

Barriers to ocular tissue donation in acute clinical settings

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ABSTRACT

Introduction: Nearly all patients who die in Intensive Care Units (ICU's) and Emergency Departments (ED's) are potential corneal donors. However, the number of referrals from these groups remains low.

Purpose: To identify the number of potential corneal donors in four ICUs and one ED and to ascertain how many proceed with donation.

Materials and methods: The electronic medical records of all patients (n=233) who died in the five participating units from July to December 2014 were retrospectively reviewed using existing ocular tissue donor criteria to assess the number of potential donors. The Eye Donor Database and the Potential Donor Audit were also reviewed to determine how many potential corneal donors proceeded with donation.

Results: Out of the 73% (n=170) eligible corneal

donors, 79% (n=100) were potential tissue-only donors and 21% (n=36) had the potential to donate solid organs and at least one tissue (corneas). While all 36 potential organ and tissue donors were referred to the Specialist Nurse in Organ Donation (SN-OD), none of the 100 potential tissue-only was referred to Tissue Services. Of the 36 potential organ and tissue donors referred to the SN-OD, only 11 proceeded with corneal donation.

Conclusion: The results of this audit highlight a low conversion rate from a relatively high number of potential corneal donors. There is a need to increase corneal donation awareness among healthcare professionals and the public. It is also recommended the implementation of strategies to maximise the number of referrals.

Key words: Tissue donation, corneal donation, missed potential donors.

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INTRODUCTION

The aim of this project was to audit the ocular tissue donation activity in four Intensive Care Units (ICUs) and one Emergency Department (ED) in a South England NHS Trust from July 2014 to December 2014.

The objectives of the audit were to identify the number of potential corneal donors in the five participating units; to establish how many potential ocular tissue donors were referred to Tissue Services; to ascertain how many notified potential corneal donors proceeded with donation and to identify any barriers to ocular tissue donation.

Improvements in reconstructive medicine have increased the need for tissues such as heart valves, skin, bone, tendons and corneas [1]. Of all human tissues, corneas have the greatest potential donor pool. Due to the avascularity of the cornea, patients with cancer, who would be contraindicated to donate other tissues, are eligible for corneal donation [2]. Corneas can be donated up to 24 hours post-mortem, meaning that the potential for corneal donation is greater than that of solid organs [3]. Despite the high potential of ocular tissue donors in the UK, the number of corneas available for transplant fails to meet the demand [3].

Corneas can be retrieved from either tissue-only donors or organ donors, who have also the potential to donate tissues [3]. For organ donors, the Specialist Nurse in Organ Donation (SN-OD) in liaison with the multidisciplinary team deals with the organ and tissue donation process from the time of referral until retrieval [3]. However, for tissue-only donors, nurses are expected to make the referral to Tissue Services as soon as possible after death. Upon referral, Tissue Donor Coordinators (TDC's) from Tissue Services assess the deceased patient's medical and social history to determine their suitability for tissue donation [3]. TDC's also check whether the deceased had expressed their wish to donate by registering themselves on the Organ Donor Register (ODR). In the absence of both medical contraindications and objections from the Coroner, the TDC telephones the family and offers them the option of tissue donation. Under The Human Tissue Act (HTA) [4], lawful consent is required for the retrieval, storage and use of tissue for transplantation and other scheduled purposes. Relatives must be provided with sufficient and precise information on which to base their decision. If a patient is on the ODR or has written a will expressing their wish to donate, that consent should not be overruled by relatives except in special circumstances. When the wishes of the patient are unknown, consent may be obtained by a person in a qualifying relationship as stated by the HTA [4]. If the family agrees to donation, the TDC arranges the necessary steps to facilitate tissue retrieval and storage for subsequent transplantation [5].

There is limited research on possible barriers to tissue donation activity in ICU and ED. Consequently, the literature review examined international studies from western countries focusing on tissue donation in ICU, ED, hospital wards and hospices conducted from 2002 to 2015.

