



BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

Family Refusal of eye tissue donation from solid organ donors – a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1st April 2014 – 31st March 2017).

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-045250
Article Type:	Original research
Date Submitted by the Author:	25-Sep-2020
Complete List of Authors:	Bracher, Mike; University of Southampton, School of Health Sciences Madi-Segwagwe, Banyana; University of Southampton, School of Health Sciences Winstanley, Emma; National Health Service Blood and Transplant Services - Organ and Tissue Donation and Transplantation Gillan, Helen; National Health Service Blood and Transplant Services- Organ and Tissue Donation and Transplantation Long-Sutehall, Tracy; University of Southampton,
Keywords:	Corneal and external diseases < OPHTHALMOLOGY, Transplant pathology < PATHOLOGY, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Family Refusal of eye tissue donation from solid organ donors – a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1st April 2014 – 31st March 2017).

Mike Bracher (MB) (m.j.bracher@soton.ac.uk)^{1§}

Banyana C. Madi-Segwagwe (BMS) (b.c.madi-segwagwe@soton.ac.uk)¹

Emma Winstanley (EW) (emma.winstanley@nhsbt.nhs.uk)²

Helen Gillan (HG) (helen.gillan@nhsbt.nhs.uk)²

Tracy Long-Sutehall (TLS) (t.long@soton.ac.uk)¹

1. School of Health Sciences, University of Southampton, UK
2. UK National Health Service Blood and Transplant Services- Organ and Tissue Donation and Transplantation (NHS BT – OTDT), UK

§ Corresponding author

Mike Bracher, School of Health Sciences, University of Southampton.

Email: m.j.bracher@soton.ac.uk; Tel: 023 80 593929

Word count = Abstract = 299; Article = 4934

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives: There is a long-standing undersupply of eye tissue in the UK and globally, and the UK National Health Service Blood and Transplant Service (NHSBT) has called for further research exploring barriers to eye donation. This study aims to: I) describe reported reasons for non-donation of eye tissue from solid organ donors in the UK between 1st April 2014–31st March 2017; II) discuss these findings with respect to existing theories relating to non-donation of eyes by family members.

Design: Mixed methods review of national secondary data set covering reasons for non-donation of eyes recorded by Specialist Nurses in Organ Donation (SNODs) for 2790 potential solid organ donors. Application of qualitative content analysis to free-text data for 126 recorded cases of family decline of eye donation.

Setting: National data set covering solid organ donation (secondary care).

Participants: 2790 potential donors assessed for eligibility to donate eyes between 1st April 2014 and 31st March 2017.

Results: Reasons for non-retrieval of eyes were recorded as: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%). In over 50% of recorded cases, reasons for non-donation were based on family or deceased wishes (reasons known or unknown). Further analysis of free-text data identifies and explores sub-groups within each category. Findings are discussed with respect to existing theoretical perspectives.

Conclusion: Eye donation processes involve distinct psychological and socio-cultural factors for both families and HCPs that have yet to be fully explored in research or integrated into service design. We suggest the following areas for future research and service development attention: the potential of a disc-only corneal retrieval procedure to increase donation acceptance; public education regarding donation processes; exploration of how request processes affect acceptance of corneal donation; procedures for assessment of familial responses to information provided during the consent conversation.

Keywords: cornea, tissue donation, consent, eye banking, refusal

Strengths and limitations of this study

- Mixed methods review of national secondary data set covering reasons for non-donation of eyes recorded by Specialist Nurses in Organ Donation (SNODs) for 2790 potential solid organ donors in the UK.
- Application of qualitative content analysis to free-text data for 126 recorded cases of family decline of eye donation, with findings discussed in relation to existing theoretical perspectives to identify areas for further research and service development.
- Data generated by SNODs and therefore reflect a mixture of direct observations and interpretations of both spoken responses and other communicative behaviours.
- Level of detail provided in the free-text comments constrained by response format (i.e. a hand-written box) limiting the amount of information that SNODs could insert.

Background

Globally, 53% of the world's population has no access to the benefits of sight saving and sight restoring transplantation surgery due to a short fall in the supply of ophthalmic tissue (cornea and sclera) that is only available via eye donation [1]. According to Pascolini et al (2010) over 10 million people worldwide have bilateral corneal blindness which could be restored with a corneal transplant [1]. According to the Royal National Institute of Blind (RNIB) over two million people in the UK are living with sight loss [2] caused by conditions such as Keratoconus and Fuchs' Corneal Dystrophy that 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 eye diseases, for example endothelial failure post cataract surgery [3]. The RNIB report 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 (unpaid carer burden and reduced employment rates) reported as £4.34 billion annually [2]. Critically, the organisation predicts predicted that by 2050 the number of people with sight loss will double to nearly four million [2]. It is therefore imperative that the tissue needed to intervene in these conditions via corneal transplantation, reconstructive surgery, glaucoma surgery, and research into the causes and treatment of eye disease is available

However, there is a long-standing shortfall in supply of eye tissue in the UK and globally, with eyes being the least donated of all organs and tissues when decision makers are offered a 'list' that they need to agree to that can be retrieved for use in transplantation (n.b. as eyes are referred to as both organs *and* tissues in different contexts, we will refer to them as organs from here on) [4,5]. The UK National Health Services Blood and Transplant (NHSBT) Eye Bank in Speke, Liverpool and Bristol (who supply most eye tissue used for surgical purposes in the UK) seeks to have 10 eye donors per day consistently to satisfy demand for the treatment of patients. This number is not consistently met.

Increasing supply is a key strategic aim for NHSBT Tissue and Eye Services Division [6] and they, along with the UK Royal College of Ophthalmology (RCO) [7], have expressed a need for research exploring barriers to eye donation. This knowledge is needed not only as a basis for developing new routes to supply, but also to inform guidance underpinning donation conversations with family members who are approached to consider the option of eye donation. Increasing supply requires understanding of how patients and families relate to eye tissue donation (i.e. attitudes, beliefs, information needs etc.) and how these processes shape donation outcomes, specifically family members declining eye donation.

Eye donation from solid organ donors continues to prove problematic, with slow progress in increasing supply from this specific cohort of donors. For example, eye donation from solid organ donors generated 320 eyes between 1st April 2015 to 31st March 2016 (4), and 446 eyes between 1st April 2019 to 31st March 2020 [5]. As evidence reports that nationally on average only 40% (range 31-64%) of next-of-kin (NoK) agree to eye donation when approached to consider solid organ donation (4) whilst 67% of NoK agree to solid organ donation, what contributes to this difference is an important area for review.

1 In this paper we aim to contribute to the knowledge base around non-donation of eye tissue from solid organ donors
2 by reporting, for the first time, national clinical data collected and provided by NHS Blood and Transplant between
3 2014–2017, aligned with key theoretical perspectives reported to explain donating behaviours. This body of work from
4 the past 30 years will advance knowledge and understanding of the reasons why of all organs and tissues that can be
5 donated eyes remain the least donated organ [4,5].
6
7
8
9

10 **Study objectives:**

- 11
12
13 i. *Describe the reported reasons why eye donation did not take place from solid organ donors in the UK between*
14 *1st April 2014 – 31st March 2017.*
15
16 ii. *Discuss these findings in the context of existing theoretical perspectives relating to non-donation of eyes by*
17 *family members*
18
19

20 **Study design**

21
22
23 To gain further insight into the factors leading to low numbers of eyes being secured from solid organ donation, a
24 working party (Eye Donation from Solid Organ Donors – EPSOD, 2014-2017) was convened with the remit to: plan
25 and action an effective response to demand and supply problems, make evidence-based recommendations to
26 NHSBT and external stakeholders regarding potential service improvements that would impact on the current low
27 supply of eye tissue.
28
29
30
31

32 *Ethical approval*

33
34
35 Ethical approval was not sought for the study as this was an analysis of anonymised secondary data, released to the
36 study team by NHSBT under a UK Transplant Registry Data Release agreement relating to UK General Data
37 Protection Regulations (GDPR) 2018, the UK Data Protection Act 2018, the UK Human Rights Act 1998, and the UK
38 Common Law Duty of Confidentiality.
39
40
41

42 *Patient and Public involvement*

43
44
45 It was not appropriate or possible to involve patients or the public in the design, or conduct, or reporting, or
46 dissemination plans of our research, due to the anonymity of participants and conditions of the data release
47 agreement.
48
49

50 **Data collection**

51
52
53 Data for 2790 potential donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate
54 eyes between 1st April 2014 and 31st March 2017, were collected using a standardised proforma. Specialist Nurses in
55 Organ Donation (SNODs) were requested to record the key domain (Textbox 1) for non-procurement of eye tissue and
56 asked to add further commentary via use of a free-text box. Data was gathered by SNODs with the requirement that
57 they complete data collection for each potential donor following the discussion with family members, and other
58 stakeholders (e.g. coroner). Data for each SNOD were collated into a monthly regional team return to the NHSBT
59
60

statistical team, who generated descriptive statistical data reported in this paper. Following synthesis of all data reasons for decline with key domains were numerically labelled: *medical reasons* (117), *coroner reasons* (107), *family discussions* (87 & 88), and a catch-all category termed *all other reasons* (197/198) (Textbox 1). Data were collected over three years, with a cessation in 2018 due to the operationalisation of eye donation moving from the Organ Donation and Transplant division of NHSBT to its Tissue and Eye Services division. The full data set relating to non-procurement of eye tissue is presented in *Additional File, Table 1* – however this paper focuses on data relating specifically to ***family decline of eye donation***.

Textbox 1 – Domains/sub-domains inviting a free-text comment

Domain	Sub-domain
<i>Medical reasons</i>	117-Other medical reasons, please specify
<i>All other reasons</i>	198-Not specified 197-Other reasons, please specify
<i>Other/not specified family reasons</i>	88-Family, not specified 87-Family other reasons, please specify
<i>Coroner refused consent</i>	107-Other coroner reasons, please specify

Analysis

Analysis included generation of descriptive statistics on reasons for non-donation of eyes recorded by SNODs for 2790 potential donors (Table 1) and application of qualitative content analysis to free-text data for 126 recorded reasons for family decline of eye donation. Analysis of free-text data was undertaken using Nvivo computer-assisted qualitative data analysis (CAQDAS) software (version 12) [9].

As international empirical evidence from the past 30 years indicates, eye donation involves reactions that do not impact other forms of donation including: discomfort reactions [10,11], disfigurement [3], the belief that eyes will be needed in the afterlife, eyes being viewed as the ‘windows to the soul’ [3,6], as well as disgust-related aversion (‘yuk’/‘ick factor’) findings from this national dataset have been grouped under these headings.

The aim of this analytic process was to generate a descriptive analysis of data recording reasons for non-donation of eye tissue as reported by SNODs (Objective 1), and to underpin a theoretically informed discussion aimed at unpacking the key reasons why family members decline the option of eye donation when this is a valid option (i.e. no medical reasons for non-donation are evident) (Objective 2). By engaging with existing theory regarding donation decision making, this paper also aims to inform interventions that can lead to an increase in the donation of eye tissue for the use in transplant operations.

Descriptive statistics

Reasons for non-donation of eye tissue (overview)

The data related to 2790 potential donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate eyes between 1st April 2014 and 31st March 2017, but from whom eye tissue was not retrieved (reporting periods cover UK financial year, see Table 1). The most common reasons for non-retrieval of eyes were: family wishes

(n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%); and coroner refusal (n=160, 6%), with ‘All other reasons’ accounting for n=212 (8%) of cases (reasons were not recorded in n=58 (2%) cases – see Table 1). The reporting in this paper will focus on data related to **family and deceased wishes** only as these contribute to over 50% of recorded reasons why eye donation did not proceed when donation discussions took place.

Table 1 – Summary of recorded reasons for non-donation of eye donation from solid organ donors for the period 1st April 2014-31st March 2017 (focus categories for this paper are shaded grey).

Period	Family wishes		Medical reasons		Deceased wishes		Coroner refused		All other reasons		(Reasons not recorded)		TOTAL	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(% all years)
1 April 2014 to 31 March 2015	452	0.51	242	0.27	68	0.08	51	0.06	53	0.06	26	0.03	892	0.32
1 April 2015 to 31 March 2016	420	0.48	253	0.29	68	0.08	58	0.07	50	0.06	32	0.04	881	0.32
1 April 2016 to 31 March 2017	467	0.46	346	0.34	44	0.04	51	0.05	109	0.11	0	0	1017	0.36
All years	1339	0.48	841	0.3	180	0.07	160	0.06	212	0.08	58	0.02	2790	

Decline of eye donation based on family and deceased wishes

Where non-procurement of eye tissue was recorded under *Family wishes* (n=1339), the most common reasons related to disfigurement concerns (n=588, 44% of family decline), or ‘personal views’ about eye donation held by Next of Kin (NoK) (n=478, 36% - see Table 2).

For cases where non-procurement of eye tissue was recorded under *Deceased’s wishes* (n=180 cases, 7% of total), 128 (71% of deceased wishes cases) were due to the fact that the deceased had registered (on the organ donor register which is always checked by SNODs in preparation for discussing donation options) that they did not want to donate eye tissue. A further 52 (29%) cases of non-procurement of eye tissue resulted from discussions with NoK where they stated that the deceased wish not to donate eyes was known to them – see Table 2.

Table 2 – Reasons for non-donation cases for eye tissue by category and major sub-category for the period 1st April 2014-31st March 2017.

Domain	Sub-domain	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All Years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44
	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A*	N/A*	2	0.00	1	0.00	3	0.00
	Other/not specified family reasons**	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.74	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.26	20	0.45	52	0.29

*category was not included in data collection for this period.

**Includes sub-domains inviting free-text comment (i.e. 'please specify')

Findings from analysis of free-text data (family decline)

Table 3 lists results of content analysis, showing all resulting categories of recorded reasons for family decline (n = 126). Of note is that in 65 cases (10%) of SNODs reporting 'family refused', 'No additional information' was recorded in the free-text comment box. For these cases, we therefore have no information on which to base any commentary regarding family decline. The findings and discussion are therefore related to the italicised categories in Table 3 (n=61 cases within this group).

Table 3 - Summary of free-text comments relating to reasons for family reasons of eye donation

Family Reasons Categories	Cases (n)*	Cases (% of n=126 cases with free-text comment relating to family reasons)
No additional information	65	0.52
Family uncomfortable with eye donation	22	0.17
Family reasons indicated but case not classified as either '88-Family, not specified' or '87-Family other reasons, please specify'	17	0.13
Consent for Solid organ donation but not eyes	10	0.08
Nothing 'visible' to be removed	7	0.06
Family withdrew initial consent	6	0.05
Family Infer Patient Wishes (e.g. NoK recorded as indicating deceased 'would not have wanted' eye donation)	3	0.02
Family refuse moving of body for retrieval	3	0.02
No ODR restrictions but family refuse eye donation	2	0.02
Family reasons due to religious reasons	2	0.02
Tendons only	1	0.01
Family wish to donate to scientific research	1	0.01
Family believed patient ineligible due to medical contraindication	1	0.01
Family member worried that they may inadvertently work with tissues in professional role in donated but not transplanted	1	0.01

*Note: cases do not equal 126 as some can belong to more than one category (e.g. a comment could relate to both 'Consent for Solid organ donation but not eyes' and 'No ODR restrictions but family refuse eye donation')

Findings from analysis of free-text comments

Cases are reported as a percentage of the 126 free text comments available relating to family refusal (% of n=126).

Discomfort reactions

For 22 cases (17%) free-text responses recorded by SNODs indicated family discomfort with eye donation. In addition to general expressions of discomfort with eye donation comments also referred to personal attachment to the eyes of the deceased, which influenced family decision making (examples Textbox 2).

Textbox 2. Recorded family comments relating to discomfort reactions to eye tissue donation.

Four brothers who had had discussion and all felt "funny" about eyes.

Family did not like the idea of eye donation.

Family reported they didn't like the idea of someone else seeing through their loved ones eyes'...

'Family did not want eyes removing as they felt they were part of her'

Family were very much against eye donation as they said they were "windows to the soul"

... eyes refused as wife couldn't bear the thought of him without them .

Partner believed the eyes were the window to the soul

Disfigurement concerns

Linked to discomfort reactions, concerns about disfiguring the body of the deceased was raised by seven family members (6%) with SNODS recording that family members only wanted solid organs to be retrieved. It is notable that comments include words and phrases such as *'nothing visible, 'external' 'outside'* underlining that family members are concerned about how the body will look post donation (Textbox 3).

Textbox 3. Recorded family comments relating to disfigurement concerns.

This is how we saw him

Family did not like the thought of external surgery to the body other than through the initial operation site.

Family did not want anything "external" donated

Family did not want eye donation as not wanting anything visible

Family not wanting the face touching

Only wanted internal organs donated, nothing from the "outside"

Solid organ only – not eye tissue!

As well as concerns about disfigurement and the reported wish that *'nothing visible be removed'* in a further 10 cases (8%), family consent was recorded as being given for solid organs but declined for eyes. In Textbox 4, we see examples of differing decisions recorded for tissues (eyes are also referred to as tissues) and solid organs. Some comments record SNOD-perceived strength of feeling as a factor restricting further discussion about eye donation. Of note here is that we do not have evidence indicating on what basis the assessment about 'appropriateness is based', e.g. *"Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation"*, or how much time was taken in this approach for donation. Higher consent/authorisation rates are reported when parents perceive that they have had adequate time to discuss donation within the family and with the healthcare team [12,13]. In one case, we see a priority invoked as the reason for decline, *'life saving organs only'* suggesting that a *value* was being associated with different organ or tissues.

Textbox 4. Recorded family comments relating to reasons for eye tissue accompanying consent for solid organs.

[Family] did not want any tissue donation organs are enough.
Family did not want any tissue donation only solid organs
Family only wanted kidneys donated, no other reason given.
Family very uncomfortable with tissue donation and only wanted organs as they cannot be seen
Kidneys only would not discuss anything else
Life-saving organs only
On ODR no restrictions, partner consented to kidney only, nothing else.
Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation
Wife wanted solid organs only
Son certain he did not want to donate eyes, or any tissue. Was a very strong no to tissue and did not elaborate too much despite open questioning.

Change in decision-making

Six cases (5%) described initial consent for eye donation being provided by families which was later withdrawn (see Textbox 5). Comments suggest the potential influence of post decision dissonance (see discussing section) [14] and the impact of wider family views stimulating a reversal of the decision to agree to eye donation.

[Father] changed his mind after consent provided.
Even though partner consented initially, family wanted patient embalmed and wanted body home ASAP.
Family withdrew consent as needed quick release.
Family withdrew eye consent, reason not specified.
Initial consent provided for eyes and skin but then changed their mind, no reason given.
Parents consented for all tissues but withdrew consent whilst visiting him in Chapel of rest saying he had 'given enough' and they did not want him to be touched anymore

Textbox 5.
Recorded family comments relating to a change in decision to donate eyes.

Discussion

The data presented in this study indicate that the main reason for the non-procurement of eye tissue from solid organ donors in the UK is the decline of this option by bereaved family members. One thousand, three hundred and thirty-nine approaches for eye donation resulted in family decline, despite this being a valid donation option over the time period of data collection. Therefore, potentially, over 2,000 eyes did not become available for use in transplant operations and research into eye diseases resulting in loss of sight due to family decline.

This picture of potential donor eyes not becoming available in the context of solid organ donation is reflected in the global literature, with authors in the USA reporting that of 10,000 potential solid organ donors where a consent rate of 47% for organ donation was achieved, only 24% eye donation consent rate was achieved [15,16] reporting data from a survey carried out with 371 individuals renewing their driving licence in Sydney Australia, indicated that of the 369 participants who responded to the questions related to willingness to donate corneas 153 (41%) indicated that they would not donate their corneas. This reluctance for eye donation is not just reflected in Western contexts (e.g. Europe, North America, Australasia): for example, Acharya et al. (2019) surveyed 407 bereaved NoK of potential eye donors in Delhi (India), reporting that the majority 239 (59%) of NoK would decline eye donation [17]. Commentary from all three papers highlight concerns regarding disfigurement, discomfort with the thought of eye removal, and spiritual/atheistic links to the eyes.

The comments illustrated in textboxes 2-4 support the findings from international literature, that personal attitudes to and beliefs about the propriety of eye donation are influential in shaping negative orientations toward this option and thus to decline of donation when it is raised with NoK.

How can we understand these reactions?

