

Eye Donation from Palliative and Hospice care contexts: the EDiPPPP mixed methods study.

Report authors

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Scientific summary

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Background:

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Globally, the estimated number of visually impaired people is reported by the 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 due to a short fall 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 two 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 5,000 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 four million in the UK mainly due 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 (NHS BT) 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 – March 2022 donation of eyes from all sources (solid organ donation, tissue donation) generated 4,555 eyes from 2,286 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 4,555 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 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 EDiPPPP study investigated the potential of these locations to meet the current supply deficits.

Research questions and study objectives:

RQ1a: Potential - What is the potential for eye donation in Hospital Palliative Care services (HPC) and Hospice Care services (HC)?

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

Objective I) to scope the size and clinical characteristics of the potential ED population from research sites.

Objective II) 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 planning?

Objective III) identify factors (attitudinal, behavioural) that enable or challenge service providers to consider and propose the option of ED as part of end-of-life care planning from a local and national perspective.

Objective IV) identify service users' views regarding the option of ED and the propriety of discussing ED as part of admission procedures or as part of end-of-life care 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 HCS?

Objective V) 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

EDiPPPP was structured in line with the six steps in quality intervention development (6SQuID) 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 & WP2), participant observation (WP1), secondary analysis of primary data (WP2), national survey (WP2), transparent expert consultation (WP3).

Participants: WP1 - 105 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 (PPI, cross discipline HCP, stakeholder groups) participated the transparent expert consultation (TEC).

Data collection sites: three HC and three HPC services in the North, Midlands, and 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 eye donation across HC and HPC settings. Of 1,199 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 cases were agreed as eligible). Twenty-four percent (n=289) of all cases were agreed as ineligible. In less than 4% of all cases agreed as eligible 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 Health Care Professionals (HCP) were generally favourable toward 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. Whilst participants indicated beliefs that ED is worthwhile, in most cases neither ED discussions nor referral 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 toward 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 option for themselves or their loved ones and 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 acknowledge 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 end-of-life care 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 (6SQulD) 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 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:

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- In view of the significant potential for ED in hospice care 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 (for example the upper age limit for eye donation, current stock levels etc).
- 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.
- Provision of feedback data that informs clinical sites of their referral rates, donation rates, use of donated eye tissue need to be provided so that motivation to embed ED in routine practice is maintained.

- Clinical sites need access to the Organ Donor Register 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 hospice care 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 end of life care planning. This is necessary in order to enable exploration of donation options, and to support related planning and decision making within end-of-life care 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 – Support Toolkit for Eye donation in Palliative care Settings.
2. Research exploring the wider publics' 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).

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

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