According to the literature, one of the main reasons behind the shortage of corneas is the high refusal rate. Worldwide studies show refusal rates between 29 % and 72% [6,7]. Nationally, of the 21.1 million British people registered on the ODR, 10.7% do not wish to donate their corneas [8]. When the patient's wishes are unknown, more than 50% of families who give consent to organ donation decline the option of corneal donation [9]. Unlike organ donation, many people are unaware of the option of becoming a tissue donor upon death [1]. According to Rodriguez-Villar et al [1], high refusal rates suggest the need for public campaigns to increase tissue donation awareness.

In the UK, the families who decline eye donation give reasons based on personal views and disfigurement concerns [9]. According to some researchers [10] the symbolism and personal meaning attached to the eyes is important to people. Eyes are associated with beauty and identity and are seen by many as the '*windows to the soul*' [10, pp.62]. The findings from a qualitative study [10] exploring the selective refusal of eye donation, suggest that people might be more likely persuaded of the benefits of eye donation and override the social meaning of eyes if the request for eye donation matches their lived experiences.

Muraine et al [7] argue that the shortage of corneas is not mainly due to families' refusals but other logistical difficulties such as problems contacting the relatives as well as lack of identification and referral of potential eye donors. In this French study the consent rate was 71% (n=39/55), which might be explained by the presumed consent or 'opt out' system used in France. Presumed consent assumes that everyone will become a donor upon their death unless the individual has previously expressed objection [11]. This is in contrast with the 'opt in' system used in the UK (except Wales), whereby people voluntarily register themselves on the ODR to express their wish to donate. Despite these differences in law and regulations, both systems require approval from the deceased family to ensure that their relative would have wanted to donate [11].

Failure to recognise potential donors has been linked with lack of knowledge among healthcare professionals regarding the medical contraindications and donor suitability criteria [6]. Educational programmes focusing on tissue donation [12] and the implementation of prompts in documentation [13] have been proven to increase the number of referrals. Tissue Services advocate that nurses refer all deceased patients regardless of their

potential for donation [5]. This is thought to minimise the rate of missed potentials due to an incorrect assessment by health professionals, who might not be exposed to donation very often [12].

Discussing the option of organ and tissue donation should be a usual part of end-of-life care [14]. The nurses' role is to offer the option of donation and empower families to make an informed choice based on their loved one's wishes [15]. Nurses looking after patients at the end of their lives are ideally placed to initiate discussions about donation [15]. Yet, many nurses feel hesitant to raise the subject [16,17].

The service evaluation conducted in one British ED department [17] assessed the frequency in which ED nurses initiated discussions about tissue donation with bereaved families over a period of two years. Of the 242 deaths, only 45 families were approached for tissue donation. Similarly, another survey [18] reported that less than 10% of the hospice staff (n=434) hardly ever or never initiated discussions regarding corneal donation with their patients or their families. Some of the barriers for not initiating these discussions included lack of training; anxiety about the possible impact of the discussion on patients and their families and personal perceptions on meaning of the eyes and the belief that donation was not part of the hospice culture.

It is argued [19] that health professionals who have an appropriate knowledge and positive attitudes towards donation are more confident in approaching families. In a service evaluation [12], ED nurses from two Scottish hospitals attended a two-day workshop focusing on the communication skills necessary to request ocular and other tissue donation. Post-intervention, in one of the participating hospitals, the percentage of eligible families approached for eye donation increased from 0 to 77%.

Many studies conclude that educational programmes on donation increases nurses' knowledge and confidence in the topic, which ultimately increases the donation conversion rates [12,16,19]. From the available interventions aimed at increasing conversion rates, modification of behaviour by providing instruction is the most common [20]. Theoretical and practical instruction can take the form of workshops, seminars, staff meetings, conferences, presentations and simulations [15]. However, the efficacy of such educational programmes has not been evaluated [20].

Even though nurses are generally supportive of donation, many of them avoid raising the subject of tissue donation due to anxiety and fear to add distress to the already bereaved families [21]. Whether donation helps or not in the bereavement process is controversial. While some studies indicate that donation might help in the bereavement process [22], others suggest that donation does not have any

impact on grief [23]. However, it is generally accepted that most of the families who give consent to donation consider this as a positive experience and that some people would be offended if they had not been offered this option [23]. Regardless whether consent is given or not, the majority of relatives are pleased when sensitive request for donation is made [15].