Concerns with, and negative reactions to the option of eye donation, as well as the critical shortage of eye tissue for use in transplant operations and research, are persistent and pervasive in the UK and across many other parts of the world. Therefore, we will now discuss these factors in light of theoretical work aimed at illuminating factors underpinning these outcomes. The discussion will look at theories developed from social cognitive psychology, which outline general concepts influencing behaviour, and more specific theories/models focussed on psychological concepts that propose explanations for the reactions reported both in this data and the wider global literature. Whilst an exhaustive review of relevant theory is not possible in this paper, we focus on application of key findings and thinking to the national recorded data with the aim of: I) making recommendations to guide communication with patients, carers or other NoK when making an approach regarding the option of eye donation; II) stimulating thinking on communications strategy (e.g. future publicity and campaigns) by organisations responsible for securing a reliable and sufficient supply of eye tissue.

Social Cognitive models

Most early studies exploring factors influencing individual donation decision making applied concepts laid out in social-cognitive models such as the Theory of Reasoned Action (TRA) [18] and the Theory of Planned Behaviour (TPB) [19,20].

Horton and Horton (1991) developed one of the earliest models proposing that the action of signing or requesting an organ donor card and willingness to donate own, or a deceased loved one's organs after death was a product of: *values, knowledge, attitudes (toward donation), willingness and action* [21]. Their path analysis and causal modelling study included two cohorts of participants: University students (N= 295), and members of the public (N = 465). Whilst establishing that the tested concepts were related to donation decision making, it was also clear from results that there was no linear causal relationship between knowledge, values, attitudes, willingness, and action related to donation behaviours [21]. Further modelling by Radecki and Jaccard (1999) identifying barriers to sharing donation intentions with legal next of kin supported the general finding that behavioural intention (or willingness) does not predict action [22].

This brief review reminds us that while prior attitudes toward a behaviour are influential, that they do not 'ensure' action will follow intention. Models such as TRA [18] and TPB [19,20] are fundamentally models that presume a process of rational decision making that is not evidenced in studies where donating and non-donating family decision makers have been included and interviewed.

Research by Kopfman and Smith (1996) aimed at informing donation campaigns introduced new thinking as whilst looking at concepts such as 'knowledge, attitudes and intention to donate' and identifying that those who measured low in intent to donate were more likely to 'have inaccurate knowledge about donation and gain lower scores on a measure for altruism', they also highlighted that *'those low in intention felt that signing a donor card would be frightening'* [23]. We see here one of the first instances of what have been referred to as *non-rational* [23] or later *non-cognitive* factors [24,25] (anxiety/fear) being reported. Further work by authors carrying out qualitative research increasingly identified deeply held beliefs and feelings that were reported as influencing the decision to donate organs of self and others, or register an intent to become an organ donor on death, including: anxiety, mistrust, superstition-based fear and views about what should or should not be done to a body post death [10,11,14,16,24,26–30].

Sanner's Discomfort Reactions

We gain some important insights if we revisit Sanner's work exploring public views of post-death procedures on the body [10,11]. Although this work was carried out in the 1990's with 400 members of the public aged from 18 – 75 years, it identified particular 'discomfort reactions' in relation to post-death procedures that are both relevant and of value in moving forward our understanding of reactions to requests for eye donation. Interviews with three subgroups selected from the original 400 who represented negative, positive and undecided views regarding donating their own organs identified that people with "intense discomfort reactions tended to ignore or suppress positive motives (*e.g. attitudes, intentions*) toward donating organs" [10].

Sanner identified 600 statements that referred to what may or may not be done to the body after death, and after content analysis of these statements she constructed 20 'motive' categories. These categories were analysed to 'discern psychologically meaningful reaction patterns' by applying a frame of reference based on psychodynamic defence theory and resulted in six central motive complexes [11] (Table 4).

Table 4 – Motive complexes and categories relating to discomfort reactions to post-death procedures (Sanner, 1994)

Motive complexes	Sanner's motive categories (for details see Sanner, 1994) [11]
The illusion of lingering life	1. Uneasiness at the thought of cutting the dead body 2. Anxiety about not keeping the dead body intact 3. Discomfort with donation of certain organs 4. Difficulty with cutting children 5. Fear of destruction (of the body) 6. Uneasiness with exposure (via autopsy or dissection) 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 11. Apprehension about the funeral 13. Discomfort at giving useless organs
Protection of the value of the individual	5. Fear of destruction 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 10. Apprehension about the funeral 13. Discomfort of giving useless organs 15. Distrust of the doctors
Distress, anxiety and alienation	14. Problems with the concept of death 15. Distrust of the doctors 16. Anxiety about biomedical and social development
Respecting the limits set by nature/God	12. Dislike of having one's organ surviving in another body or having another organ living on in one's own body 17. Anxiety about offending God/nature
Altruism	18. Helpfulness and solidarity 19. Contribution to medical research
Rationality	20. Organs from the deceased can be used in the treatment of the living

Not only can we see these discomfort reactions articulated in the free-text comments recorded during data collection by SNODs (Textboxes 2 – 4), non-rational reactions have been evidenced by other authors and include: *fear that doctors would hasten the death of declared donors in order to procure transplantable organs* [26], *belief that donation would negatively impact rebirth or reincarnation (deceased would be reborn blind)* [31], with later work identifying the impact of *emotional beliefs including the 'ick' factor* and the role of *'Body Integrity'* [27] (for a detailed view of all variables tested in development of the Organ Donor Model (ODM) see Morgan et al. [24,27,32]). The 'ick' factor and concerns about body integrity are of particular relevance to eye donation and will therefore be discussed in more detail.

The Ick factor and Bodily Integrity

According to Morgan et al (2008) [27] *Ick factors* are those related to a basic disgust response to the idea of eye donation, as it involves what may be perceived by family members as interventions that are disfiguring and even disrespectful. Fear of body disfigurement is proposed as triggering defensive emotions that according to Parisi and Katz, *"seem to be deeply rooted in the unconscious and to have relatively little cognitive content"* (1986: 576) [33]. These defensive emotions are influenced by sociocultural and psychological factors developed early in childhood, strongly influenced by one's particular culture and ethnicity, and which are reported by Sherman and Sherman (2001) to be resistant to modification [34]. Furthermore, defensive emotions and reactions are reported to underpin donation-negative attitudes and carry more weight in the decision-making process than donation-favourable ones. These findings potentially provide insight into why persuasive attempts that focus on rational messages fail or are less successful than expected by organisations that oversee donation and transplantation services.

1 A final comment here is the reference in Textbox 2 to ‘eyes being the windows to the soul’¹. This perception has been
2 reported in a number of studies exploring eye donation and links to both the belief in the need to maintain the integrity
3 of the body after death [10,27,35] and a concern about the deceased not being able to see in the afterlife [16,36–38].
4 For some “eyes, more than any other body part, personify an individual” [15, p.1190] and therefore have greater
5 potential to stimulate ‘dissonance’ for individuals approached to consider the option of eye donation.
6
7

8
9 *Cognitive dissonance and the context of death*
10

11
12 Cognitive dissonance is described as an emotional state set up when two simultaneously held cognitions are
13 inconsistent or when there is a conflict between beliefs and overt behaviour [39]. Therefore, relating this to eye
14 donation, dissonance arises when family members approached to consider eye donation are aware (for example by
15 media campaigns such as ‘Give the gift of sight’) [40] or are made aware (e.g. by SNODS, or other family members)
16 that eye donation can reverse blindness and have to rationalise their aversion/disgust/discomfort of eye removal
17 which they perceive as an integral part of the person they love (as indicated in Textbox 2). Lawlor and Kerridge (2014)
18 go so far as to suggest that despite participants in their study “recognising the potential good that could come from
19 corneal donation, many still maintained that removing the eyes would potentially have a significant adverse effect on
20 their ongoing relationship with the deceased” [15, p.62].
21
22

23
24 We propose that non-cognitive factors including: discomfort reactions, disfigurement concerns, the ick factor and the
25 importance of body integrity are key areas of emotional and psychological conflict for family members approached to
26 consider eye donation. In their secondary analysis of primary data from donating and non-donating family members
27 in the UK, Long et al (2008) proposed that family members engage in a series of practical and psychological activities
28 aimed at rationalising real or potential emotional and cognitive conflict when faced with the option of donation post
29 death of a family member [14]. If family members are not able to rationalise conflict (e.g. sacrifice of an intact body to
30 a perceived disfiguring operation even if it is for the benefit of others) NoK will decline donation.
31
32

33
34 A key context missing from social cognitive models and also much qualitative research into barriers to donation is the
35 context of death. Apart from living donation, solid organ donation cannot proceed until someone has died, in the case
36 of solid organ a death that is sudden and unexpected. Death not only robs the next-of-kin of a significant relationship,
37 but also robs them of many of their usual coping mechanisms, imposing a sequence of events that Sque et al (2003)
38 describe as leaving family members feeling dispossessed of physical and psychological equilibrium [28].
39
40

41
42 Furthermore, from a sociological perspective, Kellehear (2008) remarks that an understanding of “‘dying as a social
43 relationship’ [is] vital to understanding the levels of disagreement with organ donation due to the social basis of
44 attachment, meaning-making and identity” [38, p.1541]. Responses indicating attachment to the deceased (e.g.
45 ‘family reported they didn’t like the idea of someone else seeing through their loved ones eyes, Textbox 2), as well as
46 the need for an intact body (e.g. ‘only wanted internal organs donated, nothing from the outside’, Textbox 3) are
47 evidenced in this national data set, alongside the importance of the identity of the deceased (e.g. ‘eyes refused as wife
48 couldn’t bear the thought of him without them’, Textbox 2). It is in this emotional landscape that the topic of eye
49
50
51
52
53
54
55
56
57
58
59
60

donation is raised, a context that appears unique to eye donation. It is therefore essential that those making the approach to request eye donation understand the non-rational, emotional, and sociological factors underpinning NoK decision-making if an increase in the donation of eyes is to be achieved.

Whilst messages to support positive attitudes toward donation are now embedded in social and other media campaigns in the UK (e.g. Giving the 'Gift of Life' gift of life, 'Yes I Donate' etc. [42]), messages employed to reduce negative attitudes have not taken sufficient account of the psychological, emotional and sociological factors that are specifically relevant to the donation of eye tissue. As stated in the introduction, eyes are the least donated organ and this, we argue, is because the thought of removing the eyes may stimulate intense discomfort reactions, such as disgust, concerns of visible disfigurement and dissonance that suppress positive motives (e.g. attitudes) toward donating eyes.

Limitations:

Data were generated by SNODs who recorded reasons shared with them by family members, and therefore the data reflect a mixture of direct observations and interpretations of both spoken responses and other communicative behaviours. While data reflect specific reasons given to SNODs by family members in some cases, many chose not to give a reason for their decision. Where reasons were given, we cannot claim with certainty whether all factors relevant to the decision were disclosed, and/or the extent to which participant understandings of their own reasons for refusal are stable over time (i.e. whether the way family members understood their decision rationale at the point of reporting/observation changed over time). Feedback received by the working group indicates that SNODs were likely not to probe family responses, just recording '*family refused*', '*No additional information*' if in their view the discussion may lead to decline of organs. The detail provided in the comments is constrained by the response format (i.e. a hand-written box) limiting the amount of information that SNODs could insert leading to wide variation in length of entries ranging between 1-187 words (median=6, IQR=7).

Conclusion and recommendations:

In view of the reported 53% of the world's population not having access to the benefits of sight saving and sight restoring transplantation surgery [1] and over two million people in the UK living with sight loss [2] this paper presents important data that could help organisations and HCPs involved in approaching bereaved family member for eye donation re-design modes of approach and the structure of consent conversations. In view of the data reported that potentially, over 2,000 eyes did not become available for use in transplant operations and research due to family members declining this donation option, further research is needed focussed on the construction, delivery and content of the donation conversation. We therefore propose the following recommendations for future service and communication strategy development.

- Communicate propriety of the donation operation - The 'sacrifice' of an unscathed body could be an important barrier to actualising donation even in populations where there is a high level of awareness of the benefits of transplantation [43]. The propriety of the donation operation needs to be stressed in public education and in discussions with the bereaved family approached about organ donation as discovering what worries people about organ donation is the first step towards crafting more effective organ donation campaigns [32].

- 1 • Explore the potential of a disc-only corneal retrieval procedure to increase acceptance of donation - Enucleation
2 (removal) of the entire eye (as usual in the UK) has been reported as being a potential barrier to donation of
3 eye tissue by relatives in view of disfigurement concerns. Removal of the corneoscleral disc only has been
4 aligned with higher consent rates [44], however currently robust data about whether this would be a more
5 acceptable intervention with decision makers is missing. Research comparing consent rates for these two options
6 would be a valuable addition to the knowledge base on which to base future service planning.
- 7 • Improve public education regarding the donation process - Public awareness campaigns, as well as consent
8 conversations with families currently focus on the benefits of transplantation. In contrast, little public
9 education has centred on the donation process itself which could prepare individuals for this potential life
10 event. According to Siminoff et al. (2001) *"Since it is not reasonable to expect that family decision-makers
11 can or even should relinquish strongly held beliefs about organ donation when experiencing the severe stress
12 of a loved one's death, prior education is the best mechanism we may have to inform the public and prepare
13 families for an organ donation request"* [14, p.76].
- 14 • Explore how the request process affects acceptance of donation - There remains significant room for
15 improvement in the request process, as to date this pivotal aspect of the donation process has received little
16 attention. Of note, there has been no research looking into the impact of the hierarchy of organs outlined in
17 the consent conversation. For example, if a patient is suitable to donate all organs and tissues, the first organ
18 mentioned is usually kidneys, followed by other abdominal organs and tissues, thoracic organs and tissues,
19 then tissues (within which eyes are listed). It has been proposed that the order in which organs are requested
20 may affect donation rates for eyes due to what has been referred to as 'list shock' - the idea that family
21 members may be overwhelmed by the 'list' of organ and tissue that can be donated (this term was first coined
22 by Margaret Verble and Judy Worth (personal communication, 21.08.2020).
- 23 • Explore processes for assessment of familial responses to information provided during the consent
24 conversation – future research should explore processes for assessing familial responses to information shared
25 in consent conversation, and how HCPs conducting conversations may appropriately and sensitively explore
26 areas that provoke a reaction (instead of avoiding them). Investigations of the latter type of particular need in
27 light of evidence indicating that many HCP's are poor *prima facie* judges of who may or may not be willing to
28 donate (14).

29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48 **Acknowledgement**

49 The authors would like to thank colleagues at the division of Statistics and Clinical Studies (NHSBT) for their help and
50 support.

51
52
53 **Funding statement**

54 This work was supported by The UK National Institute for Health Research (NIHR) grant number 17/49/42.

55 Article Processing Charges for this work are supported by NHS Blood and Transplant Tissue and Eye Services.

56
57
58
59 **Competing interests**

60 EW and HG are employed by NHS Blood and Transplant.

1 TLS, EW and HG were members of the 'Eye Donation from Solid Organ Donors – EPSOD, 2014-2017' working party
2 within NHS Blood and Transplant.
3

4 **Author Contributions**

5
6 TLS, EW and HG devised the project. TLS obtained funding from NIHR (17/49/42), and provided oversight to the
7 project. EW and HG provided support for article processing charges. MJB sourced secondary data from NHSBT and
8 conducted secondary data analysis (descriptive statistics and qualitative content analysis), with input from BMS and
9 TLS, and was responsible for primary authorship. TLS provided specialist input into the discussion and
10 recommendations, supported by HG and EW. All co-authors contributed substantially to the development of the paper
11 and resulting recommendations.
12
13

14
15 JM managed the study as chief investigator. MB was primarily responsible for study design, protocol, data collection
16 and analysis with input from JM, KW, KS, AA and CRM. All authors contributed significant revisions to drafts of the
17 manuscript, and have read and approved the final manuscript.
18
19

20 **Data sharing statement**

21
22 No additional unpublished data are available from this study.
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

References

1 Pascolini D, Mariotti SP. Global estimates of visual impairment: 2010. *Br J Ophthalmol* 2012;**96**:614–8. doi:10.1136/bjophthalmol-2011-300539

2 RNIB & Specsavers. The State of the Nation Eye Health 2016. *The State of the Nation* 2016;:27.

3 Gaum L, Reynolds I, Jones MNA, *et al*. Tissue and corneal donation and transplantation in the UK. *Br J Anaesth* 2012;**108**:i43–7. doi:10.1093/bja/aer398

4 NHS-BT Organ and Tissue Advisory Group (OTAG). Tissue and Eye Procurement from Solid Organ Donors (TEPSOD) Activity Report. 2016. http://odt.nhs.uk/pdf/advisory_group_papers/OTAG/Tissue_&_Eye_Procurement_from_Solid_Organ_Donation.pdf

5 NHS-BT. Organ Donation and Transplantation - Activity report 2016/2017. 2017. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4657/activity_report_2016_17.pdf

6 NHS-BT. NHS Blood and Transplant - Eye and Tissue Strategy. Liverpool, UK: 2016.

7 Royal College of Ophthalmologists. Standards for the retrieval of human ocular tissue used in transplantation, research and training. London, UK: 2013. <https://www.rcophth.ac.uk/publications/current-clinical-guidelines/>

8 NHS-BT. NHS Blood and Transplant, Statistics and Clinical Studies Division (Personal communication). 2020.

9 QSR International Ltd. NVivo qualitative data analysis software. 2018. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home> (accessed 23 Apr 2020).

10 Sanner M. A Comparison of Public Attitudes Toward Autopsy, Organ Donation, and Anatomic Dissection: A Swedish Survey. *JAMA J Am Med Assoc* 1994;**271**:284–8. doi:10.1001/jama.1994.03510280046031

11 Sanner M. Attitudes toward organ donation and transplantation. *Soc Sci Med* 1994;**38**:1141–52. doi:10.1016/0277-9536(94)90229-1

12 Weiss AH, Fortinsky RH, Laughlin J, *et al*. Parental consent for pediatric cadaveric organ donation. *Transplant Proc* 1997;**29**:1896–901. doi:10.1016/S0041-1345(97)00110-3

13 Rodrigue JR, Cornell DL, Howard RJ. Pediatric organ donation: What factors most influence parents??? donation decisions?*. *Pediatr Crit Care Med* 2008;**9**:180–5. doi:10.1097/PCC.0b013e3181668605

14 Long T, Sque M, Addington-Hall J. Conflict rationalisation: How family members cope with a diagnosis of brain stem death. *Soc Sci Med* 2008;**67**:253–61. doi:10.1016/j.socscimed.2008.03.039

15 Siminoff LA, Marshall HM. The rapid assessment of hospital procurement barriers in donation: assessing hospitals for change. *J Healthc Qual* 2009;**31**:24–33. doi:10.1111/j.1945-1474.2009.00034.x

