ1b: What consequences will any increase in ED from these settings have for NHSBT-TEs in relation to resources/infrastructure/logistics?

Objective 1: To scope the size and clinical characteristics of the potential ED population from research sites.

Objective 2: To map the donation climate of each research site via a systematic assessment tool: the Rapid Assessment of hospital Procurement barriers in Donation (RAPiD).

RQ2: Practice, Preference and Perceptions – What system-based/attitudinal and educational barriers/facilitators to ED influence the identification and referral of potential eye donors in clinical settings, and the embedding of ED in end-of-life care (EoLC) planning?

Objective 3: Identify factors (attitudinal, behavioural) that enable or challenge service providers to consider and propose the option of ED as part of EoLC planning from a local and national perspective.

Objective 4: Identify service users' views regarding the option of ED and the propriety of discussing ED as part of admission procedures or as part of EoLC-planning conversations.

RQ3: What behaviour change strategies will be effective in increasing ED across the community of service providers and service users within HPC and HC?

Objective 5: Develop an empirically based theoretically informed intervention designed to change behaviours in relation to the identification, approach/request and referral of patients from HPC and HC for ED.

Methods

Eye donation from palliative and hospice care contexts: investigating potential, practice, preference and perceptions was structured in line with the six steps in quality intervention development (6SQiD) framework. Study design used mixed methods, applying theoretical perspectives and intervention mapping methodologies to deliver three interlinked and developmental work packages (WP).

Data sources

Literature review, retrospective note review (WP1), interviews/focus groups (WP1 and 2), participant observation (WP1), secondary analysis of primary data (WP2), national survey (WP2), transparent expert consultation (WP3).

Participants

Work package 1 – 105 healthcare professionals (HCPs) participated in interviews or focus groups. WP2 – 62 service users participated in interviews, 156 service providers participated in the national survey. WP3 – 21 expert consultees [patient and public involvement (PPI), cross-discipline HCP, stakeholder groups] participated in the transparent expert consultation (TEC).

Data collection sites

Three HC and three HPC services in the North, Midlands and the South of England (one of each service type in each region, for a total of two sites per region); online survey (UK).

Data analysis

Interviews and focus groups: qualitative content analysis, following the five-level qualitative data analysis (QDA) framework. Survey data: descriptive statistics for closed questions, qualitative content analysis for free-text questions.

Results and findings

The retrospective note review (WP1) indicated significant potential for ED across HC and HPC settings. Of the 1199 deceased patient case notes, 46% ($n = 553$) were agreed as being eligible for referral for ED [in HC settings 56% ($n = 337$) of cases and in HPC 36% ($n = 216$) of the cases were agreed as eligible]. Twenty-four per cent ($n = 289$) of all the cases were agreed as ineligible. In <4% of all cases agreed as eligible, there was an approach or referral to the retrieving organisation (e.g. NHSBT-TES) recorded, indicating very low levels of ED-related practice at the study sites.

Findings from interviews with service providers indicated that HCPs were generally favourable towards ED, perceiving it as worthwhile and something that should be discussed with patients and carers. Most participants indicated support for raising the option of ED, willingness to do so and a preference for discussion during EoLC planning. While participants indicated beliefs that ED is worthwhile, in most cases, neither ED discussions nor referrals were reported when participants were asked about this, and the majority indicated that they never, or hardly ever, initiated discussions about ED with their patients or family members (ED was usually only discussed 'if' the topic was raised by relatives).

Most HCP respondents to the national survey indicated awareness of ED as an option for EoLC patients, but that this was not currently embedded in routine practice in their clinical setting. Furthermore, almost half of survey respondents indicated that their service did not actively encourage the option of ED being discussed with patients and/or their family members, and staff within clinical settings did not routinely discuss ED in team meetings.

Service providers' reluctance to raise the issue of ED was linked explicitly by participants to gaps in knowledge around related processes (including eligibility criteria and processes for referral), resulting in a lack of confidence to initiate donation discussions. Over half of participants had no formal training regarding ED, and of those who had, the majority completed this more than 24 months prior to participation. Interview and survey data indicated a lack of training and education aimed at HCPs in both HC and HPC services.

Findings from all data collection sources involving service providers indicated that most participants do not actively raise the option of ED with patients or family members and that concerns exist regarding the potential impact on patients and/or family members of discussing ED. Responses indicate that ED is often not included in local written clinical guidance, information for patients and families or admission documentation. Further investigation of policy documentation and information resources at partner sites indicated widespread lack of clinical guidance and policy to assist HCPs in implementing and embedding ED in routine clinical practice.

Findings from interviews with patients and carer (WP2) indicated positive views towards ED, even where there was reluctance or uncertainty about choosing the option for themselves or family members. Most patients and carers were not aware of ED as an option for themselves or their loved ones, and they believed that a patient with a cancer diagnosis could not be an eye donor. Findings indicate that patients are willing and able to be asked about their preferences regarding ED, with no patient or carer respondents indicating that the topic would be too distressing if raised appropriately. Almost all patient and carer participants expressed a clear preference that information about ED should be made available to patients and their families by HCPs early in the process. Participants acknowledged that ED is a

sensitive issue, but most expressed views compatible with an expectation that HCPs would have the skills (communication, empathy, judgement) to facilitate a discussion.