MATERIALS AND METHODS

An audit was conducted to assess the ocular tissue donation practice. The audit involved retrospective examination of the electronic medical records of all patients who died in the five participating units between periods of July 2014 to December 2014. The records were reviewed using existing ocular tissue donor criteria for eye donation to assess the number of potential corneal donors. Contraindications to ocular tissue donation for transplantation were obtained from the Royal College of Ophthalmologists [5] and the National Blood Service Guidelines [2] and most of them are grouped under the headings listed in Appendix 1. The local Eye Donor Database and the Potential Donor Audit [24] were also reviewed for the same period to determine how many potential ocular tissue donors were referred to Tissue Services, whether consent was obtained and how many of them proceeded with corneal donation. The audit tool can be seen in Appendix 2. Unlike some types of research, audits cannot eliminate confounding factors that could explain the outcomes. Therefore, although the results might seem suggestive, audits cannot establish with certainty whether any improvements in practice are directly related to the changes implemented [25].

Sample

A purposive sample (n=233) consisting of all electronic medical records from patients who died in any of the four adult ICUs or ED during the period from July 2014 to December 2014 was selected for this study. The rationale for selecting this sample was that these acute clinical units covered by the SN-OD had the largest potential for organ and tissue donation. Medical records of patients who died in Neonatal and paediatric ICUs were excluded from this study due to the fact that the lowest age limit to donate eyes set up by Tissue Services is 3 years. Furthermore, as the number of deaths in these units is low, the potential for eye donation is minimal.

Ethical considerations

Audit of practice does not require ethical approval [26]. Permission to conduct this project was gained from the ICU Lead in Research and Development and the managers of all participating units. This involved following the ethical principles

stated in the NHS Trust ethical guidelines. In compliance with the Data Protection Act [27], the confidentiality and anonymity of the patient's data was preserved as the data retrieved did not contain any personal details that could reveal the patient's identity. Electronic medical records were accessed with the use of a personal password; thus ensuring the security of the patient's data.

RESULTS

After using the existing criteria and medical contraindications to ocular tissue donation [2,5], 73% (n=170) of the deceased patients were found eligible for corneal donation (Table 1). Of the

170 eligible eye donors, 79% (n=100) were potential tissue-only donors and 21% (n=36) had the potential to donate organs and at least one tissue (corneas). All 36 potential organ donors who could also donate tissue were referred to the SN-OD. Regardless of the unit in which the patient died, none of the 100 potential tissue-only donors were referred to Tissue Services. From the 36 potential organ-tissue donors, only 11 proceeded with eye donation. The causes for non-proceeding with eye donation from potential organ-tissue donors were: family refusal (n=23), NOK could not be contacted (n=1) and coroner's objection to retrieve eyes (n=1). For graphic presentation of findings please Fig. 1 and Fig. 2 and 3.

Table 1. Outcomes of potential donors

Potential donors	Referral rate	Refusal rate	Conversion rate
Potential organ-tissue donors n=36	100% (n=36/36)	64% (n=23/36)	31% (n=11/36)
Potential tissue-only donors n=134	0% (n=0/134)	N/A	0% (n=0/134)
Potential tissue-only donors & potential organ-tissue donors n=170	21% (n=36/170)	64% (n=23/36)	6% (n=11/170)