- 16 Lawlor M, Kerridge I. Understanding Selective Refusal of Eye Donation: Identity, Beauty, and Interpersonal Relationships. *J Bioeth Inq* 2014;**11**:57–64. doi:10.1007/s11673-013-9497-9
- 17 Acharya M, Farooqui J, Dave A, *et al.* Eye donation in north India: Trends, awareness, influences and barriers. *Indian J Ophthalmol* 2019;**67**:1570. doi:10.4103/ijo.IJO_2151_18
- 18 Fishbein M, Ajzen I. *Belief, Attitude, Intention, and Behavior: An Introduction to Theory and Research*. Addison-Wesley Publishing Company 1975. <https://books.google.co.uk/books?id=8o0QAQAAIAAJ>
- 19 Ajzen I. The Theory of Planned Behavior. *Organ Behav Hum Decis Process* 1991;**50**:179–211. https://www.dphu.org/uploads/attachements/books/books_4931_0.pdf
- 20 Ajzen I. From Intentions to Actions: A Theory of Planned Behavior BT - Action Control: From Cognition to Behavior. In: Kuhl J, Beckmann J, eds. . Berlin, Heidelberg: : Springer Berlin Heidelberg 1985. 11–39. doi:10.1007/978-3-642-69746-3_2
- 21 Horton RL, Horton PJ. A model of willingness to become a potential organ donor. *Soc Sci Med* 1991;**33**:1037–51. doi:10.1016/0277-9536(91)90009-2
- 22 Radecki CM, Jaccard J. Signing an Organ Donation Letter: The Prediction of Behavior From Behavioral Intentions1. *J Appl Soc Psychol* 1999;**29**:1833–53. doi:10.1111/j.1559-1816.1999.tb00154.x
- 23 Kopfman JE, Smith SW. Understanding the audiences of a health communication campaign: A discriminant analysis of potential organ donors based on intent to donate. *J Appl Commun Res* 1996;**24**:33–49. doi:10.1080/00909889609365438
- 24 Morgan S, Miller J. Communicating about gifts of life: the effect of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *J Appl Commun Res* 2002;**30**:163–78. doi:10.1080/00909880216580
- 25 Quick BL, LaVoie NR, Reynolds-Tylus T, *et al.* Does Donor Status, Race, and Biological Sex Predict Organ Donor Registration Barriers? *J Natl Med Assoc* 2016;**108**:140–6. doi:10.1016/j.jnma.2016.05.007
- 26 Siminoff LA, Arnold RM, Hewlett J. The process of organ donation and its effect on consent. *Clin Transplant* 2001;**15**:39–47. <http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L32094333%5Cnhttp://dx.doi.org/10.1034/j.1399-0012.2001.150107.x%5Cnhttp://elvis.ubvu.vu.nl:9003/vulink?sid=EMBASE&issn=09020063&id=doi:10.1034%2Fj.1399-0012.2001.150107.x&atitle=The>
- 27 Morgan SE, Stephenson MT, Harrison TR, *et al.* Facts versus 'Feelings'. *J Health Psychol* 2008;**13**:644–58. doi:10.1177/1359105308090936
- 28 Sque M, Long T, Payne S. Organ and tissue donation: exploring the needs of families. Final report of a three-year study commissioned by the British Organ Donor Society, funded by the National Lottery Community Fund. University of Southampton 2003. <http://users.argonet.co.uk/body/Report.html>
- 29 Sque M, Long T, Payne S. Organ donation: Key factors influencing families' decision-making. *Transplant Proc* 2005;**37**:543–6. doi:10.1016/j.transproceed.2004.11.038
- 30 Lawlor M, Kerridge I. Anything but the eyes: Culture, identity, and the selective refusal of corneal donation. *Transplantation*. 2011;**92**:1188–90. doi:10.1097/TP.0b013e318235c817
- 31 Tandon R, Verma K, Vanathi M, *et al.* Factors affecting eye donation from postmortem cases in a tertiary care hospital. *Cornea* 2004;**23**:597–601. doi:10.1097/01.ico.0000121706.58571.f6
- 32 Morgan S, Miller J, Arasaratnam L. Signing cards, saving lives: an evaluation of the worksite organ donation promotion project. *Commun Monogr* 2002;**69**:253–73. doi:10.1080/03637750216540
- 33 Parisi N, Katz I. Attitudes toward posthumous organ donation and commitment to donate. *Heal Psychol* 1986;**5**:565–80. doi:10.1037//0278-6133.5.6.565
- 34 Sherman NC, Smith RJ, Sherman MF, *et al.* Disgust Sensitivity and Attitudes toward Organ Donation among African-American College Students. *Psychol Rep* 2001;**89**:11–23. doi:10.2466/pr0.2001.89.1.11

35 Lester H, Tait L, England E, *et al.* Patient involvement in primary care mental health: a focus group study. *Br J Gen Pract J R Coll Gen Pract* 2006;**56**:415–
22.<http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=16762122&site=ehost-live>

36 Hessing DJ, Elffers H. Attitude toward Death, Fear of Being Declared Dead Too Soon, and Donation of Organs after Death. *OMEGA - J Death Dying* 1987;**17**:115–26. doi:10.2190/5NB6-DJDW-B68G-6T56

37 Shindel A, Nelson C, Brandes S. Urologist practice patterns in the management of premature ejaculation: a nationwide survey. *J Sex Med* 2008;**5**:199–
205.<http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=17971107&site=ehost-live>

38 Wells J, Sque M. ‘Living choice’: the commitment to tissue donation in palliative care. *Int J Palliat Nurs* 2002;**8**:22–7. doi:10.12968/ijpn.2002.8.1.10231

39 M. DW, Reber AS. *The Penguin Dictionary of Psychology*. 1986. doi:10.2307/1422298

40 Gift of Sight. Gift of Sight. 2020.<https://www.giftofsight.org.uk/> (accessed 7 Jul 2020).

41 Kellehear A. Dying as a social relationship: A sociological review of debates on the determination of death. *Soc Sci Med* 2008;**66**:1533–44. doi:10.1016/j.socscimed.2007.12.023

42 NHSBT. Organ Donation and Transplantation. 2020.

43 Sque M, Long-Sutehall T. Bereavement, decision-making and the family in organ donation. In: *Organ Shortage: Ethics, Law and Pragmatism*. 2011. 67–86. doi:10.1017/CBO9780511973536.005

44 Hudde T, Reinhard T, Möller M, *et al.* Korneosklerale transplantatentnahme an der leiche: Erfahrungen der Lions-Hornhautbank Nordrhein-Westfalen in den jahren 1995 und 1996. *Ophthalmologie* 1997;**94**:780–4. doi:10.1007/s003470050203

Additional File

Table 1 - Reasons for non-donation cases for eye tissue by category and major sub-category for the period 1st April 2014-31st March 2017

Category	Sub-category	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All Years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44
	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A	N/A	2	0.00	1	0.00	3	0.00
	Other/not specified family reasons	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.54	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.16	20	0.45	52	0.29
Coroner refused consent	Homicide / Murder / Manslaughter	7	0.14	8	0.14	10	0.20	25	0.16
	Sustained injury in custody/prison	3	0.06	1	0.02	2	0.04	6	0.04
	Police refusal	18	0.35	N/A	N/A	1	0.02	19	0.12
	Suspicious death	23	0.45	24	0.11	16	0.31	63	0.39
	Other coroner reasons, please specify	51	1.00	24	0.11	22	0.43	97	0.61
Medical reasons	High risk behaviour	61	0.25	74	0.29	58	0.17	193	0.23
	Haemodilution	14	0.06	15	0.06	24	0.07	53	0.06
	Neurological conditions of unknown cause	47	0.19	34	0.13	44	0.13	125	0.15
	Positive virology	16	0.07	20	0.08	10	0.03	46	0.05
	Above age criteria	N/A	N/A	5	0.02	10	0.03	15	0.02
	Other medical reasons, please specify	104	0.43	105	0.42	200	0.58	409	0.49
All other reasons	Concerns about storage	1	0.02	2	0.04	3	0.03	6	0.03
	Other reasons, please specify	28	0.53	28	0.26	39	0.36	95	0.45
	Not specified	24	0.45	20	0.20	67	0.61	111	0.52

Table 2.1 Main reason for non-eye donation (all reasons) 1 April 2014 to 31 March 2015		
Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	35	(4.0)
Driving licence	1	(0.1)
Discussion with family	17	(1.9)
Verbal or written statement in life	1	(0.1)
Sub total	54	(6.1)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	11	(1.2)
Knew deceased wishes not to donate eyes	3	(0.3)
Sub total	14	(1.6)
Deceased wishes	68	(7.7)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	95	(10.8)
I do not like the idea of eye donation	62	(7.0)
Uncomfortable with removal of whole eye	16	(1.8)
Personal connection/link to deceased eyes	22	(2.5)
Sub total	195	(22.1)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	32	(3.6)
Only organs	79	(9.0)
Face not to be touched	61	(6.9)
Concerns about how the deceased would look	12	(1.4)
Nothing above the neck	2	(0.2)
Sub total	186	(21.1)
<i>Decision made on current physical/emotional state</i>		
Family disagreement	4	(0.5)
Family overwhelmed	6	(0.7)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	1	(0.1)
Sub total	13	(1.5)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need for eyes to be buried/cremated	1	(0.1)
Need eyes to see in the afterlife	3	(0.3)
Sub total	4	(0.5)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	26	(3.0)
Family, not specified	28	(3.2)
Sub total	54	(6.1)
Family wishes	452	(51.3)
Reason for non-eye donation	N	(%)
Coroner refused consent		
Homicide / Murder / Manslaughter	7	(0.8)
Police refusal	3	(0.3)
Suspicious death	18	(2.0)
Other coroner reasons, please specify	23	(2.6)
Sub total	51	(5.7)
Medical reasons		
High risk behaviour	61	(6.8)
Haemodilution	14	(1.6)
Neurological conditions of unknown cause	47	(5.3)

Positive virology	16	(1.8)
Other medical reasons, please specify	104	(11.7)
Sub total	242	(27.1)
All other reasons		
Concerns about storage	1	(0.1)
Other reasons, please specify	28	(3.1)
Not specified	24	(2.7)
Sub total	53	(5.9)
TOTAL	892	(100.0)

For peer review only

Table 2.2 **Main reason for non-eye donation (all reasons)**
1 April 2015 to 31 March 2016

Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	21	(2.1)
Passport	1	(0.1)
Discussion with family	22	(2.2)
Verbal or written statement in life	6	(0.6)
Sub total	50	(5.0)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	15	(1.5)
Perceived wishes with disfigurement	3	(0.3)
Sub total	18	(1.8)
Deceased wishes	68	(6.8)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	54	(5.4)
I do not like the idea of eye donation	69	(6.9)
Uncomfortable with removal of whole eye	10	(1.0)
Personal connection/link to deceased eyes	21	(2.1)
Sub total	154	(15.5)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	40	(4.0)
Only organs	88	(8.9)
Face not to be touched	38	(3.8)
Concerns about how the deceased would look	13	(1.3)
Nothing above the neck	1	(0.1)
Sub total	180	(18.1)
<i>Decision made on current physical/emotional state</i>		
Family tired	1	(0.1)
Family disagreement	1	(0.1)
Family overwhelmed	5	(0.5)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	3	(0.3)
Sub total	12	(1.2)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need eyes to see in the afterlife	12	(1.2)
Sub total	12	(1.2)
<i>Decision made on lack of knowledge</i>		
Family unaware that eyes can be donated	1	(0.1)
Family had questions about the process	1	(0.1)
Sub total	2	(0.2)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	26	(2.6)
Family, not specified	34	(3.4)
Sub total	60	(6.0)
Family wishes	420	(42.3)
Coroner refused consent		
Homicide / Murder / Manslaughter	8	(0.9)
Sustained injury in custody/prison	1	(0.1)
Suspicious death	25	(2.8)

Other coroner reasons, please specify	24	(2.7)
Sub total	58	(6.6)
Medical reasons		
High risk behaviour	74	(8.4)
Haemodilution	15	(1.7)
Neurological conditions of unknown cause	34	(3.9)
Positive virology	20	(2.3)
Above age criteria	5	(0.6)
Other medical reasons, please specify	105	(11.9)
Sub total	253	(28.7)
All other reasons		
Concerns about storage	2	(0.2)
Other reasons, please specify	28	(3.2)
Not specified	20	(2.3)
Sub total	50	(5.7)
TOTAL	881	(100.0)

Table 1.3 Main reason for non-eye donation (all reasons) 1 April 2016 to 31 March 2017		
Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	13	(1.3)
Discussion with family	6	(0.6)
Verbal or written statement in life	5	(0.5)
Sub total	24	(2.4)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	18	(1.8)
Perceived wishes with disfigurement	2	(0.2)
Sub total	20	(2.0)
Deceased wishes	44	(4.3)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	40	(3.9)
I do not like the idea of eye donation	41	(4.0)
Uncomfortable with removal of whole eye	11	(1.1)
Personal connection/link to deceased eyes	37	(3.6)
Sub total	129	(12.7)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	95	(9.4)
Only organs	92	(9.1)
Face not to be touched	23	(2.3)
Concerns about how the deceased would look	10	(1.0)
Nothing above the neck	2	(0.2)
Sub total	222	(21.9)
<i>Decision made on current physical/emotional state</i>		
Family tired	3	(0.3)
Family disagreement	5	(0.5)
Family overwhelmed	6	(0.6)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	11	(1.1)
Sub total	27	(2.7)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need eyes to see in the afterlife	5	(0.5)
Sub total	5	(0.5)
<i>Decision made on lack of knowledge</i>		
Family had questions about the process	1	(0.1)
Sub total	1	(0.1)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	35	(3.4)
Family, not specified	48	(4.7)
Sub total	83	(8.2)
Family wishes	467	(46.0)
Coroner refused consent		
Homicide / Murder / Manslaughter	10	(1.0)
Sustained injury in custody/prison	2	(0.2)
Police refusal	1	(0.1)
Suspicious death	16	(1.6)
Other coroner reasons, please specify	22	(2.2)
Sub total	51	(5.1)

Medical reasons		
High risk behaviour	58	(5.8)
Haemodilution	24	(2.4)
Neurological conditions of unknown cause	44	(4.4)
Positive virology	10	(1.0)
Above age criteria	10	(1.0)
Other medical reasons, please specify	200	(20.1)
Sub total	346	(34.8)
All other reasons		
Concerns about storage	3	(0.3)
Other reasons, please specify	39	(3.9)
Not specified	67	(6.7)
Sub total	109	(11.0)
TOTAL	1017	(100.0)

BMJ Open

Family Refusal of eye tissue donation from potential solid organ donors – a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1st April 2014 – 31st March 2017).

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-045250.R1
Article Type:	Original research
Date Submitted by the Author:	19-Jan-2021
Complete List of Authors:	Bracher, Mike; University of Southampton, School of Health Sciences Madi-Segwagwe, Banyana; University of Southampton, School of Health Sciences Winstanley, Emma; National Health Service Blood and Transplant Services - Organ and Tissue Donation and Transplantation Gillan, Helen; National Health Service Blood and Transplant Services- Organ and Tissue Donation and Transplantation Long-Sutehall, Tracy; University of Southampton,
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Sociology
Keywords:	Corneal and external diseases < OPHTHALMOLOGY, Transplant pathology < PATHOLOGY, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Family Refusal of eye tissue donation from potential solid organ donors – a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1st April 2014 – 31st March 2017).

Mike Bracher (MB) (m.j.bracher@soton.ac.uk)^{1§}

Banyana C. Madi-Segwagwe (BMS) (b.c.madi-segwagwe@soton.ac.uk)¹

Emma Winstanley (EW) (emma.winstanley@nhsbt.nhs.uk)²

Helen Gillan (HG) (helen.gillan@nhsbt.nhs.uk)²

Tracy Long-Sutehall (TLS) (t.long@soton.ac.uk)¹

1. School of Health Sciences, University of Southampton, UK
2. UK National Health Service Blood and Transplant Services- Organ and Tissue Donation and Transplantation (NHS BT – OTDT), UK

§ Corresponding author

Mike Bracher, School of Health Sciences, University of Southampton.

Email: m.j.bracher@soton.ac.uk; Tel: 023 80 593929

Word count = Abstract = 299; Article = 5201

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives: Long-standing undersupply of eye tissue exists both in the UK and globally, and the UK National Health Service Blood and Transplant Service (NHSBT) has called for further research exploring barriers to eye donation. This study aims to: I) describe reported reasons for non-donation of eye tissue from solid organ donors in the UK between 1st April 2014–31st March 2017; II) discuss these findings with respect to existing theories relating to non-donation of eyes by family members.

Design: Secondary analysis of a national primary data set of recorded reasons for non-donation of eyes from 2790 potential solid organ donors. Data analysis including descriptive statistics and qualitative content analysis of free-text data for 126 recorded cases of family decline of eye donation.

Setting: National data set covering solid organ donation (secondary care).

Participants: 2790 potential organ donors assessed for eye donation eligibility between 1st April 2014 and 31st March 2017.

Results: Reasons for non-retrieval of eyes were recorded as: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%). In >50% of recorded cases, reasons for non-donation were based on: family’s knowledge of the deceased wishes, their perception of the deceased wishes, and specific concerns regarding processes or effects of eye donation (for the deceased body). Findings are discussed with respect to existing theoretical perspectives.

Conclusion: Eye donation involves distinct psychological and socio-cultural factors for families and HCPs that have not been fully explored in research or integrated into service design. We propose areas for future research and service development including: potential of only retrieving corneal discs as opposed to full eyes to reduce disfigurement concerns; public education regarding donation processes; exploration of how request processes potentially influence acceptance of eye donation; procedures for assessment of familial responses to information provided during consent conversations.

Keywords: secondary analysis, eye donation, cornea, consent, family decline of donation

Strengths and limitations of this study

- This secondary analysis paper is the first reporting of primary data discussing reasons for non-donation of eyes recorded by Specialist Nurses in Organ Donation (SNODs) for 2790 potential solid organ donors in the UK.
- The authors applied qualitative content analysis to free-text data and discuss findings in relation to existing theoretical perspectives to identify areas for further research and service development.
- The paper reports proxy commentary recorded as free text data generated by SNODs when recording reasons provided by family members for declining donation of eye tissue, and therefore is limited in depth of detail available for reporting.
- Due to study design limitations, factors that may have influenced family decision making (i.e. potential donor demographics/regional differences, changes in legislation) cannot be addressed in this paper.
- Due to data sharing restrictions the paper presents descriptive statistics only.

Background

Globally, 53% of the world's population has no access to the benefits of sight saving and sight restoring transplantation surgery due to a short fall in the supply of ophthalmic tissue (cornea and sclera) that is only available via eye donation [1]. According to Pascolini et al. (2010) over 10 million people worldwide have bilateral corneal blindness which could be restored with a corneal transplant [1]. According to the Royal National Institute of Blind (RNIB) over two million people in the UK are living with sight loss [2] caused by conditions such as Keratoconus and Fuchs' Corneal Dystrophy, that 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 eye diseases, for example endothelial failure post-cataract surgery [3]. The RNIB report 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 (unpaid carer burden and reduced employment rates) reported as £4.34 billion annually [2]. Critically, the organisation predicts predicted that by 2050 the number of people with sight loss will double to nearly four million [2]. It is therefore imperative that the tissue needed to intervene in these conditions via corneal transplantation, reconstructive surgery, glaucoma surgery, and research into the causes and treatment of eye disease is available

However, there is a long-standing shortfall in supply of eye tissue in the UK and globally, with eyes being the least donated of all organs and tissues when decision makers are offered a 'list' that they need to agree to that can be retrieved for use in transplantation (n.b. as eyes are referred to as both organs *and* tissues in different contexts, we will refer to them as organs from here on) [4,5]. The UK National Health Services Blood and Transplant (NHSBT) Eye Bank in Speke, Liverpool and Bristol (who supply most eye tissue used for surgical purposes in the UK) seeks to have 10 eye donors per day consistently to satisfy demand for the treatment of patients. This number is not consistently met.

Increasing supply is a key strategic aim for NHSBT Tissue and Eye Services Division [6] and they, along with the UK Royal College of Ophthalmology (RCO) [7], have expressed a need for research exploring barriers to eye donation. This knowledge is needed not only as a basis for developing new routes to supply, but also to inform guidance underpinning donation conversations with family members who are approached to consider the option of eye donation. Increasing supply requires understanding of how patients and families relate to eye tissue donation (i.e. attitudes, beliefs, information needs etc.) and how these processes shape donation outcomes, specifically family members declining eye donation.

Eye donation from solid organ donors continues to prove problematic, with slow progress in increasing supply from this specific cohort of donors. For example, eye donation from solid organ donors generated 320 eyes between 1st April 2015 to 31st March 2016 [4] , and 446 eyes between 1st April 2019 to 31st March 2020 [8]. Current evidence indicates that nationally on average only 40% (range 31-64%) of next-of-kin (NoK) agree to eye donation when approached to consider solid organ donation , whilst 67% of NoK agree to solid organ donation [5], and therefore what contributes to this difference is an important area for investigation.

In this paper we aim to contribute to the knowledge base around non-donation of eye tissue from solid organ donors by reporting, for the first time, national clinical data collected and provided by NHS Blood and Transplant between 2014–2017, aligned with key theoretical perspectives reported to explain donating behaviours. This body of work from the past 30 years will advance knowledge and understanding of the reasons why of all organs and tissues that can be donated, eyes remain the least donated organ [4,5].

Study objectives:

- i. *Describe the reported reasons why eye donation did not take place from potential solid organ donors in the UK between 1st April 2014 – 31st March 2017.*
- ii. *Discuss these findings in the context of existing theoretical perspectives relating to non-donation of eyes by family members*

Study design

To gain further insight into the factors leading to low numbers of eyes being secured from solid organ donation, a working party (Eye Donation from Solid Organ Donors – EPSOD, 2014-2017) was convened with the remit to: plan and action an effective response to demand and supply problems, and make evidence-based recommendations to NHSBT and external stakeholders regarding potential service development that would impact on the current low supply of eye tissue.

Ethical approval

Ethical approval was not required for this secondary analysis of previously collected primary data. Primary data collected as part of the service development was shared with the UOS team in line with a Service Level Agreement (SLA) between UOS and NHSBT Tissue and Eye Services Division since 2007. The sharing, analysis and reporting of data was carried out in line with a UK Transplant Registry Data Release agreement relating to UK General Data Protection Regulations (GDPR) 2018, the UK Data Protection Act 2018, the UK Human Rights Act 1998, and the UK Common Law Duty of Confidentiality.

