

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

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Plain language summary

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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.

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