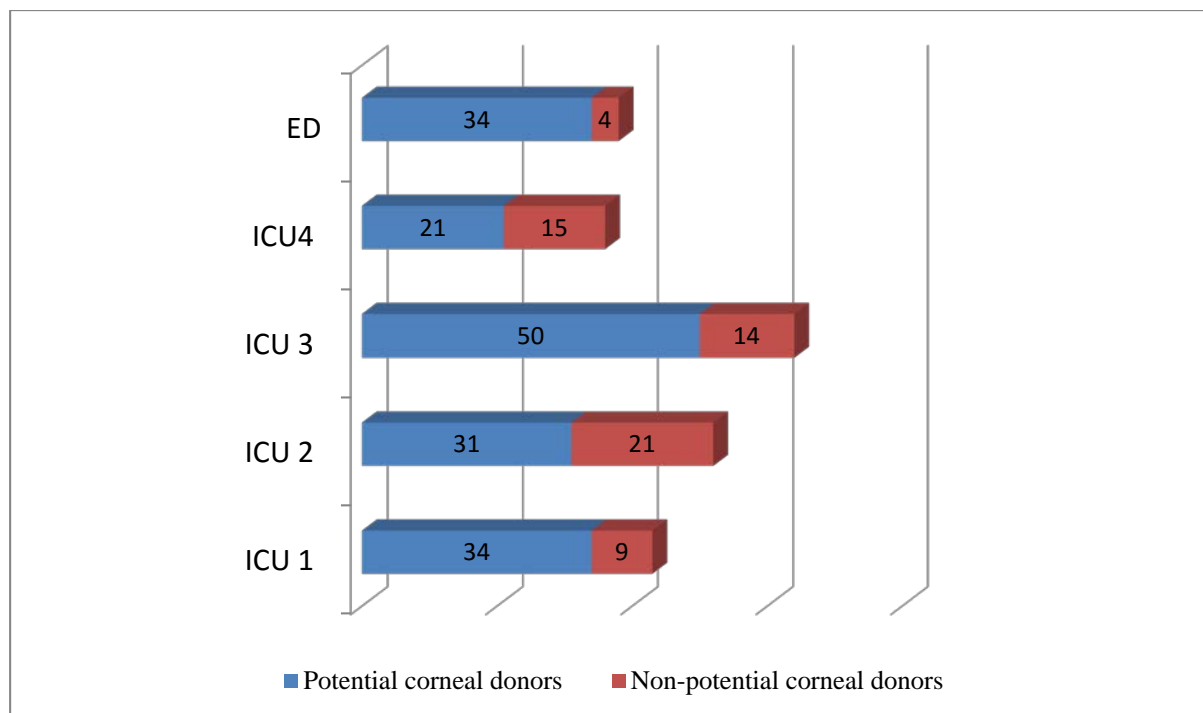


Figure 2. Referral versus non-referral of potential corneal donors according to the unit where the deceased patient died