Patient and Public involvement

The paper presents a secondary analysis of primary data collected by NHSBT Tissue Services as part of a service development initiative. As such there were no patients or members of the public involved in the design or conduct of the primary service development initiative. No dissemination of the primary data has occurred until this secondary analysis. As part of secondary analysis carried out by UOS team, and in line with the team’s commitment to the value of PPI input, a summary of key findings was made to members of the NHSBT Tissue Services Donor Advisory Group (DAG), which includes next of kin of donating patients and public representatives). Members were invited to ask questions as part of an update to their regular meeting in Q4 2020.

Data collection

Data for 2790 potential* donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate eyes between 1st April 2014 and 31st March 2017, were collected using a standardised proforma (*n.b. potential donor refers to a deceased person who could become an organ donor unless medical criteria for non-donation, or consent/authorisation is withheld by next of kin). Specialist Nurses in Organ Donation (SNODs) were requested to record reasons for non-procurement of eye tissue selecting from the domains listed in Table 1. SNODs were also asked to add further commentary via use of a free-text box. Data was gathered by SNODs with the requirement that they complete data collection for each potential donor following discussion with family members and other stakeholders (e.g. coroner). Data for each SNOD were collated into a monthly regional team returns to the NHSBT statistical team, who generated descriptive statistical data reported in this paper. Data were collected over three years, with a cessation in 2018 due to the operationalisation of eye donation moving from the Organ Donation and Transplant division of NHSBT to its Tissue and Eye Services division. The full data set for descriptive statistics relating to non-procurement of eye tissue is presented in *Additional File, Table 1* – however this paper focuses on data relating specifically to **family decline of eye donation**.

Analysis

Secondary Analysis [9] included generation of descriptive statistics on reasons for non-donation of eyes recorded by SNODs for 2790 potential donors (Table 1) and application of qualitative content analysis [10] to free-text data for 126 recorded reasons for family decline of eye donation. Analysis of free-text data was undertaken using Nvivo computer-assisted qualitative data analysis (CAQDAS) software (version 12) [11].

As international empirical evidence from the past 30 years indicates, eye donation involves reactions that do not impact other forms of donation including: discomfort reactions [12,13], disfigurement [3], the belief that eyes will be needed in the afterlife, eyes being viewed as the ‘windows to the soul’ [6,14], as well as disgust-related aversion (‘yuk’/‘ick factor’) (findings from this national dataset have been grouped under these headings).

The aim of the analytic process was to generate a descriptive analysis of data recording reasons for non-donation of eye tissue as reported by SNODs (Objective 1), and to underpin a theoretically informed discussion aimed at unpacking the key reasons why family members decline the option of eye donation when this is a possibility (i.e. no medical reasons for non-donation are evident) (Objective 2). By engaging with existing theory regarding donation decision making, this paper also aims to inform interventions that can lead to an increase in donation of eye tissue for use in transplant operations.

Descriptive statistics

Reasons for non-donation of eye tissue (overview)

The data related to 2790 potential donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate eyes between 1st April 2014 and 31st March 2017, but from whom eye tissue was not retrieved (reporting periods cover UK financial year, see Table 1). The most common reasons for non-retrieval of eyes were: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%); and coroner refusal (n=160,

6%), with ‘All other reasons’ accounting for n=212 (8%) of cases (reasons were not recorded in n=58 (2%) cases – see Table 1). The reporting in this paper will focus on data related to **family and deceased wishes** only as these contribute to over 50% of recorded reasons why eye donation did not proceed when donation discussions took place.

Table 1 – Summary of recorded reasons for non-donation of eye tissue from potential solid organ donors for the period 1st April 2014-31st March 2017 (focus categories for this paper are shaded grey).

Period	Family wishes		Medical reasons		Deceased wishes		Coroner refused		All other reasons		(Reasons not recorded)		TOTAL	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(% all years)
1 April 2014 to 31 March 2015	452	0.51	242	0.27	68	0.08	51	0.06	53	0.06	26	0.03	892	0.32
1 April 2015 to 31 March 2016	420	0.48	253	0.29	68	0.08	58	0.07	50	0.06	32	0.04	881	0.32
1 April 2016 to 31 March 2017	467	0.46	346	0.34	44	0.04	51	0.05	109	0.11	0	0	1017	0.36
All years	1339	0.48	841	0.3	180	0.07	160	0.06	212	0.08	58	0.02	2790	

Decline of eye donation based on family and deceased wishes

Where non-procurement of eye tissue was recorded under *Family wishes* (n=1339), the most common reasons related to disfigurement concerns (n=588, 44% of family decline), or ‘personal views’ about eye donation held by Next of Kin (NoK) (n=478, 36% - see Table 2).

For cases where non-procurement of eye tissue was recorded under *Deceased’s wishes* (n=180 cases, 7% of total), 128 (71% of deceased wishes cases) were due to the fact that the deceased had registered (on the organ donor register, which is always checked by SNODs in preparation for discussing donation options) that they did not want to donate eye tissue. A further 52 (29%) cases of non-procurement of eye tissue resulted from discussions with NoK where they stated that the deceased’s wish not to donate eyes was known to them – see Table 2.

Table 2 – Reasons for non-donation of eye tissue from potential solid organ donors by category and major sub-category for the period 1st April 2014-31st March 2017.

Domain	Sub-domain	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All Years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44

	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A*	N/A*	2	0.00	1	0.00	3	0.00
	Other/not specified family reasons**	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.74	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.26	20	0.45	52	0.29

*category was not included in data collection for this period.

**Includes sub-domains inviting free-text comment (i.e. 'please specify')

Findings from analysis of free-text data (family decline)

Table 3 lists results of content analysis, showing all resulting categories of recorded reasons for family decline (n = 126). Of note is that in 65 cases (10%) of SNODs reporting 'family refused', 'No additional information' was recorded in the free-text comment box. For these cases, we therefore have no information on which to base any commentary regarding family decline. The findings and discussion are therefore related to the italicised categories in Table 3 (n=61 cases within this group).

Table 3 - Summary of free-text comments relating to family reasons for decline of eye tissue donation from potential solid organ donors

Family Reasons Categories	Cases (n)*	Cases (% of n=126 cases with free-text comment relating to family reasons)
<i>No additional information</i>	65	0.52
<i>Family uncomfortable with eye donation</i>	22	0.17
<i>Family reasons indicated but case not classified as either '88-Family, not specified' or '87-Family other reasons, please specify'</i>	17	0.13
<i>Consent for Solid organ donation but not eyes</i>	10	0.08
<i>Nothing 'visible' to be removed</i>	7	0.06
<i>Family withdrew initial consent</i>	6	0.05
Family Infer Patient Wishes (e.g. NoK recorded as indicating deceased 'would not have wanted' eye donation)	3	0.02
Family refuse moving of body for retrieval	3	0.02
No ODR restrictions but family refuse eye donation	2	0.02
Family reasons due to religious reasons	2	0.02
Tendons only	1	0.01
Family wish to donate to scientific research	1	0.01
Family believed patient ineligible due to medical contraindication	1	0.01
Family member worried that they may inadvertently work with tissues in professional role in donated but not transplanted	1	0.01

*Note: cases do not equal 126 as some can belong to more than one category (e.g. a comment could relate to both 'Consent for Solid organ donation but not eyes' and 'No ODR restrictions but family refuse eye donation')

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

27

28

29

30

31

32

33

34

35

36

37

38

39

40

41

42

43

44

45

46

47

48

49

50

51

52

53

54

55

56

57

58

59

60

Findings from analysis of free-text comments

Cases are reported as a percentage of the 126 free text comments available relating to family refusal (% of n=126).

Discomfort reactions

For 22 cases (17%) free-text responses recorded by SNODs indicated family discomfort with eye donation. In addition to general expressions of discomfort with eye donation comments also referred to personal attachment to the eyes of the deceased, which influenced family decision making (examples Textbox 1).

Textbox 1. Recorded family comments relating to discomfort reactions to eye tissue donation.

[B]rothers who had had discussion and all felt "funny" about eyes.
Family did not like the idea of eye donation.
Family reported they didn't like the idea of someone else seeing through their loved ones eyes'...
'Family did not want eyes removing as they felt they were part of her'
Family were very much against eye donation as they said they were "windows to the soul"
... eyes refused as wife couldn't bear the thought of him without them.
Partner believed the eyes were the window to the soul

Disfigurement concerns

Linked to discomfort reactions, concerns about disfiguring the body of the deceased was raised by seven family members (6%) with SNODs recording that family members only wanted solid organs to be retrieved. It is notable that comments include words and phrases such as 'nothing visible', 'external', and 'outside' underlining that family members are concerned about how the body will look post donation (Textbox 2).

Textbox 2. Recorded family comments relating to disfigurement concerns.

This is how we saw him
Family did not like the thought of external surgery to the body other than through the initial operation site.
Family did not want anything "external" donated
Family did not want eye donation as not wanting anything visible
Family not wanting the face touching
Only wanted internal organs donated, nothing from the "outside"

Solid organ only – not eye tissue!

As well as concerns about disfigurement and the reported wish that 'nothing visible be removed' in a further 10 cases (8%), family consent was recorded as being given for solid organs but declined for eyes. In Textbox 3, we see examples of differing decisions recorded for tissues (eyes are also referred to as tissues) and solid organs. Some comments record SNOD-perceived strength of feeling as a factor restricting further discussion about eye donation. Of note here is that we do not have evidence indicating on what basis the assessment about 'appropriateness' is based (e.g. "Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation") or how much time was taken in this approach for donation. Higher consent/authorisation rates are

reported when parents perceive that they have had adequate time to discuss donation within the family and with the healthcare team [15,16]. In one case, we see a priority invoked as the reason for decline, 'life saving organs only' suggesting that a *value* was being associated with different organ or tissues.

Textbox 3. Recorded family comments relating to reasons for eye tissue accompanying consent for solid organs.

[Family] did not want any tissue donation organs are enough.
 Family did not want any tissue donation only solid organs
 Family only wanted kidneys donated, no other reason given.
 Family very uncomfortable with tissue donation and only wanted organs as they cannot be seen
 Kidneys only would not discuss anything else
 Life-saving organs only
 On ODR no restrictions, partner consented to kidney only, nothing else.
 Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation
 Wife wanted solid organs only
 Son certain he did not want to donate eyes, or any tissue. Was a very strong no to tissue and did not elaborate too much despite open questioning.

Change in decision-making

Six cases (5%) described initial consent for eye donation being provided by families which was later withdrawn (see Textbox 4). Comments suggest the potential influence of post-decision dissonance (see *Discussion* section) [17] and the impact of wider family views stimulating a reversal of the decision to agree to eye donation.

[Father] changed his mind after consent provided.
 Even though partner consented initially, family wanted patient embalmed and wanted body home ASAP.
 Family withdrew consent as needed quick release.
 Family withdrew eye consent, reason not specified.
 Initial consent provided for eyes and skin but then changed their mind, no reason given.
 Parents consented for all tissues but withdrew consent whilst visiting him in Chapel of rest saying he had 'given enough' and they did not want him to be touched anymore

*Textbox 4.
 Recorded
 family
 comments
 relating to a
 change in
 decision to
 donate eyes.*

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Discussion

The data presented in this study indicate that the main reason for non-procurement of eye tissue from potential solid organ donors in the UK is the decline of this option by bereaved family members. One thousand, three hundred and thirty-nine approaches for eye donation resulted in family decline, despite this being a valid donation option over the time period of data collection. Therefore, potentially, over 2,000 eyes did not become available for use in transplant operations and research into eye diseases resulting in loss of sight due to family decline.

This picture of potential donor eyes not becoming available in the context of solid organ donation is reflected in the global literature, with authors in the USA reporting that of 10,000 potential solid organ donors where a consent rate of 47% for organ donation was achieved, only 24% eye donation consent rate was achieved [18]. Reporting data from a survey carried out with 371 individuals renewing their driving licence in Sydney Australia, authors indicated that of 369 participants who responded to questions related to willingness to donate corneas, 153 (41%) indicated that they would not [19]. This reluctance for eye donation is not just reflected in Western contexts (e.g. Europe, North America, Australasia): for example, Acharya et al. (2019) surveyed 407 bereaved NoK of potential eye donors in Delhi (India), reporting that the majority 239 (59%) of NoK would decline eye donation [20]. Commentary from all three papers highlight concerns regarding disfigurement, discomfort with the thought of eye removal, and spiritual/atheistic links to the eyes.

The comments illustrated in textboxes 1-4 support the findings from international literature, that personal attitudes to and beliefs about the propriety of eye donation are influential in shaping negative orientations toward this option and thus to decline of donation when it is raised with NoK.

How can we understand these reactions?

Concerns with, and negative reactions to the option of eye donation, as well as the critical shortage of eye tissue for use in transplant operations and research, are persistent and pervasive in the UK and across many other parts of the world. Therefore, we will now discuss these factors in light of theoretical work aimed at illuminating factors underpinning these outcomes. The discussion will look at theories developed from social cognitive psychology, which outline general concepts influencing behaviour, and more specific theories/models focussed on psychological concepts that propose explanations for the reactions reported both in these data and the wider global literature. Whilst an exhaustive review of relevant theory is not possible in this paper, we focus on application of key findings and thinking to the national recorded data analysed here with the aim of: I) making recommendations to guide communication with patients, carers or other NoK when making an approach regarding the option of eye donation; II) stimulating thinking on communications strategy (e.g. future publicity and campaigns) by organisations responsible for securing a reliable and sufficient supply of eye tissue.

Social Cognitive models

Most early studies exploring factors influencing individual donation decision making applied concepts laid out in social-cognitive models such as the Theory of Reasoned Action (TRA) [21] and the Theory of Planned Behaviour (TPB) [22,23]. Horton and Horton (1991) developed one of the earliest models proposing that the action of signing or requesting an organ donor card and willingness to donate own, or a deceased loved one's organs after death was a product of: *values, knowledge, attitudes (toward donation), willingness and action* [24]. Their path analysis and causal modelling study included two cohorts of participants: University students (N= 295), and members of the public (N = 465). Whilst establishing that the tested concepts were related to donation decision making, it was also clear from results that there was no linear causal relationship between knowledge, values, attitudes, willingness, and action related to donation behaviours [24]. Further modelling by Radecki and Jaccard (1999) identifying barriers to sharing donation intentions with legal next of kin supported the general finding that behavioural intention (or willingness) does not predict action [25].

This brief review reminds us that while prior attitudes toward a behaviour are influential, that they do not 'ensure' action will follow intention. Models such as TRA [21] and TPB [22,23] are fundamentally models that presume a process of rational decision making that is not evidenced in studies where donating and non-donating family decision makers have been included and interviewed.

For example, research by Kopfman and Smith (1996) aimed at informing donation campaigns introduced new thinking by looking both at concepts such as 'knowledge, attitudes and intention to donate' and identifying that those who measured low in intent to donate were more likely to 'have inaccurate knowledge about donation and gain lower scores on a measure for altruism' – and also highlighting that *'those low in intention felt that signing a donor card would be frightening'* [26]. We see here one of the first instances of what have been referred to as *non-rational* [26] or later *non-cognitive* factors [27,28] (anxiety/fear) being reported. Further work by authors carrying out qualitative research increasingly identified deeply held beliefs and feelings that were reported as influencing the decision to donate organs of self and others, or register an intent to become an organ donor on death, including: anxiety, mistrust, superstition-based fear and views about what should or should not be done to a body post death [12–14,17,18,27,29–32].

Sanner's Discomfort Reactions

We gain some important insights if we revisit Sanner's work exploring public views of post-death procedures on the body [12,13]. Although this work was carried out in the 1990's with 400 members of the public aged from 18–75 years, Sanner identified particular 'discomfort reactions' in relation to post-death procedures that are both relevant and of value in moving forward our understanding of reactions to requests for eye donation. Interviews with three subgroups selected from the original 400 who represented negative, positive, and undecided views regarding donating their own organs identified that people with "intense discomfort reactions tended to ignore or suppress positive motives (*e.g. attitudes, intentions*) toward donating organs" [12].

Sanner identified 600 statements that referred to what may or may not be done to the body after death, and after content analysis of these statements she constructed 20 ‘motive’ categories. These categories were analysed to ‘discern psychologically meaningful reaction patterns’ by applying a frame of reference based on psychodynamic defence theory, and resulted in six central motive complexes [13] (Table 4).

Table 4 – Motive complexes and categories relating to discomfort reactions to post-death procedures (Sanner, 1994)

Motive complexes	Sanner’s motive categories (for details see Sanner, 1994) [13]
The illusion of lingering life	1. Uneasiness at the thought of cutting the dead body 2. Anxiety about not keeping the dead body intact 3. Discomfort with donation of certain organs 4. Difficulty with cutting children 5. Fear of destruction (of the body) 6. Uneasiness with exposure (via autopsy or dissection) 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 11. Apprehension about the funeral 13. Discomfort at giving useless organs
Protection of the value of the individual	5. Fear of destruction 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 10. Apprehension about the funeral 13. Discomfort of giving useless organs 15. Distrust of the doctors
Distress, anxiety and alienation	14. Problems with the concept of death 15. Distrust of the doctors 16. Anxiety about biomedical and social development
Respecting the limits set by nature/God	12. Dislike of having one’s organ surviving in another body or having another organ living on in one’s own body 17. Anxiety about offending God/nature
Altruism	18. Helpfulness and solidarity 19. Contribution to medical research
Rationality	20. Organs from the deceased can be used in the treatment of the living

Not only can we see these discomfort reactions articulated in the free-text comments recorded during data collection by SNODs in our own findings (Textboxes 1 – 4), we can also see that non-rational reactions have been evidenced by other authors and include: *fear that doctors would hasten the death of declared donors in order to procure transplantable organs* [18], *belief that donation would negatively impact rebirth or reincarnation (deceased would be reborn blind)* [33], and later work identifying the impact of *emotional beliefs including the ‘ick’ factor* and the role of ‘*Body Integrity*’ [29] (for a detailed view of all variables tested in development of the Organ Donor Model (ODM) see Morgan et al. [27,29,34]). The ‘ick’ factor and concerns about body integrity are of particular relevance to eye donation and will therefore be discussed in more detail.

The Ick factor and Bodily Integrity

According to Morgan et al (2008) [29] *Ick factors* are those related to a basic disgust response to the idea of eye donation, as it involves what may be perceived by family members as interventions that are disfiguring and even disrespectful. Fear of body disfigurement is proposed as triggering defensive emotions that according to Parisi and Katz, “*seem to be deeply rooted in the unconscious and to have relatively little cognitive content*” (1986: 576) [35]. These defensive emotions are influenced by sociocultural and psychological factors developed early in childhood,

strongly influenced by one's particular culture and ethnicity, and which are reported by Sherman and Sherman (2001) to be resistant to modification [36]. Furthermore, defensive emotions and reactions are reported to underpin donation-negative attitudes and carry more weight in the decision-making process than donation-favourable ones. These findings potentially provide insight into why persuasive attempts that focus on rational messages fail or are less successful than expected by organisations that oversee donation and transplantation services.

A final comment here is the reference in Textbox 1 to '*eyes being the windows to the soul*'¹. This perception has been reported in a number of studies exploring eye donation and links to both the belief in the need to maintain the integrity of the body after death [37] and a concern about the deceased not being able to see in the afterlife [14,37,38]. For some "*eyes, more than any other body part, personify an individual*" [17, p.1190] and therefore have greater potential to stimulate 'dissonance' for individuals approached to consider the option of eye donation.

Cognitive dissonance and the context of death

Cognitive dissonance is described as an emotional state set up when two simultaneously held cognitions are inconsistent or when there is a conflict between beliefs and overt behaviour [39]. Therefore, relating this to eye donation, dissonance arises when family members approached to consider eye donation are aware (for example by media campaigns such as 'Give the gift of sight') [40] or are made aware (e.g. by SNODS, or other family members) that eye donation can reverse blindness and have to rationalise their aversion/disgust/discomfort of eye removal which they perceive as an integral part of the person they love (as indicated in Textbox 1). Lawlor and Kerridge (2014) go so far as to suggest that despite participants in their study "*recognising the potential good that could come from corneal donation, many still maintained that removing the eyes would potentially have a significant adverse effect on their ongoing relationship with the deceased*" [14, p.62].

