

**EDiPPPP -Eye Donation from Palliative and Hospice care contexts:
investigating Potential, Practice, Preference and Perceptions: a multicentre,
mixed methods study.**

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The Royal National Institute of Blind people (RNIB) report that over two million people in the UK are living with sight loss. This number is predicted to double to nearly four million by 2050. Conditions that lead to sight loss and impaired vision can be treated if ophthalmic (eye) tissue is available for example, corneal transplantation, reconstructive surgery, and research into eye diseases, but 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 (ED) in these settings, we looked at clinical notes from patients who died in the previous two 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 ED should take place within end-of-life care planning. We also asked health care professionals (HCPs) (via interviews and a national survey) about their views regarding ED being part of end-of-life planning, and what they saw as the key barriers to this becoming routine practice.

We found that many patients are eligible for ED, but very few are asked about this option, patients indicated that they wanted this option raised with them so that they could make decisions. Notes review, HCP interviews, and survey responses indicate that ED is not part of current routine clinical practice.

In view of the predicted increase in the need for ophthalmic tissue it is essential that the potential for ED demonstrate by the EDiPPPP study is accessed, 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 ophthalmic tissue that can be used in sight saving and sight-restoring transplantation, and medical research.

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