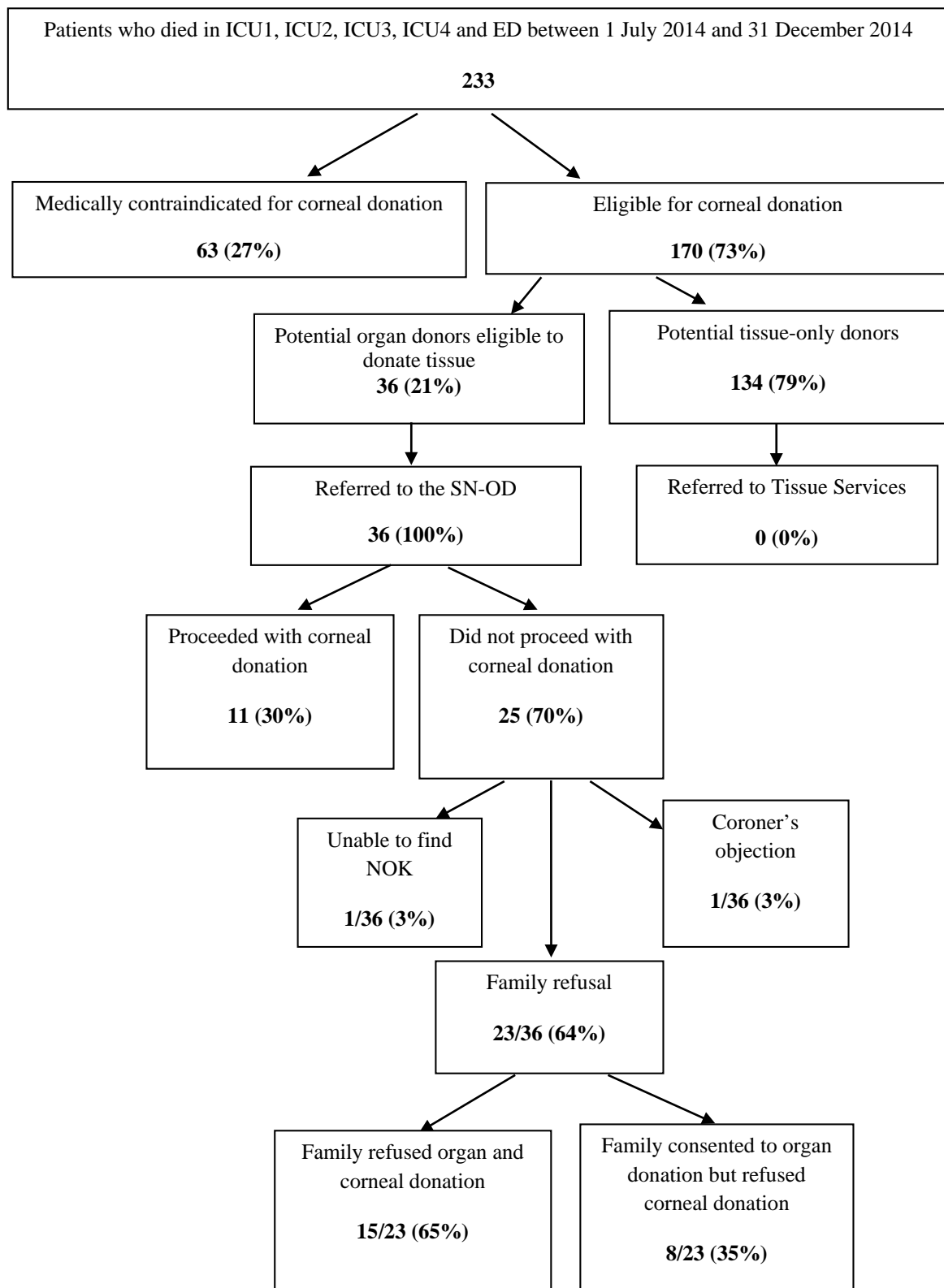


Figure 1. Breakdown of findings

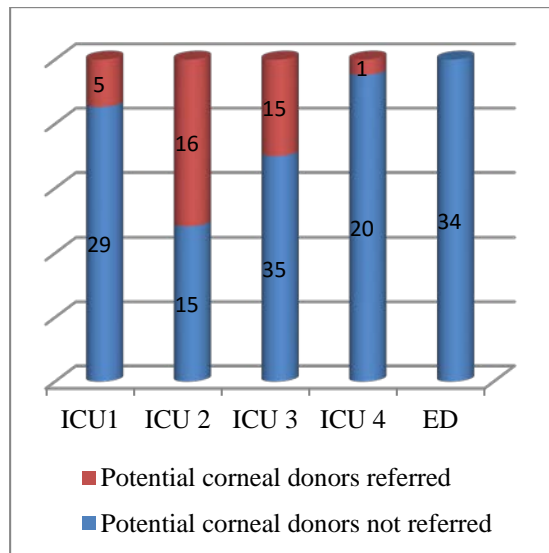


Figure 3. Referral versus non-referral of potential corneal donors according to the unit were the deceased patient died

DISCUSSION

The findings from this audit support previously reported research that missed referrals and family refusals are the two main reasons behind the low conversion rate (6%, n=11/170). Of the 36 potential organ and tissue donors, only 11 donated corneas, and this was mainly due to the high refusal rate. The 64% refusal rate from potential organ and tissue donors reported in the current study is slightly lower than national rate (70%) [9] but significantly higher than the 29% refusal rate reported by Muraine et al [7]. Nonetheless, taking into account the refusal rate (64%), coroners' objections (3%) and other logistical problems (3%), 51 deceased patients rather than 11 could have donated corneas if all 170 eligible donors had been considered.