We propose that non-cognitive factors including: discomfort reactions, disfigurement concerns, the ick factor and the importance of body integrity are key areas of emotional and psychological conflict for family members approached to consider eye donation. In their secondary analysis of primary data from donating and non-donating family members in the UK, Long et al (2008) proposed that family members engage in a series of practical and psychological activities aimed at rationalising real or potential emotional and cognitive conflict when faced with the option of donation post death of a family member [17]. If family members are not able to rationalise *conflict (e.g. sacrifice of an intact body to a perceived disfiguring operation even if it is for the benefit of others)* NoK will decline donation.

A key context missing from social cognitive models and also much qualitative research into barriers to donation is the context of death. Apart from living donation, solid organ donation cannot proceed until someone has died, in the case of solid organ a death that is sudden and unexpected. Death not only robs the next-of-kin of a significant relationship, but also robs them of many of their usual coping mechanisms, imposing a sequence of events that Sque et al (2003) describe as leaving family members feeling dispossessed of physical and psychological equilibrium [30].

Furthermore, from a sociological perspective, Kellehear (2008) remarks that an understanding of “*dying as a social relationship*’ [is] *vital to understanding the levels of disagreement with organ donation due to the social basis of attachment, meaning-making and identity*”[41, p.1541]. Responses indicating attachment to the deceased (e.g. ‘*family reported they didn’t like the idea of someone else seeing through their loved ones eyes, Textbox 1*’), as well as the need for an intact body (e.g. ‘*only wanted internal organs donated, nothing from the outside*’, Textbox 2) are evidenced in the national data set analysed in this paper, alongside the importance of the identity of the deceased (e.g. ‘*eyes refused as wife couldn’t bear the thought of him without them*’, Textbox 1). It is in this emotional landscape that the topic of eye donation is raised, a context that appears unique to eye donation. It is therefore essential that those making the approach to request eye donation understand the non-rational, emotional, and sociological factors underpinning NoK decision-making if an increase in the donation of eyes is to be achieved.

Whilst messages to support positive attitudes toward donation are now embedded in social and other media campaigns in the UK (e.g. Giving the ‘Gift of Sight’ [42], ‘Yes I Donate’ etc. [43]), messages employed to reduce negative attitudes have not taken sufficient account of the psychological, emotional and sociological factors that are specifically relevant to the donation of eye tissue. As stated in the introduction, eyes are the least donated organ and this, we argue, is because the thought of removing the eyes may stimulate intense discomfort reactions, such as disgust, concerns of visible disfigurement and dissonance that suppress positive motives (e.g. attitudes) toward donating eyes.

Limitations

Data were generated by SNODs who recorded reasons shared with them by family members, and therefore the data reflect proxy comments. Feedback received by the working group indicates that SNODs were likely not to probe family responses, just recording ‘*family refused*’, ‘*No additional information*’ if in their view the discussion may lead to the family declining organ donation. The detail provided in the comments is constrained by the response format (i.e. a hand-written box) limiting the amount of information that SNODs could insert leading to wide variation in length of entries ranging between 1-187 words (median=6, IQR=7). Thus, both the frequency and content (i.e. type and level of detail) of recorded comments were variable.

We did not have access to the demographic data of potential donors included in primary data collection under the data sharing agreement, and therefore have not been able to include any related commentary. We are also unable to provide any commentary regarding the impact of legislative changes that took place in Wales (as of 1st December 2015) [44] during primary data collection for the service development initiative, as practice responses to these changes were still being developed and implemented.

Conclusion and recommendations:

In view of the reported 53% of the world’s population not having access to the benefits of sight saving and sight restoring transplantation surgery [1] and over two million people in the UK living with sight loss [2] this paper presents important data that could help organisations and HCPs involved in approaching bereaved family member for eye donation re-design modes of approach and the structure of consent conversations. In view of the data reported that potentially, over 2,000 eyes did not become available for use in transplant operations and research due to family members declining this donation option, further research is needed focussed on the construction, delivery and content

of the donation conversation. We therefore propose the following recommendations for future service and communication strategy development.

- Communicate propriety of the donation operation - The 'sacrifice' of an unscathed body could be an important barrier to actualising donation even in populations where there is a high level of awareness of the benefits of transplantation [45]. The propriety of the donation operation needs to be stressed in public education and in discussions with the bereaved family approached about organ donation as discovering what worries people about organ donation is the first step towards crafting more effective organ donation campaigns [34].
- Explore the potential of a disc-only corneal retrieval procedure to increase acceptance of donation - Enucleation (removal) of the entire eye (as usual in the UK) has been reported as being a potential barrier to donation of eye tissue by relatives in view of disfigurement concerns. Removal of the corneoscleral disc only has been aligned with higher consent rates [46], however currently robust data about whether this would be a more acceptable intervention with decision makers is missing. Research comparing consent rates for these two options would be a valuable addition to the knowledge base on which to base future service planning.
- Improve public education regarding the donation process - Public awareness campaigns, as well as consent conversations with families currently focus on the benefits of transplantation. In contrast, little public education has centred on the donation process itself which could prepare individuals for this potential life event. According to Siminoff et al. (2001) *"Since it is not reasonable to expect that family decision-makers can or even should relinquish strongly held beliefs about organ donation when experiencing the severe stress of a loved one's death, prior education is the best mechanism we may have to inform the public and prepare families for an organ donation request"* [18, p.76].
- Explore how the request process affects acceptance of donation - There remains significant room for improvement in the request process, as to date this pivotal aspect of the donation process has received little attention. Of note, there has been no research looking into the impact of the hierarchy of organs outlined in the consent conversation. For example, if a patient is suitable to donate all organs and tissues, the first organ mentioned is usually kidneys, followed by other abdominal organs and tissues, thoracic organs and tissues, then tissues (within which eyes are listed). It has been proposed that the order in which organs are requested may affect donation rates for eyes due to what has been referred to as 'list shock' - the idea that family members may be overwhelmed by the 'list' of organ and tissue that can be donated (this term was first coined by Margaret Verble and Judy Worth (personal communication, 21.08.2020)).
- Explore processes for assessment of familial responses to information provided during the consent conversation - future research should explore processes for assessing familial responses to information shared in consent conversation, and how HCPs conducting conversations may appropriately and sensitively explore areas that provoke a reaction (instead of avoiding them). Investigations of the latter type are of particular need in light of evidence indicating that many HCP's are poor *prima facie* judges of who may or may not be willing to donate [18].
- Future research topics - topics for further research include: investigation of potential demographic and/or regional differences in reasons for decline of eye tissue; the impact of legislation changes (i.e. from 'opt-in' to

1 'opt-out' (deemed consent) on eye donation in each of the UK nations; and construction, delivery and content
2 of donation consent conversations (e.g. exploring if and how systematic aspects of conversations related to
3 seeking agreement to organ/tissue/eye donation may be related to outcomes (i.e. acceptance or refusal) [47].
4
5
6
7
8
9

10
11 **Acknowledgement**

12 The authors would like to thank colleagues at the division of Statistics and Clinical Studies (NHSBT) for their help and
13 support.
14

15 **Funding statement**

16 Article Processing Charges for this work are supported by NHS Blood and Transplant Tissue and Eye Services
17 (Award/Grant number is not applicable)
18
19

20
21 **Competing interests**

22 EW and HG are employed by NHS Blood and Transplant.
23
24 EW was Chair of the Eye Donation from Solid Organ Donors – EPSOD, 2014-2017 working party within NHS Blood and
25 Transplant.
26
27 TLS was an invited member of the Eye Donation from Solid Organ Donors – EPSOD, 2014-2017 working party within
28 NHS Blood and Transplant.
29
30
31
32
33

34 **Author Contributions**

35 EW and HG facilitated access to primary data and reviewed early drafts of this paper.
36
37
38 TLS developed the idea of a secondary analysis and proposed undertaking this under the auspices of the Service Level
39 Agreement that exists between NHSBT- TS and UoS. TLS provided specialist input into the analysis of free text
40 comments, discussion, recommendations, and edited developing drafts.
41
42
43 MJB sourced secondary data from NHSBT and conducted secondary data analysis (descriptive statistics and qualitative
44 content analysis), with input from BMS and TLS, and was responsible for primary authorship. All co-authors
45 contributed substantially to the development of the paper and resulting recommendations.
46
47
48
49

50 **Data sharing statement**

51 No additional unpublished data are available from this study.
52
53
54
55
56
57
58
59
60

References

- 1 Pascolini D, Mariotti SP. Global estimates of visual impairment: 2010. *Br J Ophthalmol* 2012;**96**:614–8. doi:10.1136/bjophthalmol-2011-300539
- 2 RNIB & Specsavers. The State of the Nation Eye Health 2016. *The State of the Nation* 2016;:27.
- 3 Gaum L, Reynolds I, Jones MNA, *et al*. Tissue and corneal donation and transplantation in the UK. *Br J Anaesth* 2012;**108**:i43–7. doi:10.1093/bja/aer398
- 4 NHS-BT Organ and Tissue Advisory Group (OTAG). Tissue and Eye Procurement from Solid Organ Donors (TEPSOD) Activity Report. 2016. http://odt.nhs.uk/pdf/advisory_group_papers/OTAG/Tissue_&_Eye_Procurement_from_Solid_Organ_Donation.pdf
- 5 NHS-BT. Organ Donation and Transplantation - Activity report 2016/2017. 2017. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4657/activity_report_2016_17.pdf
- 6 NHS-BT. NHS Blood and Transplant - Eye and Tissue Strategy. Liverpool, UK: 2016.
- 7 Royal College of Ophthalmologists. Standards for the retrieval of human ocular tissue used in transplantation, research and training. London, UK: 2013. <https://www.rcophth.ac.uk/publications/current-clinical-guidelines/>
- 8 NHSBT. Organ Donation and Transplantation Activity Report 2019/20. Liverpool, UK: 2020. doi:10.1016/B978-0-12-373932-2.00158-7
- 9 Long-Sutehall T, Sque M, Addington-Hall J. Secondary analysis of qualitative data: a valuable method for exploring sensitive issues with an elusive population? *J Res Nurs* 2011;**16**:335–44. doi:10.1177/1744987110381553
- 10 Schreier M. Qualitative Content Analysis. In: *The SAGE Handbook of Qualitative Data Analysis*. 1 Oliver's Yard, 55 City Road, London EC1Y 1SP United Kingdom: : SAGE Publications Ltd 170–83. doi:10.4135/9781446282243.n12
- 11 QSR International Ltd. NVivo qualitative data analysis software. 2018. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home> (accessed 23 Apr 2020).
- 12 Sanner M. A Comparison of Public Attitudes Toward Autopsy, Organ Donation, and Anatomic Dissection: A Swedish Survey. *JAMA J Am Med Assoc* 1994;**271**:284–8. doi:10.1001/jama.1994.03510280046031
- 13 Sanner M. Attitudes toward organ donation and transplantation. *Soc Sci Med* 1994;**38**:1141–52. doi:10.1016/0277-9536(94)90229-1
- 14 Lawlor M, Kerridge I. Understanding Selective Refusal of Eye Donation: Identity, Beauty, and Interpersonal Relationships. *J Bioeth Inq* 2014;**11**:57–64. doi:10.1007/s11673-013-9497-9
- 15 Weiss AH, Fortinsky RH, Laughlin J, *et al*. Parental consent for pediatric cadaveric organ donation. *Transplant Proc* 1997;**29**:1896–901. doi:10.1016/S0041-1345(97)00110-3
- 16 Rodrigue JR, Cornell DL, Howard RJ. Pediatric organ donation: What factors most influence parents' donation decisions? *Pediatr Crit Care Med* 2008;**9**:180–5. doi:10.1097/PCC.0b013e3181668605

- 17 Long T, Sque M, Addington-Hall J. Conflict rationalisation: How family members cope with a diagnosis of brain stem death. *Soc Sci Med* 2008;**67**:253–61. doi:10.1016/j.socscimed.2008.03.039
- 18 Siminoff LA, Arnold RM, Hewlett J. The process of organ donation and its effect on consent. *Clin Transplant* 2001;**15**:39–47. doi:10.1034/j.1399-0012.2001.150107.x
- 19 Lawlor M, Kerridge I, Ankeny R, *et al.* Specific unwillingness to donate eyes: The impact of disfigurement, knowledge and procurement on corneal donation. *Am. J. Transplant.* 2010;**10**:657–63. doi:10.1111/j.1600-6143.2009.02986.x
- 20 Acharya M, Farooqui J, Dave A, *et al.* Eye donation in north India: Trends, awareness, influences and barriers. *Indian J Ophthalmol* 2019;**67**:1570. doi:10.4103/ijo.IJO_2151_18
- 21 Fishbein M, Ajzen I. *Belief, Attitude, Intention, and Behavior: An Introduction to Theory and Research.* Addison-Wesley Publishing Company 1975. <https://books.google.co.uk/books?id=8o0QAQAIAAJ>
- 22 Ajzen I. The Theory of Planned Behavior. *Organ Behav Hum Decis Process* 1991;**50**:179–211. https://www.dphu.org/uploads/attachements/books/books_4931_0.pdf
- 23 Ajzen I. From Intentions to Actions: A Theory of Planned Behavior BT - Action Control: From Cognition to Behavior. In: Kuhl J, Beckmann J, eds. . Berlin, Heidelberg: : Springer Berlin Heidelberg 1985. 11–39. doi:10.1007/978-3-642-69746-3_2
- 24 Horton RL, Horton PJ. A model of willingness to become a potential organ donor. *Soc Sci Med* 1991;**33**:1037–51. doi:10.1016/0277-9536(91)90009-2
- 25 Radecki CM, Jaccard J. Signing an Organ Donation Letter: The Prediction of Behavior From Behavioral Intentions1. *J Appl Soc Psychol* 1999;**29**:1833–53. doi:10.1111/j.1559-1816.1999.tb00154.x
- 26 Kopfman JE, Smith SW. Understanding the audiences of a health communication campaign: A discriminant analysis of potential organ donors based on intent to donate. *J Appl Commun Res* 1996;**24**:33–49. doi:10.1080/00909889609365438
- 27 Morgan S, Miller J. Communicating about gifts of life: the effect of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *J Appl Commun Res* 2002;**30**:163–78. doi:10.1080/00909880216580
- 28 Quick BL, LaVoie NR, Reynolds-Tylus T, *et al.* Does Donor Status, Race, and Biological Sex Predict Organ Donor Registration Barriers? *J Natl Med Assoc* 2016;**108**:140–6. doi:10.1016/j.jnma.2016.05.007
- 29 Morgan SE, Stephenson MT, Harrison TR, *et al.* Facts versus 'Feelings'. *J Health Psychol* 2008;**13**:644–58. doi:10.1177/1359105308090936
- 30 Sque M, Long T, Payne S. Organ and tissue donation: exploring the needs of families. Final report of a three-year study commissioned by the British Organ Donor Society, funded by the National Lottery Community Fund. University of Southampton 2003. <http://users.argonet.co.uk/body/Report.html>
- 31 Sque M, Long T, Payne S. Organ donation: Key factors influencing families' decision-making. *Transplant Proc* 2005;**37**:543–6. doi:10.1016/j.transproceed.2004.11.038
- 32 Lawlor M, Kerridge I. Anything but the eyes: Culture, identity, and the selective refusal of corneal donation. *Transplantation.* 2011;**92**:1188–90. doi:10.1097/TP.0b013e318235c817
- 33 Tandon R, Verma K, Vanathi M, *et al.* Factors affecting eye donation from postmortem cases in a tertiary care hospital. *Cornea* 2004;**23**:597–601. doi:10.1097/01.ico.0000121706.58571.f6
- 34 Morgan S, Miller J, Arasaratnam L. Signing cards, saving lives: an evaluation of the worksite organ donation promotion project. *Commun Monogr* 2002;**69**:253–73. doi:10.1080/03637750216540
- 35 Parisi N, Katz I. Attitudes toward posthumous organ donation and commitment to donate. *Heal Psychol* 1986;**5**:565–80. doi:10.1037//0278-6133.5.6.565
- 36 Sherman NC, Smith RJ, Sherman MF, *et al.* Disgust Sensitivity and Attitudes toward Organ Donation among African-American College Students. *Psychol Rep* 2001;**89**:11–23. doi:10.2466/pr0.2001.89.1.11

- 37 Hessing DJ, Elffers H. Attitude toward Death, Fear of Being Declared Dead Too Soon, and Donation of Organs after Death. *OMEGA - J Death Dying* 1987;**17**:115–26. doi:10.2190/5NB6-DJDW-B68G-6T56
- 38 Wells J, Sque M. 'Living choice': the commitment to tissue donation in palliative care. *Int J Palliat Nurs* 2002;**8**:22–7. doi:10.12968/ijpn.2002.8.1.10231
- 39 M. DW, Reber AS. *The Penguin Dictionary of Psychology*. 1986. doi:10.2307/1422298
- 40 Gift of Sight. Gift of Sight. 2020.<https://www.giftofsight.org.uk/> (accessed 7 Jul 2020).
- 41 Kellehear A. Dying as a social relationship: A sociological review of debates on the determination of death. *Soc Sci Med* 2008;**66**:1533–44. doi:10.1016/j.socscimed.2007.12.023
- 42 NHSBT. Giving the gift of sight. 2020.<https://www.blood.co.uk/news-and-campaigns/the-donor-magazine-autumn-2017/giving-the-gift-of-sight/> (accessed 12 Jan 2021).
- 43 NHSBT. Organ donation graphics - Download and share our graphics to promote organ donation. 2020.<https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/organ-donation-graphics/> (accessed 12 Jan 2021).
- 44 NHSBT. Organ donation law in Wales. 2020. <https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-wales/> (accessed 12 Jan 2021).
- 45 Sque M, Long-Sutehall T. Bereavement, decision-making and the family in organ donation. In: *Organ Shortage: Ethics, Law and Pragmatism*. 2011. 67–86. doi:10.1017/CBO9780511973536.005
- 46 Hudde T, Reinhard T, Möller M, *et al.* Korneosklerale transplantatentnahme an der leiche: Erfahrungen der Lions-Hornhautbank Nordrhein-Westfalen in den jahren 1995 und 1996. *Ophthalmologie* 1997;**94**:780–4. doi:10.1007/s003470050203
- 47 Elizabeth Weathersbee T, Maynard DW. Dialling for donations: Practices and actions in the telephone solicitation of human tissues. *Sociol Heal Illn* 2009;**31**:803–16. doi:10.1111/j.1467-9566.2009.01189.x

Additional File

Table 1 - Reasons for non-donation cases for eye tissue by category and major sub-category for the period 1st April 2014-31st March 2017

Category	Sub-category	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All Years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44
	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A	N/A	2	0.00	1	0.00	3	0.00
	Other/not specified family reasons	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.14	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.26	20	0.45	52	0.29
Coroner refused consent	Homicide / Murder / Manslaughter	7	0.14	8	0.14	10	0.20	25	0.16
	Sustained injury in custody/prison	3	0.06	1	0.02	2	0.04	6	0.04
	Police refusal	18	0.35	N/A	N/A	1	0.02	19	0.12
	Suspicious death	23	0.45	24	0.41	16	0.31	63	0.39
	Other coroner reasons, please specify	51	1.00	24	0.41	22	0.43	97	0.61
Medical reasons	High risk behaviour	61	0.25	74	0.29	58	0.17	193	0.23
	Haemodilution	14	0.06	15	0.06	24	0.07	53	0.06
	Neurological conditions of unknown cause	47	0.19	34	0.13	44	0.13	125	0.15
	Positive virology	16	0.07	20	0.08	10	0.03	46	0.05
	Above age criteria	N/A	N/A	5	0.02	10	0.03	15	0.02
	Other medical reasons, please specify	104	0.43	105	0.42	200	0.58	409	0.49
All other reasons	Concerns about storage	1	0.02	2	0.04	3	0.03	6	0.03
	Other reasons, please specify	28	0.53	28	0.56	39	0.36	95	0.45
	Not specified	24	0.45	20	0.20	67	0.61	111	0.52