Both service users and service providers indicated that the issue of ED is best raised early in patients' dying trajectory (as patients transition from active to palliative care) or when other end-of-life planning topics are being discussed (e.g. resuscitation). All participants agreed that a judgement as to when to introduce the topic must be based on the patients physical, emotional and cognitive situation and that these issues should be assessed by HCPs before raising the issue. Patients were more concerned about *how* this topic would be raised than *when* it would be raised. Most patient participants were of the view that their wishes should take priority and that family members' views should not overrule patient wishes regarding ED unless there was no statement of wishes given by the patient prior to death.

Conclusions

In view of the predicted increase in the need for eye tissue, it is essential that the potential for ED demonstrated by the EDiPPPP study is realised, and that the option of ED is routinely raised with patients and family members as part of EoLC planning. This would give patients the opportunity to fulfil what may be a lifelong wish to be a donor and increase the supply of tissue for sight-saving and sight-restoring transplantation and medical research.

The integration of the three work packages has facilitated a systematic, detailed and robust understanding of current practice. This research draws on multiple perspectives, validating the selection of methodology, epistemology and theory underpinning EDiPPPP study design. The study commenced with planning supported by the six steps in quality intervention development (6SQiD) framework and concluded with development of a complex intervention, the *Support Toolkit for Eye donation in Palliative care Settings* (STEPS). The study has thus facilitated the clarification of key issues contributing to low levels of supply of eye tissue and produced an empirically based, theoretically informed complex intervention for implementation by national services (NHSBT-TES). The EDiPPPP project, therefore, represents a significant empirical and strategic contribution to addressing the problem of eye tissue undersupply at a national level. Specific implications for healthcare practice and service development are given below.

Implications for service development

- In view of the significant potential for ED in HC settings, it is essential that the option of ED is routinely raised with patients and family members if this potential is to be realised.
- End-of-life planning across clinical settings needs to embrace the range of options available to patients and families regarding donation and enable what may be a lifelong wish to be a donor.
- NHSBT-TES need to develop accessible, web-based clinical information to support HCPs in the early identification and assessment of all patients admitted to HC and HPC settings against eligibility criteria. The EDiPPPP-developed *Eligibility ED Assessment Checklist (EEDAC)* represents a ready-to-use tool to facilitate this process.
- NHSBT-TES need to develop easily accessible web content to answer HCP questions about ED (e.g. eligibility, processes for referral and/or retrieval of eye tissue). Web content needs to be updated regularly to include any changes to donor eligibility determined by NHSBT-TES (e.g. the upper age limit for eye donation, current stock levels).
- A dedicated link nurse (employed by NHSTB-TES) would facilitate a close partnership with referring sites and act as a resource and ED champion.
- An evidence-based, centrally generated (by NHSBT-TES) education and training programme needs to be developed that can be rolled out nationally via various modalities (e-learning for health platforms, in-house education teams, donation champions, etc.), thereby ensuring clinicians have up-to-date and regularly updated training to support their practice.

- Feedback data that inform clinical sites of their referral rates, donation rates and use of donated eye tissue need to be provided so that the motivation to embed ED in routine practice is maintained.
- Clinical sites need access to the Organ Donor Register (ODR) so that they can establish whether patients have opted out of donation or constrained eyes (indicating that they do not want to donate their eyes).
- Specific information and guidance regarding implementation of deemed consent legislation is urgently needed by HCPs working in HC settings.

Implications for healthcare practice

- Clinical guidance indicates that HCP practice should embed and normalise the discussion of ED with patients and their families as part of EoLC planning. This is necessary to enable the exploration of donation options, and to support related planning and decision-making within EoLC conversations.
- Public awareness-raising initiatives are needed that inform patients in HC and HPC services about the option of ED. This can be achieved by ensuring that the information resources recommended in the preceding points are shared with UK-based HC and HPC organisations and their professional bodies (e.g. the Association of Palliative Medicine and Hospice UK).

Recommendations for research

1. Evaluation of the STEPS.
2. Research exploring the wider public's knowledge and views regarding ED.
3. Research exploring cultural views regarding Deemed Consent legislation.
4. Research exploring the use of language by NHSBT-TES in their public facing infographics, communications and campaigns (specifically the use of the term Eye Donation).

Study registration

The EDiPPPP study is registered with ISRCTN (ISRCTN14243635: Eye donation from palliative care and hospice care settings).

Funding details

This project was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (HSDR 17/49/42), and will be published in full in *Health and Social Care Delivery Research*; Vol. 11, No. 20. See the NIHR Journals Library website for further project information.

Health and Social Care Delivery Research

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA) and NCBI Bookshelf.

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@nhr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nhr.ac.uk/hsdr.

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.nhr.ac.uk/explore-nhr/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.nhr.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