It was previously reported [7] that healthcare professionals were not referring potential eye donors. A new referral system was subsequently implemented, which removed the healthcare professionals' responsibility of making the referral to the TDC. This new referral system involved the TDC having to contact the hospital mortuary every morning to obtain a list of all deceased inpatients and assess their potential for corneal donation. After the implementation of the new referral system, the TDC's were able to identify 40.5% of potential eye donors. In the Trust where this audit was conducted a similar referral system was introduced with the exception that the TDC is based in the bereavement office. This referral system is limited by the working pattern of the TDC. As the TDC is not in hospital every day, many potential eye donors might still go unidentified.

Based on the literature, missed referrals might be due to poor knowledge regarding the donor

suitability criteria [6] or failure to offer families the option of donation [17]. The local policy advocates the referral of all deceased patients regardless their potential for tissue donation. Therefore, unfamiliarity with the donor criteria should not be a barrier towards the identification of potential donors. The nurses' role in the Trust is to provide families with a leaflet containing information about tissue donation and to inform them that a TDC might call them to discuss this option further. This removes unit nurses' responsibility of having to discuss the option of tissue donation with bereaved families [28]. Nevertheless, nurses still need to raise the subject and to do so they need to understand the benefits of tissue donation, what it involves and how they can support families and cover their emotional and informational needs [29].

From all participating units, ICU had the largest number of proceeding donors. However, while all 36 potential organ-tissue donors were referred to the SN-OD, none of the 134 potential tissue-only donors were referred to Tissue Services, regardless where the patient died. When considering national and local strategies to support organ donation compared to those available to support tissue donation, these results should not be surprising. Unlike tissue donation, organ donation is in the public agenda and has the support of the media, governmental documents, policies and professional guidelines. Clinical Leads for Organ Donation and SN-ODs act as a leaders promoting organ donation within acute clinical areas. Unfortunately, there is a lack of leadership in terms of tissue donation. Nurses' practice regarding tissue donation is said to be influenced by their knowledge and attitudes [19]. In the Trust, clinicians and nurses attend regular teaching sessions and workshops focusing on organ donation. Due to the time limitation of these sessions and the focus being on organ donation, tissue donation is covered very briefly. Based on the lack of training, it is not surprising that the number of families approached for tissue donation is low.

When comparing the referral rates between organ-tissue donors and tissue-only donors, differences in both referral systems need to be considered. While referring a potential organ donor only involves a phone call, referring a potential tissue-only donor requires talking to families, filling in referral forms and faxing these to Tissue Services. In busy units such as ED, finding the time to discuss tissue donation with families and filling in referral forms might be challenging [15,28]. Telling health professionals' about the benefits of tissue donation not only for the recipients but also for the bereaved families might improve staff attitudes and commitment to perform these tasks [19].

CONCLUSIONS

This audit used a purposive sample taken from a single centre therefore the findings from this audit cannot be generalised to all acute clinical settings. Retrospective reviews rely on the available information of the underlying documents [17]. In the context of this project, medical records did not always provide detailed social information, which in some cases would have ruled out the potential for eye donation. It is possible that the number of potential corneal donors might have been overestimated. However, the audit tool for data collection included the basic parameters to measure success such as the number of potential donors, referral rate and consent rate used in the validated PDA tool [24].

Findings from this audit revealed a low conversion rate from a relatively high number of potential ocular tissue donors. Congruent with previous studies, missed referrals and family refusals have been identified as main barriers of corneal procurement. These barriers suggest the need for education of healthcare professionals and the general public. It is also concluded that there is a need for implementation of strategies that maximise the number of referrals and that nurses are trained and encouraged to use these referral systems.

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Conflicts of interest

The authors declare no conflicts of interest in this work.