Table 2.1 Main reason for non-eye donation (all reasons) 1 April 2014 to 31 March 2015		
Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	35	(4.0)
Driving licence	1	(0.1)
Discussion with family	17	(1.9)
Verbal or written statement in life	1	(0.1)
Sub total	54	(6.1)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	11	(1.2)
Knew deceased wishes not to donate eyes	3	(0.3)
Sub total	14	(1.6)
Deceased wishes	68	(7.7)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	95	(10.8)
I do not like the idea of eye donation	62	(7.0)
Uncomfortable with removal of whole eye	16	(1.8)
Personal connection/link to deceased eyes	22	(2.5)
Sub total	195	(22.1)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	32	(3.6)
Only organs	79	(9.0)
Face not to be touched	61	(6.9)
Concerns about how the deceased would look	12	(1.4)
Nothing above the neck	2	(0.2)
Sub total	186	(21.1)
<i>Decision made on current physical/emotional state</i>		
Family disagreement	4	(0.5)
Family overwhelmed	6	(0.7)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	1	(0.1)
Sub total	13	(1.5)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need for eyes to be buried/cremated	1	(0.1)
Need eyes to see in the afterlife	3	(0.3)
Sub total	4	(0.5)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	26	(3.0)
Family, not specified	28	(3.2)
Sub total	54	(6.1)
Family wishes	452	(51.3)
Reason for non-eye donation	N	(%)
Coroner refused consent		
Homicide / Murder / Manslaughter	7	(0.8)
Police refusal	3	(0.3)
Suspicious death	18	(2.0)
Other coroner reasons, please specify	23	(2.6)
Sub total	51	(5.7)
Medical reasons		
High risk behaviour	61	(6.8)
Haemodilution	14	(1.6)
Neurological conditions of unknown cause	47	(5.3)

Positive virology	16	(1.8)
Other medical reasons, please specify	104	(11.7)
Sub total	242	(27.1)
All other reasons		
Concerns about storage	1	(0.1)
Other reasons, please specify	28	(3.1)
Not specified	24	(2.7)
Sub total	53	(5.9)
TOTAL	892	(100.0)

For peer review only

Table 2.2 **Main reason for non-eye donation (all reasons)**
1 April 2015 to 31 March 2016

Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	21	(2.1)
Passport	1	(0.1)
Discussion with family	22	(2.2)
Verbal or written statement in life	6	(0.6)
Sub total	50	(5.0)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	15	(1.5)
Perceived wishes with disfigurement	3	(0.3)
Sub total	18	(1.8)
Deceased wishes	68	(6.8)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	54	(5.4)
I do not like the idea of eye donation	69	(6.9)
Uncomfortable with removal of whole eye	10	(1.0)
Personal connection/link to deceased eyes	21	(2.1)
Sub total	154	(15.5)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	40	(4.0)
Only organs	88	(8.9)
Face not to be touched	38	(3.8)
Concerns about how the deceased would look	13	(1.3)
Nothing above the neck	1	(0.1)
Sub total	180	(18.1)
<i>Decision made on current physical/emotional state</i>		
Family tired	1	(0.1)
Family disagreement	1	(0.1)
Family overwhelmed	5	(0.5)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	3	(0.3)
Sub total	12	(1.2)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need eyes to see in the afterlife	12	(1.2)
Sub total	12	(1.2)
<i>Decision made on lack of knowledge</i>		
Family unaware that eyes can be donated	1	(0.1)
Family had questions about the process	1	(0.1)
Sub total	2	(0.2)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	26	(2.6)
Family, not specified	34	(3.4)
Sub total	60	(6.0)
Family wishes	420	(42.3)
Coroner refused consent		
Homicide / Murder / Manslaughter	8	(0.9)
Sustained injury in custody/prison	1	(0.1)
Suspicious death	25	(2.8)

Other coroner reasons, please specify	24	(2.7)
Sub total	58	(6.6)
Medical reasons		
High risk behaviour	74	(8.4)
Haemodilution	15	(1.7)
Neurological conditions of unknown cause	34	(3.9)
Positive virology	20	(2.3)
Above age criteria	5	(0.6)
Other medical reasons, please specify	105	(11.9)
Sub total	253	(28.7)
All other reasons		
Concerns about storage	2	(0.2)
Other reasons, please specify	28	(3.2)
Not specified	20	(2.3)
Sub total	50	(5.7)
TOTAL	881	(100.0)

Table 2.3 Main reason for non-eye donation (all reasons) 1 April 2016 to 31 March 2017		
Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	13	(1.3)
Discussion with family	6	(0.6)
Verbal or written statement in life	5	(0.5)
Sub total	24	(2.4)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	18	(1.8)
Perceived wishes with disfigurement	2	(0.2)
Sub total	20	(2.0)
Deceased wishes	44	(4.3)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	40	(3.9)
I do not like the idea of eye donation	41	(4.0)
Uncomfortable with removal of whole eye	11	(1.1)
Personal connection/link to deceased eyes	37	(3.6)
Sub total	129	(12.7)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	95	(9.4)
Only organs	92	(9.1)
Face not to be touched	23	(2.3)
Concerns about how the deceased would look	10	(1.0)
Nothing above the neck	2	(0.2)
Sub total	222	(21.9)
<i>Decision made on current physical/emotional state</i>		
Family tired	3	(0.3)
Family disagreement	5	(0.5)
Family overwhelmed	6	(0.6)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	11	(1.1)
Sub total	27	(2.7)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need eyes to see in the afterlife	5	(0.5)
Sub total	5	(0.5)
<i>Decision made on lack of knowledge</i>		
Family had questions about the process	1	(0.1)
Sub total	1	(0.1)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	35	(3.4)
Family, not specified	48	(4.7)
Sub total	83	(8.2)
Family wishes	467	(46.0)
Coroner refused consent		
Homicide / Murder / Manslaughter	10	(1.0)
Sustained injury in custody/prison	2	(0.2)
Police refusal	1	(0.1)
Suspicious death	16	(1.6)
Other coroner reasons, please specify	22	(2.2)
Sub total	51	(5.1)

Medical reasons		
High risk behaviour	58	(5.8)
Haemodilution	24	(2.4)
Neurological conditions of unknown cause	44	(4.4)
Positive virology	10	(1.0)
Above age criteria	10	(1.0)
Other medical reasons, please specify	200	(20.1)
Sub total	346	(34.8)
All other reasons		
Concerns about storage	3	(0.3)
Other reasons, please specify	39	(3.9)
Not specified	67	(6.7)
Sub total	109	(11.0)
TOTAL	1017	(100.0)

BMJ Open

Family Refusal of eye tissue donation from potential solid organ donors – a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1st April 2014 – 31st March 2017).

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-045250.R2
Article Type:	Original research
Date Submitted by the Author:	09-Jul-2021
Complete List of Authors:	Bracher, Mike; University of Southampton, School of Health Sciences Madi-Segwagwe, Banyana; University of Southampton, School of Health Sciences Winstanley, Emma; National Health Service Blood and Transplant Services - Organ and Tissue Donation and Transplantation Gillan, Helen; National Health Service Blood and Transplant Services- Organ and Tissue Donation and Transplantation Long-Sutehall, Tracy; University of Southampton,
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Sociology
Keywords:	Corneal and external diseases < OPHTHALMOLOGY, Transplant pathology < PATHOLOGY, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Family Refusal of eye tissue donation from potential solid organ donors – a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1st April 2014 – 31st March 2017).

Mike Bracher (MJB) (m.j.bracher@soton.ac.uk)^{1§}

Banyana C. Madi-Segwagwe (BMS) (b.c.madi-segwagwe@soton.ac.uk)¹

Emma Winstanley (EW) (emma.winstanley@nhsbt.nhs.uk)²

Helen Gillan (HG) (helen.gillan@nhsbt.nhs.uk)²

Tracy Long-Sutehall (TLS) (t.long@soton.ac.uk)¹

1. School of Health Sciences, University of Southampton, UK
2. UK National Health Service Blood and Transplant Services- Organ and Tissue Donation and Transplantation (NHS BT – OTDT), UK

§ Corresponding author

Mike Bracher, School of Health Sciences, University of Southampton.

Email: m.j.bracher@soton.ac.uk; Tel: 023 80 593929

Word count = Abstract = 299; Article = 5201

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives: Long-standing undersupply of eye tissue exists both in the UK and globally, and the UK National Health Service Blood and Transplant Service (NHSBT) has called for further research exploring barriers to eye donation. This study aims to: I) describe reported reasons for non-donation of eye tissue from solid organ donors in the UK between 1st April 2014–31st March 2017; II) discuss these findings with respect to existing theories relating to non-donation of eyes by family members.

Design: Secondary analysis of a national primary data set of recorded reasons for non-donation of eyes from 2790 potential solid organ donors. Data analysis including descriptive statistics and qualitative content analysis of free-text data for 126 recorded cases of family decline of eye donation.

Setting: National data set covering solid organ donation (secondary care).

Participants: 2790 potential organ donors assessed for eye donation eligibility between 1st April 2014 and 31st March 2017.

Results: Reasons for non-retrieval of eyes were recorded as: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%). In >50% of recorded cases, reasons for non-donation were based on: family’s knowledge of the deceased wishes, their perception of the deceased wishes, and specific concerns regarding processes or effects of eye donation (for the deceased body). Findings are discussed with respect to existing theoretical perspectives.

Conclusion: Eye donation involves distinct psychological and socio-cultural factors for families and HCPs that have not been fully explored in research or integrated into service design. We propose areas for future research and service development including: potential of only retrieving corneal discs as opposed to full eyes to reduce disfigurement concerns; public education regarding donation processes; exploration of how request processes potentially influence acceptance of eye donation; procedures for assessment of familial responses to information provided during consent conversations.

Keywords: secondary analysis, eye donation, cornea, consent, family decline of donation

Strengths and limitations of this study

- This secondary analysis paper is the first reporting of primary data discussing reasons for non-donation of eyes recorded by Specialist Nurses in Organ Donation (SNODs) for 2790 potential solid organ donors in the UK.
- The authors applied qualitative content analysis to free-text data and discuss findings in relation to existing theoretical perspectives to identify areas for further research and service development.
- The paper reports proxy commentary recorded as free text data generated by SNODs when recording reasons provided by family members for declining donation of eye tissue, and therefore is limited in depth of detail available for reporting.
- Due to study design limitations, factors that may have influenced family decision making (i.e. potential donor demographics/regional differences, changes in legislation) cannot be addressed in this paper.
- Due to data sharing restrictions the paper presents descriptive statistics only.

Background

Globally, 53% of the world's population has no access to the benefits of sight saving and sight restoring transplantation surgery due to a short fall in the supply of ophthalmic tissue (cornea and sclera) that is only available via eye donation [1]. According to Pascolini et al. (2010) over 10 million people worldwide have bilateral corneal blindness which could be restored with a corneal transplant [1]. According to the Royal National Institute of Blind (RNIB) over two million people in the UK are living with sight loss [2] caused by conditions such as Keratoconus and Fuchs' Corneal Dystrophy, that 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 eye diseases, for example endothelial failure post-cataract surgery [3]. The RNIB report 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 (unpaid carer burden and reduced employment rates) reported as £4.34 billion annually [2]. Critically, the organisation predicts predicted that by 2050 the number of people with sight loss will double to nearly four million [2]. It is therefore imperative that the tissue needed to intervene in these conditions via corneal transplantation, reconstructive surgery, glaucoma surgery, and research into the causes and treatment of eye disease is available

However, there is a long-standing shortfall in supply of eye tissue in the UK and globally, with eyes being the least donated of all organs and tissues when decision makers are offered a 'list' that they need to agree to that can be retrieved for use in transplantation (n.b. as eyes are referred to as both organs *and* tissues in different contexts, we will refer to them as organs from here on) [4,5]. The UK National Health Services Blood and Transplant (NHSBT) Eye Bank in Speke, Liverpool and Bristol (who supply most eye tissue used for surgical purposes in the UK) seeks to have 10 eye donors per day consistently to satisfy demand for the treatment of patients. This number is not consistently met.

Increasing supply is a key strategic aim for NHSBT Tissue and Eye Services Division [6] and they, along with the UK Royal College of Ophthalmology (RCO) [7], have expressed a need for research exploring barriers to eye donation. This knowledge is needed not only as a basis for developing new routes to supply, but also to inform guidance underpinning donation conversations with family members who are approached to consider the option of eye donation. Increasing supply requires understanding of how patients and families relate to eye tissue donation (i.e. attitudes, beliefs, information needs etc.) and how these processes shape donation outcomes, specifically family members declining eye donation.

Eye donation from solid organ donors continues to prove problematic, with slow progress in increasing supply from this specific cohort of donors. For example, eye donation from solid organ donors generated 320 eyes between 1st April 2015 to 31st March 2016 [4] , and 446 eyes between 1st April 2019 to 31st March 2020 [8]. Current evidence indicates that nationally on average only 40% (range 31-64%) of next-of-kin (NoK) agree to eye donation when approached to consider solid organ donation , whilst 67% of NoK agree to solid organ donation [5], and therefore what contributes to this difference is an important area for investigation.

1 In this paper we aim to contribute to the knowledge base around non-donation of eye tissue from solid organ donors
2 by reporting, for the first time, national clinical data collected and provided by NHS Blood and Transplant between
3 2014–2017, aligned with key theoretical perspectives reported to explain donating behaviours. This body of work from
4 the past 30 years will advance knowledge and understanding of the reasons why of all organs and tissues that can be
5 donated, eyes remain the least donated organ [4,5].
6
7
8
9

10 **Study objectives:**

- 11
12
13 i. *Describe the reported reasons why eye donation did not take place from potential solid organ donors in the UK*
14 *between 1st April 2014 – 31st March 2017.*
15
16 ii. *Discuss these findings in the context of existing theoretical perspectives relating to non-donation of eyes by*
17 *family members*
18
19

20 **Study design**

21
22
23 To gain further insight into the factors leading to low numbers of eyes being secured from solid organ donation, a
24 working party (Eye Donation from Solid Organ Donors – EPSOD, 2014-2017) was convened with the remit to: plan
25 and action an effective response to demand and supply problems; and make evidence-based recommendations to
26 NHSBT and external stakeholders regarding potential service development that would impact on the current low
27 supply of eye tissue.
28
29
30
31

32 *Ethical approval*

33
34
35 Ethical approval was not required for this secondary analysis of previously collected primary data. Primary data
36 collected as part of the service development was shared with the UOS team in line with a Service Level Agreement
37 (SLA) between UOS and NHSBT Tissue and Eye Services Division since 2007. The sharing, analysis and reporting of
38 data was carried out in line with a UK Transplant Registry Data Release agreement relating to UK General Data
39 Protection Regulations (GDPR) 2018, the UK Data Protection Act 2018, the UK Human Rights Act 1998, and the UK
40 Common Law Duty of Confidentiality.
41
42
43
44

45 *Patient and Public involvement*

46
47
48 The paper presents a secondary analysis of primary data collected by NHSBT Tissue Services as part of a service
49 development initiative. As such there were no patients or members of the public involved in the design or conduct of
50 the primary service development initiative. No dissemination of the primary data has occurred until this secondary
51 analysis. As part of secondary analysis carried out by UOS team, and in line with the team’s commitment to the value
52 of PPI input, a summary of key findings was made to members of the NHSBT Tissue Services Donor Advisory Group
53 (DAG), which includes next of kin of donating patients and public representatives). Members were invited to ask
54 questions as part of an update to their regular meeting in Q4 2020.
55
56
57
58
59
60

Data collection

Data for 2790 potential* donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate eyes between 1st April 2014 and 31st March 2017, were collected using a standardised proforma (*n.b. potential donor refers to a deceased person who could become an organ donor unless medical criteria for non-donation, or consent/authorisation is withheld by next of kin). Specialist Nurses in Organ Donation (SNODs) were requested to record reasons for non-procurement of eye tissue selecting from the domains listed in Table 1. SNODs were also asked to add further commentary via use of a free-text box. Data was gathered by SNODs with the requirement that they complete data collection for each potential donor following discussion with family members and other stakeholders (e.g. coroner). Data for each SNOD were collated into a monthly regional team returns to the NHSBT statistical team, who generated descriptive statistical data reported in this paper. Data were collected over three years, with a cessation in 2018 due to the operationalisation of eye donation moving from the Organ Donation and Transplant division of NHSBT to its Tissue and Eye Services division. The full data set for descriptive statistics relating to non-procurement of eye tissue is presented in *Additional File 1 (Tables 1-2.3)* – however this paper focuses on data relating specifically to **family decline of eye donation**.

Analysis

Secondary Analysis [9] included generation of descriptive statistics on reasons for non-donation of eyes recorded by SNODs for 2790 potential donors (Table 1) and application of qualitative content analysis [10] to free-text data for 126 recorded reasons for family decline of eye donation. Analysis of free-text data was undertaken using Nvivo computer-assisted qualitative data analysis (CAQDAS) software (version 12) [11].

As international empirical evidence from the past 30 years indicates, eye donation involves reactions that do not impact other forms of donation including: discomfort reactions [12,13], disfigurement [3], the belief that eyes will be needed in the afterlife, eyes being viewed as the ‘windows to the soul’ [6,14], as well as disgust-related aversion (‘yuk’/‘ick factor’) (findings from this national dataset have been grouped under these headings).

The aim of the analytic process was to generate a descriptive analysis of data recording reasons for non-donation of eye tissue as reported by SNODs (Objective 1), and to underpin a theoretically informed discussion aimed at unpacking the key reasons why family members decline the option of eye donation when this is a possibility (i.e. no medical reasons for non-donation are evident) (Objective 2). By engaging with existing theory regarding donation decision making, this paper also aims to inform interventions that can lead to an increase in donation of eye tissue for use in transplant operations.

Descriptive statistics

Reasons for non-donation of eye tissue (overview)

The data related to 2790 potential donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate eyes between 1st April 2014 and 31st March 2017, but from whom eye tissue was not retrieved (reporting periods cover UK financial year, see Table 1). The most common reasons for non-retrieval of eyes were: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%); and coroner refusal (n=160,

6%), with ‘All other reasons’ accounting for n=212 (8%) of cases (reasons were not recorded in n=58 (2%) cases – see Table 1). The reporting in this paper will focus on data related to **family and deceased wishes** only as these contribute to over 50% of recorded reasons why eye donation did not proceed when donation discussions took place.

Table 1 – Summary of recorded reasons for non-donation of eye tissue from potential solid organ donors for the period 1st April 2014-31st March 2017 (focus categories for this paper are shaded grey).

Period	Family wishes		Medical reasons		Deceased wishes		Coroner refused		All other reasons		(Reasons not recorded)		TOTAL	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(% all years)
1 April 2014 to 31 March 2015	452	0.51	242	0.27	68	0.08	51	0.06	53	0.06	26	0.03	892	0.32
1 April 2015 to 31 March 2016	420	0.48	253	0.29	68	0.08	58	0.07	50	0.06	32	0.04	881	0.32
1 April 2016 to 31 March 2017	467	0.46	346	0.34	44	0.04	51	0.05	109	0.11	0	0	1017	0.36
All years	1339	0.48	841	0.3	180	0.07	160	0.06	212	0.08	58	0.02	2790	

Decline of eye donation based on family and deceased wishes

Where non-procurement of eye tissue was recorded under *Family wishes* (n=1339), the most common reasons related to disfigurement concerns (n=588, 44% of family decline), or ‘personal views’ about eye donation held by Next of Kin (NoK) (n=478, 36% - see Table 2).

For cases where non-procurement of eye tissue was recorded under *Deceased’s wishes* (n=180 cases, 7% of total), 128 (71% of deceased wishes cases) were due to the fact that the deceased had registered (on the organ donor register, which is always checked by SNODs in preparation for discussing donation options) that they did not want to donate eye tissue. A further 52 (29%) cases of non-procurement of eye tissue resulted from discussions with NoK where they stated that the deceased’s wish not to donate eyes was known to them – see Table 2.

Table 2 – Reasons for non-donation of eye tissue from potential solid organ donors by category and major sub-category for the period 1st April 2014-31st March 2017.

Domain	Sub-domain	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All Years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44

	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A*	N/A*	2	0.00	1	0.00	3	0.00
	Other/not specified family reasons**	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.74	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.26	20	0.45	52	0.29

*category was not included in data collection for this period.

**Includes sub-domains inviting free-text comment (i.e. 'please specify')

Findings from analysis of free-text data (family decline)

Table 3 lists results of content analysis, showing all resulting categories of recorded reasons for family decline (n = 126). Of note is that in 65 cases (10%) of SNODs reporting 'family refused', 'No additional information' was recorded in the free-text comment box. For these cases, we therefore have no information on which to base any commentary regarding family decline. The findings and discussion are therefore related to the italicised categories in Table 3 (n=61 cases within this group).