APPENDIX 1: CONTRAINDICATIONS TO OCULAR TISSUE TRANSPLANTATION

(The Royal College of Ophthalmologists, 2013; National Blood Service, 2013)

1. INFECTIONS

- 1.1 acquired immunodeficiency syndrome (HIV/AIDS)
- 1.2 viral hepatitis (A,B,C)
- 1.3 HTLV
- 1.4 behavioural risk of contracting HIV, hepatitis or HTLV
- 1.5 tattoos and body piercing within the 4 months before death
- 1.6 acupuncture within 6 months before death if performed by a non qualified professional

- 1.7 imprisonment within the 12 months before death
- 1.8 bleeding disorders treated with blood-derived coagulation concentrates
- 1.9 viral encephalitis or encephalitis of unknown origin, viral meningitis
- 1.10 rabies
- 1.11 congenital rubella
- 1.12 tuberculosis
- 1.13 Reyes syndrome
- 1.14 Progressive multifocal leukoencephalopathy

2. PREVIOUS SURGERY

ORTRANSPLANT/MEDICAL TREATMENT

- 2.1 receipt of an organ, cornea, sclera or other human tissue transplant
- 2.2 receipt of dura mater or brain/spinal surgery before August 1992
- 2.3 receipt of human pituitary hormones

3. UNKNOWN AETIOLOGY AND CNS DISORDERS

- 3.1 Creutzfeldt-Jacob disease and central nervous system diseases of unknown aetiology (e.g., Alzheimer's disease, other dementias, Parkinson's disease, multiple sclerosis, motor neurone disease)

4. MALIGNANCIES

- 4.1 leukaemia, lymphoma, myeloma, polycythaemia, sideroblastic anaemia and myelodysplastic syndrome

5. EYE DISEASES

- 5.1 active ocular inflammation/uveitis
- 5.2 any congenital or acquired disorders of the eye, or previous corneal laser surgery
- 5.3 retinoblastoma
- 5.4 malignant tumours of the anterior segment

6. AGE

- 6.1 There is no upper age limit to donate corneas. However, the NHSBT Tissue Services National Referral Centre excludes patients over 90 to avoid discarding corneas due to poor quality. Therefore, this age limit has also been applied.

APPENDIX 2: DATA AUDIT TOOL

Date of death:/...../..... Unit where the patient died:.....

REFERENCES

1. Rodriguez-Villar C, Paredes D, Alberola M, Ruiz A, Roque R, Saavedra S, Vizcaino F, Portillo M, Bohils M, Adalia R. Perception of transplant coordinator regarding relatives' attitude toward tissue donation request. *Transplant Proc.* 2012 Nov;44(9):2525-8.
2. National Blood Service. Guidelines for the blood transfusion services in the UK. 8th ed. London: The Stationary Office, 2013.
3. Gaum L, Reynolds I, Jones MNA, Clarkson AJ, Gillan HL, Kaye SB. Tissue and corneal