Table 3 - Summary of free-text comments relating to family reasons for decline of eye tissue donation from potential solid organ donors

Family Reasons Categories	Cases (n)*	Cases (% of n=126 cases with free-text comment relating to family reasons)
<i>No additional information</i>	65	0.52
<i>Family uncomfortable with eye donation</i>	22	0.17
<i>Family reasons indicated but case not classified as either '88-Family, not specified' or '87-Family other reasons, please specify'</i>	17	0.13
<i>Consent for Solid organ donation but not eyes</i>	10	0.08
<i>Nothing 'visible' to be removed</i>	7	0.06
<i>Family withdrew initial consent</i>	6	0.05
Family Infer Patient Wishes (e.g. NoK recorded as indicating deceased 'would not have wanted' eye donation)	3	0.02
Family refuse moving of body for retrieval	3	0.02
No ODR restrictions but family refuse eye donation	2	0.02
Family reasons due to religious reasons	2	0.02
Tendons only	1	0.01
Family wish to donate to scientific research	1	0.01
Family believed patient ineligible due to medical contraindication	1	0.01
Family member worried that they may inadvertently work with tissues in professional role in donated but not transplanted	1	0.01

*Note: cases do not equal 126 as some can belong to more than one category (e.g. a comment could relate to both 'Consent for Solid organ donation but not eyes' and 'No ODR restrictions but family refuse eye donation')

Findings from analysis of free-text comments

Cases are reported as a percentage of the 126 free text comments available relating to family refusal (% of n=126).

Discomfort reactions

For 22 cases (17%) free-text responses recorded by SNODs indicated family discomfort with eye donation. In addition to general expressions of discomfort with eye donation comments also referred to personal attachment to the eyes of the deceased, which influenced family decision making (examples Textbox 1).

Textbox 1. Recorded family comments relating to discomfort reactions to eye tissue donation.

[B]rothers who had had discussion and all felt "funny" about eyes.
Family did not like the idea of eye donation.
Family reported they didn't like the idea of someone else seeing through their loved ones eyes'...
'Family did not want eyes removing as they felt they were part of her'
Family were very much against eye donation as they said they were "windows to the soul"
... eyes refused as wife couldn't bear the thought of him without them.
Partner believed the eyes were the window to the soul

Disfigurement concerns

Linked to discomfort reactions, concerns about disfiguring the body of the deceased was raised by seven family members (6%) with SNODs recording that family members only wanted solid organs to be retrieved. It is notable that comments include words and phrases such as 'nothing visible', 'external', and 'outside' underlining that family members are concerned about how the body will look post donation (Textbox 2).

Textbox 2. Recorded family comments relating to disfigurement concerns.

This is how we saw him
Family did not like the thought of external surgery to the body other than through the initial operation site.
Family did not want anything "external" donated
Family did not want eye donation as not wanting anything visible
Family not wanting the face touching
Only wanted internal organs donated, nothing from the "outside"

Solid organ only – not eye tissue!

As well as concerns about disfigurement and the reported wish that 'nothing visible be removed' in a further 10 cases (8%), family consent was recorded as being given for solid organs but declined for eyes. In Textbox 3, we see examples of differing decisions recorded for tissues (eyes are also referred to as tissues) and solid organs. Some comments record SNOD-perceived strength of feeling as a factor restricting further discussion about eye donation. Of note here is that we do not have evidence indicating on what basis the assessment about 'appropriateness' is based (e.g. "Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation") or how much time was taken in this approach for donation. Higher consent/authorisation rates are

reported when parents perceive that they have had adequate time to discuss donation within the family and with the healthcare team [15,16]. In one case, we see a priority invoked as the reason for decline, 'life saving organs only' suggesting that a *value* was being associated with different organ or tissues.

Textbox 3. Recorded family comments relating to reasons for eye tissue accompanying consent for solid organs.

[Family] did not want any tissue donation organs are enough.
 Family did not want any tissue donation only solid organs
 Family only wanted kidneys donated, no other reason given.
 Family very uncomfortable with tissue donation and only wanted organs as they cannot be seen
 Kidneys only would not discuss anything else
 Life-saving organs only
 On ODR no restrictions, partner consented to kidney only, nothing else.
 Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation
 Wife wanted solid organs only
 Son certain he did not want to donate eyes, or any tissue. Was a very strong no to tissue and did not elaborate too much despite open questioning.

Change in decision-making

Six cases (5%) described initial consent for eye donation being provided by families which was later withdrawn (see Textbox 4). Comments suggest the potential influence of post-decision dissonance (see *Discussion* section) [17] and the impact of wider family views stimulating a reversal of the decision to agree to eye donation.

[Father] changed his mind after consent provided.
 Even though partner consented initially, family wanted patient embalmed and wanted body home ASAP.
 Family withdrew consent as needed quick release.
 Family withdrew eye consent, reason not specified.
 Initial consent provided for eyes and skin but then changed their mind, no reason given.
 Parents consented for all tissues but withdrew consent whilst visiting him in Chapel of rest saying he had 'given enough' and they did not want him to be touched anymore

*Textbox 4.
 Recorded
 family
 comments
 relating to a
 change in
 decision to
 donate eyes.*

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Discussion

The data presented in this study indicate that the main reason for non-procurement of eye tissue from potential solid organ donors in the UK is the decline of this option by bereaved family members. One thousand, three hundred and thirty-nine approaches for eye donation resulted in family decline, despite this being a valid donation option over the time period of data collection. Therefore, potentially, over 2,000 eyes did not become available for use in transplant operations and research into eye diseases resulting in loss of sight due to family decline.

This picture of potential donor eyes not becoming available in the context of solid organ donation is reflected in the global literature, with authors in the USA reporting that of 10,000 potential solid organ donors where a consent rate of 47% for organ donation was achieved, only 24% eye donation consent rate was achieved [18]. Reporting data from a survey carried out with 371 individuals renewing their driving licence in Sydney Australia, authors indicated that of 369 participants who responded to questions related to willingness to donate corneas, 153 (41%) indicated that they would not [19]. This reluctance for eye donation is not just reflected in Western contexts (e.g. Europe, North America, Australasia): for example, Acharya et al. (2019) surveyed 407 bereaved NoK of potential eye donors in Delhi (India), reporting that the majority 239 (59%) of NoK would decline eye donation [20]. Commentary from all three papers highlight concerns regarding disfigurement, discomfort with the thought of eye removal, and spiritual/atheistic links to the eyes.

The comments illustrated in textboxes 1-4 support the findings from international literature, that personal attitudes to and beliefs about the propriety of eye donation are influential in shaping negative orientations toward this option and thus to decline of donation when it is raised with NoK.

How can we understand these reactions?

Concerns with, and negative reactions to the option of eye donation, as well as the critical shortage of eye tissue for use in transplant operations and research, are persistent and pervasive in the UK and across many other parts of the world. Therefore, we will now discuss these factors in light of theoretical work aimed at illuminating factors underpinning these outcomes. The discussion will look at theories developed from social cognitive psychology, which outline general concepts influencing behaviour, and more specific theories/models focussed on psychological concepts that propose explanations for the reactions reported both in these data and the wider global literature. Whilst an exhaustive review of relevant theory is not possible in this paper, we focus on application of key findings and thinking to the national recorded data analysed here with the aim of: I) making recommendations to guide communication with patients, carers or other NoK when making an approach regarding the option of eye donation; II) stimulating thinking on communications strategy (e.g. future publicity and campaigns) by organisations responsible for securing a reliable and sufficient supply of eye tissue.

Social Cognitive models

Most early studies exploring factors influencing individual donation decision making applied concepts laid out in social-cognitive models such as the Theory of Reasoned Action (TRA) [21] and the Theory of Planned Behaviour (TPB) [22,23]. Horton and Horton (1991) developed one of the earliest models proposing that the action of signing or requesting an organ donor card and willingness to donate own, or a deceased loved one's organs after death was a product of: *values, knowledge, attitudes (toward donation), willingness and action* [24]. Their path analysis and causal modelling study included two cohorts of participants: University students (N= 295), and members of the public (N = 465). Whilst establishing that the tested concepts were related to donation decision making, it was also clear from results that there was no linear causal relationship between knowledge, values, attitudes, willingness, and action related to donation behaviours [24]. Further modelling by Radecki and Jaccard (1999) identifying barriers to sharing donation intentions with legal next of kin supported the general finding that behavioural intention (or willingness) does not predict action [25].

This brief review reminds us that while prior attitudes toward a behaviour are influential, that they do not 'ensure' action will follow intention. Models such as TRA [21] and TPB [22,23] are fundamentally models that presume a process of rational decision making that is not evidenced in studies where donating and non-donating family decision makers have been included and interviewed.

For example, research by Kopfman and Smith (1996) aimed at informing donation campaigns introduced new thinking by looking both at concepts such as 'knowledge, attitudes and intention to donate' and identifying that those who measured low in intent to donate were more likely to 'have inaccurate knowledge about donation and gain lower scores on a measure for altruism' – and also highlighting that *'those low in intention felt that signing a donor card would be frightening'* [26]. We see here one of the first instances of what have been referred to as *non-rational* [26] or later *non-cognitive* factors [27,28] (anxiety/fear) being reported. Further work by authors carrying out qualitative research increasingly identified deeply held beliefs and feelings that were reported as influencing the decision to donate organs of self and others, or register an intent to become an organ donor on death, including: anxiety, mistrust, superstition-based fear and views about what should or should not be done to a body post death [12–14,17,18,27,29–32].

Sanner's Discomfort Reactions

We gain some important insights if we revisit Sanner's work exploring public views of post-death procedures on the body [12,13]. Although this work was carried out in the 1990's with 400 members of the public aged from 18–75 years, Sanner identified particular 'discomfort reactions' in relation to post-death procedures that are both relevant and of value in moving forward our understanding of reactions to requests for eye donation. Interviews with three subgroups selected from the original 400 who represented negative, positive, and undecided views regarding donating their own organs identified that people with "intense discomfort reactions tended to ignore or suppress positive motives (*e.g. attitudes, intentions*) toward donating organs" [12].

Sanner identified 600 statements that referred to what may or may not be done to the body after death, and after content analysis of these statements she constructed 20 ‘motive’ categories. These categories were analysed to ‘discern psychologically meaningful reaction patterns’ by applying a frame of reference based on psychodynamic defence theory, and resulted in six central motive complexes [13] (Table 4).

Table 4 – Motive complexes and categories relating to discomfort reactions to post-death procedures (Sanner, 1994)

Motive complexes	Sanner’s motive categories (for details see Sanner, 1994) [13]
The illusion of lingering life	1. Uneasiness at the thought of cutting the dead body 2. Anxiety about not keeping the dead body intact 3. Discomfort with donation of certain organs 4. Difficulty with cutting children 5. Fear of destruction (of the body) 6. Uneasiness with exposure (via autopsy or dissection) 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 11. Apprehension about the funeral 13. Discomfort at giving useless organs
Protection of the value of the individual	5. Fear of destruction 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 10. Apprehension about the funeral 13. Discomfort of giving useless organs 15. Distrust of the doctors
Distress, anxiety and alienation	14. Problems with the concept of death 15. Distrust of the doctors 16. Anxiety about biomedical and social development
Respecting the limits set by nature/God	12. Dislike of having one’s organ surviving in another body or having another organ living on in one’s own body 17. Anxiety about offending God/nature
Altruism	18. Helpfulness and solidarity 19. Contribution to medical research
Rationality	20. Organs from the deceased can be used in the treatment of the living

Not only can we see these discomfort reactions articulated in the free-text comments recorded during data collection by SNODs in our own findings (Textboxes 1 – 4), we can also see that non-rational reactions have been evidenced by other authors and include: *fear that doctors would hasten the death of declared donors in order to procure transplantable organs* [18], *belief that donation would negatively impact rebirth or reincarnation (deceased would be reborn blind)* [33], and later work identifying the impact of *emotional beliefs including the ‘ick’ factor* and the role of *‘Body Integrity’* [29] (for a detailed view of all variables tested in development of the Organ Donor Model (ODM) see Morgan et al. [27,29,34]). The ‘ick’ factor and concerns about body integrity are of particular relevance to eye donation and will therefore be discussed in more detail.

The Ick factor and Bodily Integrity

According to Morgan et al (2008) [29] *ick factors* are those related to a basic disgust response to the idea of eye donation, as it involves what may be perceived by family members as interventions that are disfiguring and even disrespectful. Fear of body disfigurement is proposed as triggering defensive emotions that according to Parisi and Katz, “*seem to be deeply rooted in the unconscious and to have relatively little cognitive content*” (1986: 576) [35]. These defensive emotions are influenced by sociocultural and psychological factors developed early in childhood,

strongly influenced by one's particular culture and ethnicity, and which are reported by Sherman and Sherman (2001) to be resistant to modification [36]. Furthermore, defensive emotions and reactions are reported to underpin donation-negative attitudes and carry more weight in the decision-making process than donation-favourable ones. These findings potentially provide insight into why persuasive attempts that focus on rational messages fail or are less successful than expected by organisations that oversee donation and transplantation services.

A final comment here is the reference in Textbox 1 to '*eyes being the windows to the soul*'¹. This perception has been reported in a number of studies exploring eye donation and links to both the belief in the need to maintain the integrity of the body after death [37] and a concern about the deceased not being able to see in the afterlife [14,37,38]. For some "*eyes, more than any other body part, personify an individual*" [17, p.1190] and therefore have greater potential to stimulate 'dissonance' for individuals approached to consider the option of eye donation.

Cognitive dissonance and the context of death

Cognitive dissonance is described as an emotional state set up when two simultaneously held cognitions are inconsistent or when there is a conflict between beliefs and overt behaviour [39]. Therefore, relating this to eye donation, dissonance arises when family members approached to consider eye donation are aware (for example by media campaigns such as 'Give the gift of sight') [40] or are made aware (e.g. by SNODS, or other family members) that eye donation can reverse blindness and have to rationalise their aversion/disgust/discomfort of eye removal which they perceive as an integral part of the person they love (as indicated in Textbox 1). Lawlor and Kerridge (2014) go so far as to suggest that despite participants in their study "*recognising the potential good that could come from corneal donation, many still maintained that removing the eyes would potentially have a significant adverse effect on their ongoing relationship with the deceased*" [14, p.62].

We propose that non-cognitive factors including: discomfort reactions, disfigurement concerns, the ick factor and the importance of body integrity are key areas of emotional and psychological conflict for family members approached to consider eye donation. In their secondary analysis of primary data from donating and non-donating family members in the UK, Long et al (2008) proposed that family members engage in a series of practical and psychological activities aimed at rationalising real or potential emotional and cognitive conflict when faced with the option of donation post death of a family member [17]. If family members are not able to rationalise *conflict (e.g. sacrifice of an intact body to a perceived disfiguring operation even if it is for the benefit of others)* NoK will decline donation.

A key context missing from social cognitive models and also much qualitative research into barriers to donation is the context of death. Apart from living donation, solid organ donation cannot proceed until someone has died, in the case of solid organ a death that is sudden and unexpected. Death not only robs the next-of-kin of a significant relationship, but also robs them of many of their usual coping mechanisms, imposing a sequence of events that Sque et al (2003) describe as leaving family members feeling dispossessed of physical and psychological equilibrium [30].

Furthermore, from a sociological perspective, Kellehear (2008) remarks that an understanding of “*dying as a social relationship*’ [is] *vital to understanding the levels of disagreement with organ donation due to the social basis of attachment, meaning-making and identity*”[41, p.1541]. Responses indicating attachment to the deceased (e.g. ‘*family reported they didn’t like the idea of someone else seeing through their loved ones eyes, Textbox 1*’), as well as the need for an intact body (e.g. ‘*only wanted internal organs donated, nothing from the outside*’, Textbox 2) are evidenced in the national data set analysed in this paper, alongside the importance of the identity of the deceased (e.g. ‘*eyes refused as wife couldn’t bear the thought of him without them*’, Textbox 1). It is in this emotional landscape that the topic of eye donation is raised, a context that appears unique to eye donation. It is therefore essential that those making the approach to request eye donation understand the non-rational, emotional, and sociological factors underpinning NoK decision-making if an increase in the donation of eyes is to be achieved.

Whilst messages to support positive attitudes toward donation are now embedded in social and other media campaigns in the UK (e.g. Giving the ‘Gift of Sight’ [42], ‘Yes I Donate’ etc. [43]), messages employed to reduce negative attitudes have not taken sufficient account of the psychological, emotional and sociological factors that are specifically relevant to the donation of eye tissue. As stated in the introduction, eyes are the least donated organ and this, we argue, is because the thought of removing the eyes may stimulate intense discomfort reactions, such as disgust, concerns of visible disfigurement and dissonance that suppress positive motives (e.g. attitudes) toward donating eyes.

Limitations

Data were generated by SNODs who recorded reasons shared with them by family members, and therefore the data reflect proxy comments. Feedback received by the working group indicates that SNODs were likely not to probe family responses, just recording ‘*family refused*’, ‘*No additional information*’ if in their view the discussion may lead to the family declining organ donation. The detail provided in the comments is constrained by the response format (i.e. a hand-written box) limiting the amount of information that SNODs could insert leading to wide variation in length of entries ranging between 1-187 words (median=6, IQR=7). Thus, both the frequency and content (i.e. type and level of detail) of recorded comments were variable.

We did not have access to the demographic data of potential donors included in primary data collection under the data sharing agreement, and therefore have not been able to include any related commentary. We are also unable to provide any commentary regarding the impact of legislative changes that took place in Wales (as of 1st December 2015) [44] during primary data collection for the service development initiative, as practice responses to these changes were still being developed and implemented.

Conclusion and recommendations:

In view of the reported 53% of the world’s population not having access to the benefits of sight saving and sight restoring transplantation surgery [1] and over two million people in the UK living with sight loss [2] this paper presents important data that could help organisations and HCPs involved in approaching bereaved family member for eye donation re-design modes of approach and the structure of consent conversations. In view of the data reported that potentially, over 2,000 eyes did not become available for use in transplant operations and research due to family members declining this donation option, further research is needed focussed on the construction, delivery and content

of the donation conversation. We therefore propose the following recommendations for future service and communication strategy development.