- donation and transplantation in the UK. *Br J Anaesth.* 2012 Jan;108 Suppl 1:i43-7.
4. Human Tissue Authority. Code of Practice 1: Consent. [cited 2015 Dec 2]. Available from: https://www.hta.gov.uk/sites/default/files/Code_of_practice_1_-_Consent.pdf
 5. Royal College of Ophthalmologists. Standards for the retrieval of human ocular tissue used in transplantation. Research and Training. [cited 2015 Dec 2]. Available from: https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013_Prof_251_RCophth-Standards-for-the-Retrieval-of-Human-Ocular-Tissue.pdf
 6. Kruijff PEV, Jansen NE, Muijtens BSM, Blok-Singerling JGC, Trecklenbutg BDA, de Vos MLG, Slappendel R. Are all tissue donors recognised?: A cohort study in three Dutch hospitals. *Cell Tissue Bank.* 2014 Sep;15(3):483-90.
 7. Muraine M, Toubeau D, Menguy E, Brasseur G. Analysing the various obstacles to cornea post-mortem procurement. *Br J Ophthalmol.* 2002 Aug;86(8):864-8.
 8. NHS Blood and Transplant. NHS Organ Donor Register. Available from: http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/nhs_organ_donor_register.pdf [cited 2015 Nov 20].
 9. NHS Blood and Transplant. Ocular tissue advisory group: EPSOD activity report. [cited 2015 Nov 20]. Available from: http://www.odt.nhs.uk/pdf/advisory_group_papers/OTAG/EPSOD.pdf
 10. Lawlor M, Kerridge I. Understanding selective refusal of eye donation: identity, beauty and interpersonal relationships. *J Bioeth Inq.* 2014 Mar;11(1):57-64.
 11. Department of Health. The potential impact of an opt out system for organ donation in the UK: an independent report from the Organ Donation Taskforce. [cited 2015 Dec 2]. Available from: <http://www.odt.nhs.uk/pdf/the-potential-impact-of-an-opt-out-system-for-organ-donation-in-the-UK.pdf>
 12. Lerpiniere C, Verble M. Requesting tissue donation. *Emerg Nurse.* 2009 Mar;16(10):22-5.
 13. Ploeg RJ, Niesing J, Sieber-Rasch MH, Willems L, Kranenburg K, Geertsma A. Shortage of donation despite an adequate number of donors: a professional attitude? *Transplantation.* 2003 Sep 27;76(6):948-55.
 14. National Institute for Health and Clinical Excellence. Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. NICE clinical guideline 135. [cited 2015 Dec 2]. Available from: <https://www.nice.org.uk/guidance/cg135/evidence/cg135-organ-donation-full-guideline3>
 15. Sebach AM, McDowell D. Developing a tissue donation advocacy program in a rural emergency department. *J Emerg Nurs.* 2012 Jan;38(1):63-8.
 16. Collins TJ. Organ and tissue donation: a survey of nurse's knowledge and educational needs in an adult ITU. *Intensive Crit Care Nurs.* 2005 Aug;21(4):226-33.
 17. Van Loo M, Rabbetts C, Scott T. Emergency nurse initiation of discussion about tissue donation with suddenly bereaved relatives. *Int Emerg Nurs.* 2008 Oct;16(4):257-65.
 18. Gillon S, Hurlow A, Rayment C, Zacharias H, Lennard R. Obstacles to corneal donation amongst hospice inpatients: a questionnaire survey of multi-disciplinary team member's attitudes, knowledge, practice and experience. *Palliat Med.* 2012 Oct;26(7):939-46.
 19. Marck C, Weiland T. Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians. *Prog Transplant.* 2012 Sep;22(3):317-22.
 20. Douville F, Godin G, Vezina-Im LA. Organ and tissue donation in clinical settings: a systematic review of the impact of interventions aimed at health professionals. *Transplant Research.* 2014 Mar 14;3(1):8.
 21. Wale J, Arthur A, Faull C. An analysis of knowledge and attitudes of hospice staff towards organ and tissue donation. *BMJ Support Palliat Care.* 2014 Mar;4(1):98-103.
 22. Beard J, Ireland L, Davis N, Barr J. Tissue donation: what does it mean to families?. *Prog Transplant.* 2002 Mar;12(1):42-8.
 23. Carey I, Forbes K. The experiences of donor families in the hospice. *Palliat Med.* 2003 Apr;17(3):241-7.
 24. NHSBT. Potential Donor Audit. Available from: <http://www.odt.nhs.uk/odt/potential-donor-audit/> [cited 2015 Nov 3].
 25. Gould, D. Audit and research: similarities and differences. *Nurs Stand.* 2008 May 21-27;22(37):51-6
 26. NHS Health Research Authority. Defining research. NRES guidance to help you decide if your project requires review by a Research Ethics Committee. Available from: www.hra.nhs.uk/documents/2013/09/defining-research.pdf [cited 2015 Feb 25].
 27. Data Protection Act 1998 c. 29. Available from: www.tso.co.uk/bookshop [cited 2015 Dec 2].
 28. Long-Sutehall T, Winstanley E, Clarkson AJ, Sque M. Evaluation of the experiences of family members whose deceased relative donated tissues at the NHSBT dedicated donation facility in Speke, Liverpool. *Cell Tissue Bank.* 2012 Dec;13(4):537-46.
 29. Gumbley E, Pearson J. Tissue donation: benefits, legal issues and the nurse's role. *Nurs Stand.* 2006 Sep 13-19;21(1):51-6.