- Communicate propriety of the donation operation - The 'sacrifice' of an unscathed body could be an important barrier to actualising donation even in populations where there is a high level of awareness of the benefits of transplantation [45]. The propriety of the donation operation needs to be stressed in public education and in discussions with the bereaved family approached about organ donation as discovering what worries people about organ donation is the first step towards crafting more effective organ donation campaigns [34].
- Explore the potential of a disc-only corneal retrieval procedure to increase acceptance of donation - Enucleation (removal) of the entire eye (as usual in the UK) has been reported as being a potential barrier to donation of eye tissue by relatives in view of disfigurement concerns. Removal of the corneoscleral disc only has been aligned with higher consent rates [46], however currently robust data about whether this would be a more acceptable intervention with decision makers is missing. Research comparing consent rates for these two options would be a valuable addition to the knowledge base on which to base future service planning.
- Improve public education regarding the donation process - Public awareness campaigns, as well as consent conversations with families currently focus on the benefits of transplantation. In contrast, little public education has centred on the donation process itself which could prepare individuals for this potential life event. According to Siminoff et al. (2001) *"Since it is not reasonable to expect that family decision-makers can or even should relinquish strongly held beliefs about organ donation when experiencing the severe stress of a loved one's death, prior education is the best mechanism we may have to inform the public and prepare families for an organ donation request"* [18, p.76].
- Explore how the request process affects acceptance of donation - There remains significant room for improvement in the request process, as to date this pivotal aspect of the donation process has received little attention. Of note, there has been no research looking into the impact of the hierarchy of organs outlined in the consent conversation. For example, if a patient is suitable to donate all organs and tissues, the first organ mentioned is usually kidneys, followed by other abdominal organs and tissues, thoracic organs and tissues, then tissues (within which eyes are listed). It has been proposed that the order in which organs are requested may affect donation rates for eyes due to what has been referred to as 'list shock' - the idea that family members may be overwhelmed by the 'list' of organ and tissue that can be donated (this term was first coined by Margaret Verble and Judy Worth (personal communication, 21.08.2020)).
- Explore processes for assessment of familial responses to information provided during the consent conversation - future research should explore processes for assessing familial responses to information shared in consent conversation, and how HCPs conducting conversations may appropriately and sensitively explore areas that provoke a reaction (instead of avoiding them). Investigations of the latter type are of particular need in light of evidence indicating that many HCP's are poor *prima facie* judges of who may or may not be willing to donate [18].
- Future research topics - topics for further research include: investigation of potential demographic and/or regional differences in reasons for decline of eye tissue; the impact of legislation changes (i.e. from 'opt-in' to

1 'opt-out' (deemed consent) on eye donation in each of the UK nations; and construction, delivery and content
2 of donation consent conversations (e.g. exploring if and how systematic aspects of conversations related to
3 seeking agreement to organ/tissue/eye donation may be related to outcomes (i.e. acceptance or refusal) [47].
4
5
6
7
8
9

10
11 **Acknowledgement**

12 The authors would like to thank colleagues at the division of Statistics and Clinical Studies (NHSBT) for their help and
13 support.
14

15 **Funding statement**

16 Article Processing Charges for this work are supported by NHS Blood and Transplant Tissue and Eye Services
17 (Award/Grant number is not applicable)
18
19

20
21 **Competing interests**

22 EW and HG are employed by NHS Blood and Transplant.
23
24 EW was Chair of the Eye Donation from Solid Organ Donors – EPSOD, 2014-2017 working party within NHS Blood and
25 Transplant.
26
27 TLS was an invited member of the Eye Donation from Solid Organ Donors – EPSOD, 2014-2017 working party within
28 NHS Blood and Transplant.
29
30
31
32
33

34 **Author Contributions**

35 EW and HG facilitated access to primary data and reviewed early drafts of this paper.
36
37
38
39 TLS developed the idea of a secondary analysis and proposed undertaking this under the auspices of the Service Level
40 Agreement that exists between NHSBT- TS and UoS. TLS provided specialist input into the analysis of free text
41 comments, discussion, recommendations, and edited developing drafts.
42
43
44
45 MJB sourced secondary data from NHSBT and conducted secondary data analysis (descriptive statistics and qualitative
46 content analysis), with input from BMS and TLS, and was responsible for primary authorship. All co-authors
47 contributed substantially to the development of the paper and resulting recommendations.
48
49

50 **Data sharing statement**

51 No additional unpublished data are available from this study.
52
53
54
55
56
57
58
59
60

References

- 1 Pascolini D, Mariotti SP. Global estimates of visual impairment: 2010. *Br J Ophthalmol* 2012;**96**:614–8. doi:10.1136/bjophthalmol-2011-300539
- 2 RNIB & Specsavers. The State of the Nation Eye Health 2016. *The State of the Nation* 2016;:27.
- 3 Gaum L, Reynolds I, Jones MNA, *et al*. Tissue and corneal donation and transplantation in the UK. *Br J Anaesth* 2012;**108**:i43–7. doi:10.1093/bja/aer398
- 4 NHS-BT Organ and Tissue Advisory Group (OTAG). Tissue and Eye Procurement from Solid Organ Donors (TEPSOD) Activity Report. 2016. http://odt.nhs.uk/pdf/advisory_group_papers/OTAG/Tissue_&_Eye_Procurement_from_Solid_Organ_Donation.pdf
- 5 NHS-BT. Organ Donation and Transplantation - Activity report 2016/2017. 2017. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4657/activity_report_2016_17.pdf
- 6 NHS-BT. NHS Blood and Transplant - Eye and Tissue Strategy. Liverpool, UK: 2016.
- 7 Royal College of Ophthalmologists. Standards for the retrieval of human ocular tissue used in transplantation, research and training. London, UK: 2013. <https://www.rcophth.ac.uk/publications/current-clinical-guidelines/>
- 8 NHSBT. Organ Donation and Transplantation Activity Report 2019/20. Liverpool, UK: 2020. doi:10.1016/B978-0-12-373932-2.00158-7
- 9 Long-Sutehall T, Sque M, Addington-Hall J. Secondary analysis of qualitative data: a valuable method for exploring sensitive issues with an elusive population? *J Res Nurs* 2011;**16**:335–44. doi:10.1177/1744987110381553
- 10 Schreier M. Qualitative Content Analysis. In: *The SAGE Handbook of Qualitative Data Analysis*. 1 Oliver's Yard, 55 City Road, London EC1Y 1SP United Kingdom: : SAGE Publications Ltd 170–83. doi:10.4135/9781446282243.n12
- 11 QSR International Ltd. NVivo qualitative data analysis software. 2018. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home> (accessed 23 Apr 2020).
- 12 Sanner M. A Comparison of Public Attitudes Toward Autopsy, Organ Donation, and Anatomic Dissection: A Swedish Survey. *JAMA J Am Med Assoc* 1994;**271**:284–8. doi:10.1001/jama.1994.03510280046031
- 13 Sanner M. Attitudes toward organ donation and transplantation. *Soc Sci Med* 1994;**38**:1141–52. doi:10.1016/0277-9536(94)90229-1
- 14 Lawlor M, Kerridge I. Understanding Selective Refusal of Eye Donation: Identity, Beauty, and Interpersonal Relationships. *J Bioeth Inq* 2014;**11**:57–64. doi:10.1007/s11673-013-9497-9
- 15 Weiss AH, Fortinsky RH, Laughlin J, *et al*. Parental consent for pediatric cadaveric organ donation. *Transplant Proc* 1997;**29**:1896–901. doi:10.1016/S0041-1345(97)00110-3
- 16 Rodrigue JR, Cornell DL, Howard RJ. Pediatric organ donation: What factors most influence parents' donation decisions? *Pediatr Crit Care Med* 2008;**9**:180–5. doi:10.1097/PCC.0b013e3181668605

- 17 Long T, Sque M, Addington-Hall J. Conflict rationalisation: How family members cope with a diagnosis of brain stem death. *Soc Sci Med* 2008;**67**:253–61. doi:10.1016/j.socscimed.2008.03.039
- 18 Siminoff LA, Arnold RM, Hewlett J. The process of organ donation and its effect on consent. *Clin Transplant* 2001;**15**:39–47. doi:10.1034/j.1399-0012.2001.150107.x
- 19 Lawlor M, Kerridge I, Ankeny R, *et al.* Specific unwillingness to donate eyes: The impact of disfigurement, knowledge and procurement on corneal donation. *Am. J. Transplant.* 2010;**10**:657–63. doi:10.1111/j.1600-6143.2009.02986.x
- 20 Acharya M, Farooqui J, Dave A, *et al.* Eye donation in north India: Trends, awareness, influences and barriers. *Indian J Ophthalmol* 2019;**67**:1570. doi:10.4103/ijo.IJO_2151_18
- 21 Fishbein M, Ajzen I. *Belief, Attitude, Intention, and Behavior: An Introduction to Theory and Research.* Addison-Wesley Publishing Company 1975. <https://books.google.co.uk/books?id=8o0QAQAIAAJ>
- 22 Ajzen I. The Theory of Planned Behavior. *Organ Behav Hum Decis Process* 1991;**50**:179–211. https://www.dphu.org/uploads/attachements/books/books_4931_0.pdf
- 23 Ajzen I. From Intentions to Actions: A Theory of Planned Behavior BT - Action Control: From Cognition to Behavior. In: Kuhl J, Beckmann J, eds. . Berlin, Heidelberg: : Springer Berlin Heidelberg 1985. 11–39. doi:10.1007/978-3-642-69746-3_2
- 24 Horton RL, Horton PJ. A model of willingness to become a potential organ donor. *Soc Sci Med* 1991;**33**:1037–51. doi:10.1016/0277-9536(91)90009-2
- 25 Radecki CM, Jaccard J. Signing an Organ Donation Letter: The Prediction of Behavior From Behavioral Intentions1. *J Appl Soc Psychol* 1999;**29**:1833–53. doi:10.1111/j.1559-1816.1999.tb00154.x
- 26 Kopfman JE, Smith SW. Understanding the audiences of a health communication campaign: A discriminant analysis of potential organ donors based on intent to donate. *J Appl Commun Res* 1996;**24**:33–49. doi:10.1080/00909889609365438
- 27 Morgan S, Miller J. Communicating about gifts of life: the effect of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *J Appl Commun Res* 2002;**30**:163–78. doi:10.1080/00909880216580
- 28 Quick BL, LaVoie NR, Reynolds-Tylus T, *et al.* Does Donor Status, Race, and Biological Sex Predict Organ Donor Registration Barriers? *J Natl Med Assoc* 2016;**108**:140–6. doi:10.1016/j.jnma.2016.05.007
- 29 Morgan SE, Stephenson MT, Harrison TR, *et al.* Facts versus 'Feelings'. *J Health Psychol* 2008;**13**:644–58. doi:10.1177/1359105308090936
- 30 Sque M, Long T, Payne S. Organ and tissue donation: exploring the needs of families. Final report of a three-year study commissioned by the British Organ Donor Society, funded by the National Lottery Community Fund. University of Southampton 2003. <http://users.argonet.co.uk/body/Report.html>
- 31 Sque M, Long T, Payne S. Organ donation: Key factors influencing families' decision-making. *Transplant Proc* 2005;**37**:543–6. doi:10.1016/j.transproceed.2004.11.038
- 32 Lawlor M, Kerridge I. Anything but the eyes: Culture, identity, and the selective refusal of corneal donation. *Transplantation.* 2011;**92**:1188–90. doi:10.1097/TP.0b013e318235c817
- 33 Tandon R, Verma K, Vanathi M, *et al.* Factors affecting eye donation from postmortem cases in a tertiary care hospital. *Cornea* 2004;**23**:597–601. doi:10.1097/01.ico.0000121706.58571.f6
- 34 Morgan S, Miller J, Arasaratnam L. Signing cards, saving lives: an evaluation of the worksite organ donation promotion project. *Commun Monogr* 2002;**69**:253–73. doi:10.1080/03637750216540
- 35 Parisi N, Katz I. Attitudes toward posthumous organ donation and commitment to donate. *Heal Psychol* 1986;**5**:565–80. doi:10.1037//0278-6133.5.6.565
- 36 Sherman NC, Smith RJ, Sherman MF, *et al.* Disgust Sensitivity and Attitudes toward Organ Donation among African-American College Students. *Psychol Rep* 2001;**89**:11–23. doi:10.2466/pr0.2001.89.1.11

- 37 Hessing DJ, Elffers H. Attitude toward Death, Fear of Being Declared Dead Too Soon, and Donation of Organs after Death. *OMEGA - J Death Dying* 1987;**17**:115–26. doi:10.2190/5NB6-DJDW-B68G-6T56
- 38 Wells J, Sque M. 'Living choice': the commitment to tissue donation in palliative care. *Int J Palliat Nurs* 2002;**8**:22–7. doi:10.12968/ijpn.2002.8.1.10231
- 39 M. DW, Reber AS. *The Penguin Dictionary of Psychology*. 1986. doi:10.2307/1422298
- 40 Gift of Sight. Gift of Sight. 2020.<https://www.giftofsight.org.uk/> (accessed 7 Jul 2020).
- 41 Kellehear A. Dying as a social relationship: A sociological review of debates on the determination of death. *Soc Sci Med* 2008;**66**:1533–44. doi:10.1016/j.socscimed.2007.12.023
- 42 NHSBT. Giving the gift of sight. 2020.<https://www.blood.co.uk/news-and-campaigns/the-donor-magazine-autumn-2017/giving-the-gift-of-sight/> (accessed 12 Jan 2021).
- 43 NHSBT. Organ donation graphics - Download and share our graphics to promote organ donation. 2020.<https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/organ-donation-graphics/> (accessed 12 Jan 2021).
- 44 NHSBT. Organ donation law in Wales. 2020. <https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-wales/> (accessed 12 Jan 2021).
- 45 Sque M, Long-Sutehall T. Bereavement, decision-making and the family in organ donation. In: *Organ Shortage: Ethics, Law and Pragmatism*. 2011. 67–86. doi:10.1017/CBO9780511973536.005
- 46 Hudde T, Reinhard T, Möller M, *et al.* Korneosklerale transplantatentnahme an der leiche: Erfahrungen der Lions-Hornhautbank Nordrhein-Westfalen in den jahren 1995 und 1996. *Ophthalmologie* 1997;**94**:780–4. doi:10.1007/s003470050203
- 47 Elizabeth Weathersbee T, Maynard DW. Dialling for donations: Practices and actions in the telephone solicitation of human tissues. *Sociol Heal Illn* 2009;**31**:803–16. doi:10.1111/j.1467-9566.2009.01189.x

Additional File

Table 1 - Reasons for non-donation cases for eye tissue by category and major sub-category for the period 1st April 2014-31st March 2017

Category	Sub-category	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All Years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44
	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A	N/A	2	0.00	1	0.00	3	0.00
	Other/not specified family reasons	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.14	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.26	20	0.45	52	0.29
Coroner refused consent	Homicide / Murder / Manslaughter	7	0.14	8	0.14	10	0.20	25	0.16
	Sustained injury in custody/prison	3	0.06	1	0.02	2	0.04	6	0.04
	Police refusal	18	0.35	N/A	N/A	1	0.02	19	0.12
	Suspicious death	23	0.45	24	0.41	16	0.31	63	0.39
	Other coroner reasons, please specify	51	1.00	24	0.41	22	0.43	97	0.61
Medical reasons	High risk behaviour	61	0.25	74	0.29	58	0.17	193	0.23
	Haemodilution	14	0.06	15	0.06	24	0.07	53	0.06
	Neurological conditions of unknown cause	47	0.19	34	0.13	44	0.13	125	0.15
	Positive virology	16	0.07	20	0.08	10	0.03	46	0.05
	Above age criteria	N/A	N/A	5	0.02	10	0.03	15	0.02
	Other medical reasons, please specify	104	0.43	105	0.42	200	0.58	409	0.49
All other reasons	Concerns about storage	1	0.02	2	0.04	3	0.03	6	0.03
	Other reasons, please specify	28	0.53	28	0.56	39	0.36	95	0.45
	Not specified	24	0.45	20	0.20	67	0.61	111	0.52

Table 2.1 Main reason for non-eye donation (all reasons) 1 April 2014 to 31 March 2015		
Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	35	(4.0)
Driving licence	1	(0.1)
Discussion with family	17	(1.9)
Verbal or written statement in life	1	(0.1)
Sub total	54	(6.1)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	11	(1.2)
Knew deceased wishes not to donate eyes	3	(0.3)
Sub total	14	(1.6)
Deceased wishes	68	(7.7)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	95	(10.8)
I do not like the idea of eye donation	62	(7.0)
Uncomfortable with removal of whole eye	16	(1.8)
Personal connection/link to deceased eyes	22	(2.5)
Sub total	195	(22.1)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	32	(3.6)
Only organs	79	(9.0)
Face not to be touched	61	(6.9)
Concerns about how the deceased would look	12	(1.4)
Nothing above the neck	2	(0.2)
Sub total	186	(21.1)
<i>Decision made on current physical/emotional state</i>		
Family disagreement	4	(0.5)
Family overwhelmed	6	(0.7)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	1	(0.1)
Sub total	13	(1.5)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need for eyes to be buried/cremated	1	(0.1)
Need eyes to see in the afterlife	3	(0.3)
Sub total	4	(0.5)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	26	(3.0)
Family, not specified	28	(3.2)
Sub total	54	(6.1)
Family wishes	452	(51.3)
Reason for non-eye donation	N	(%)
Coroner refused consent		
Homicide / Murder / Manslaughter	7	(0.8)
Police refusal	3	(0.3)
Suspicious death	18	(2.0)
Other coroner reasons, please specify	23	(2.6)
Sub total	51	(5.7)
Medical reasons		
High risk behaviour	61	(6.8)
Haemodilution	14	(1.6)
Neurological conditions of unknown cause	47	(5.3)

Positive virology	16	(1.8)
Other medical reasons, please specify	104	(11.7)
Sub total	242	(27.1)
All other reasons		
Concerns about storage	1	(0.1)
Other reasons, please specify	28	(3.1)
Not specified	24	(2.7)
Sub total	53	(5.9)
TOTAL	892	(100.0)

For peer review only

Table 2.2 **Main reason for non-eye donation (all reasons)**
1 April 2015 to 31 March 2016

Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	21	(2.1)
Passport	1	(0.1)
Discussion with family	22	(2.2)
Verbal or written statement in life	6	(0.6)
Sub total	50	(5.0)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	15	(1.5)
Perceived wishes with disfigurement	3	(0.3)
Sub total	18	(1.8)
Deceased wishes	68	(6.8)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	54	(5.4)
I do not like the idea of eye donation	69	(6.9)
Uncomfortable with removal of whole eye	10	(1.0)
Personal connection/link to deceased eyes	21	(2.1)
Sub total	154	(15.5)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	40	(4.0)
Only organs	88	(8.9)
Face not to be touched	38	(3.8)
Concerns about how the deceased would look	13	(1.3)
Nothing above the neck	1	(0.1)
Sub total	180	(18.1)
<i>Decision made on current physical/emotional state</i>		
Family tired	1	(0.1)
Family disagreement	1	(0.1)
Family overwhelmed	5	(0.5)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	3	(0.3)
Sub total	12	(1.2)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need eyes to see in the afterlife	12	(1.2)
Sub total	12	(1.2)
<i>Decision made on lack of knowledge</i>		
Family unaware that eyes can be donated	1	(0.1)
Family had questions about the process	1	(0.1)
Sub total	2	(0.2)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	26	(2.6)
Family, not specified	34	(3.4)
Sub total	60	(6.0)
Family wishes	420	(42.3)
Coroner refused consent		
Homicide / Murder / Manslaughter	8	(0.9)
Sustained injury in custody/prison	1	(0.1)
Suspicious death	25	(2.8)

Other coroner reasons, please specify	24	(2.7)
Sub total	58	(6.6)
Medical reasons		
High risk behaviour	74	(8.4)
Haemodilution	15	(1.7)
Neurological conditions of unknown cause	34	(3.9)
Positive virology	20	(2.3)
Above age criteria	5	(0.6)
Other medical reasons, please specify	105	(11.9)
Sub total	253	(28.7)
All other reasons		
Concerns about storage	2	(0.2)
Other reasons, please specify	28	(3.2)
Not specified	20	(2.3)
Sub total	50	(5.7)
TOTAL	881	(100.0)

Table 2.3 Main reason for non-eye donation (all reasons) 1 April 2016 to 31 March 2017		
Reason for non-eye donation	N	(%)
<i>Decision based on deceased prior registered wishes</i>		
ODR	13	(1.3)
Discussion with family	6	(0.6)
Verbal or written statement in life	5	(0.5)
Sub total	24	(2.4)
<i>Decision based on deceased inferred wishes</i>		
Knew deceased wishes not to donate eyes	18	(1.8)
Perceived wishes with disfigurement	2	(0.2)
Sub total	20	(2.0)
Deceased wishes	44	(4.3)
<i>Decision made on personal views</i>		
Do not want eyes removed (discomfort reasons)	40	(3.9)
I do not like the idea of eye donation	41	(4.0)
Uncomfortable with removal of whole eye	11	(1.1)
Personal connection/link to deceased eyes	37	(3.6)
Sub total	129	(12.7)
<i>Decision made on disfigurement concerns</i>		
Squeamishness, yuk factor	95	(9.4)
Only organs	92	(9.1)
Face not to be touched	23	(2.3)
Concerns about how the deceased would look	10	(1.0)
Nothing above the neck	2	(0.2)
Sub total	222	(21.9)
<i>Decision made on current physical/emotional state</i>		
Family tired	3	(0.3)
Family disagreement	5	(0.5)
Family overwhelmed	6	(0.6)
Influencing voice making decisions	1	(0.1)
List shock	1	(0.1)
Wanted something left	11	(1.1)
Sub total	27	(2.7)
<i>Decision made on religious/cultural/spiritual grounds</i>		
Need eyes to see in the afterlife	5	(0.5)
Sub total	5	(0.5)
<i>Decision made on lack of knowledge</i>		
Family had questions about the process	1	(0.1)
Sub total	1	(0.1)
<i>Other/not specified family reasons</i>		
Family other reasons, please specify	35	(3.4)
Family, not specified	48	(4.7)
Sub total	83	(8.2)
Family wishes	467	(46.0)
Coroner refused consent		
Homicide / Murder / Manslaughter	10	(1.0)
Sustained injury in custody/prison	2	(0.2)
Police refusal	1	(0.1)
Suspicious death	16	(1.6)
Other coroner reasons, please specify	22	(2.2)
Sub total	51	(5.1)

Medical reasons		
High risk behaviour	58	(5.8)
Haemodilution	24	(2.4)
Neurological conditions of unknown cause	44	(4.4)
Positive virology	10	(1.0)
Above age criteria	10	(1.0)
Other medical reasons, please specify	200	(20.1)
Sub total	346	(34.8)
All other reasons		
Concerns about storage	3	(0.3)
Other reasons, please specify	39	(3.9)
Not specified	67	(6.7)
Sub total	109	(11.0)
TOTAL	1017	(100.0)