Life after Loss: Grief, Community, and the Donor Family Network

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Abstract

This ethnography consulting relatives, volunteers and third-sector organisations explores the experiences of deceased-donor relatives after consenting to organ donation (OD) in England.

The complex relationality of the donor's body in the hospital is impacted by interactions with healthcare professionals, expressions of care towards the donor, knowledge of the donor's donation preference and contextual and procedural factors. Noticeable prioritisation of the recipient and unfamiliar medicalised terminology can negatively impact the donation experience. The need to share information about donation timings and consent, possible recipient characteristics and donation outcomes can be at odds with relative's support needs and the abstract donation rhetoric and symbolism later used to honour relatives.

Reflection on the significance of OD happens along varying timescales. Personal support needs are difficult to anticipate based on standardised criteria. Sometimes, relatives are confused about whether they need to access further information and support proactively/independently. GDPR regulations and limited access pose communication challenges for volunteers, who network to construct provisions around official structures.

OD's framing as the Gift of Life is confounded by anonymity rules, multiple meanings and sometimes coupled with unfulfilled expectations. Diversification of discourses could improve resonance and accuracy, better accommodating the emerging plurality of narratives when giving or receiving an organ. Meaningful kinship bonds can emerge during relative-recipient encounters, creating mutual trust where abstract metaphors are replaced by complex conversations.

Annual events enable informal connection, offering spaces for grief, remembrance and information-sharing. Here, donation reflection and mention of the donor become normalised. Transplantation, often a complex, reality-disrupting experience, can be reclaimed as a positive. Access to events depends on knowledge of their existence, time and resources to attend and resonance of their purpose.

A comprehensive information hub beyond the existing provisions, covering accessible visual and auditory materials on regional and local information and support sources, could provide reassuring transparency.

Life after Loss: Grief, Community, and the Donor Family Network

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Contents

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Dedication

In memory of Wilfried Rudolph, my favourite teacher.

For Sarah and Toby.

1. Introduction

England, like many countries in the world, is facing an organ donor shortage. According to a report published by the National Health Service Blood and Transplant Unit (NHSBT) in 2023, the number of people waiting for a life-changing and often life-saving organ transplant on the organ donor waiting list was 6595 in the 2022-2023 reporting period. A further 3822 people, who had been on the waiting list before, were taken off it because their health had deteriorated too far or because they were not deemed suitable for receiving an organ transplant (NHSBT, 2023d). People on the waiting list rely on organ donations from live donors and deceased organ donors. In deceased organ donation in England, the consent of the family of the deceased must be given for the donation to go ahead (unless the deceased has nominated a representative outside their family to authorise a potential donation on their behalf in the event of their death) (NHSBT, 2023b). While the total number of organ donations in the UK increased by 2% in 2022-23, overall consent given when an approach about organ donation was made fell by 4% (from 66% to 62%) compared to the previous year (NHSBT, 2023d). Additionally, the organ donation report indicates that there is a trend towards more obese donors and donors with non-trauma-related deaths, as well as older donors. All these changes in donor characteristics are thought to impact transplant success (NHSBT, 2023d). The recent statistics point to an ongoing public health challenge in England and the rest of the UK. The number of people in need of an organ transplant continues to rise, and the number of organs offered for donation is insufficient to meet the increasing needs of the patients. The shortage of organs available for medical use links to a long history of the procurement of human remains for medical research and therapeutic use in England, which I will briefly outline to provide historical context to this study.

The prevalent use of human remains for medical dissection and research purposes became more prevalent in the UK in the late 1800s (Richardson, 2006). Anatomy schools recruited increasing numbers of students and had a demand for human bodies for the use in education and research. The first group that was legally deemed appropriate for such uses after their death were criminals and people who had been publicly executed (Lock, 2002). With demand for human bodies ever-rising, the Anatomy Act 1832, extended this to the poor and destitute more broadly, and it became a common strive for one’s dignity in death to have the funds for a proper funeral and to avoid the use of one’s body in medical education and research (Richardson, 2006). Death at this time was more common and rituals governing the interaction and treatment of the body in the time immediately after the death of the deceased were widespread. Such beliefs stemmed from the presumed ongoing entanglement of the soul of the deceased with the body after death (Richardson, 2006). The laying out and watching of the body were common practice and associated with the beliefs that the spirit of the deceased continued to linger or that the body retained some sentience for a period after death. Similarly, superstitions around the correct removal of the spirit from the home dictated that the body should be moved through the door with their feet first so as to prevent the spirit of the deceased from beckoning the living to follow (Richardson, 2006). The well-cared for corpse was hoped to help the deceased ascend to heaven and brought comfort to the surviving relatives. Furthermore, with fewer precise means of confirming death available, relatives gained reassurance from the confirmation that the deceased had indeed died and been observed to have done so for an extended period. In this context, historical records detail conflicts between the relatives of the deceased and medical professionals over who could retain the body after death. Famously, the need for human bodies became so great that the procurement of recently deceased human remains became very profitable and led to the uptake of killing as a means of procuring bodies to sell in the famous case of Burke and Hare in Edinburgh (Lock, 2002; Richardson, 2006). A prominent tension that came to the fore was the fact that the human remains held the greatest value when the grief of the surviving relatives was acute because the person they were grieving was recently deceased and their body intact (Lock, 2002; Richardson, 2006). Additionally, measures were often taken to further protect the bodies of the deceased from being removed from the grave for study and would sometimes be watched over by a relative or equipped with a metal cage to prevent grave robbery (Richardson, 2006). Early attempts at transplantation led to the removal of human teeth which would be transplanted, and which were often procured with financial renumeration from children, however, they were later found to cause infection and to contribute to the spread of disease because of the limited knowledge about the steps necessary to appropriately prepare for the transfer of biological material (Richardson, 2006).

The first efforts to research the possibility of organ transplantation used animal organs or human material from people who had been deceased for a longer period (Watson and Dark, 2012). There was a shift to a more social provision of healthcare that provided universal care to all when the National Health Service (NHS) was founded in 1948, which reflected a national commitment to care for poorer and wealthier people alike (Richardson, 2006). The first transplant that used the kidney of a live donor was performed in the 1950s, with the first transplant in England being completed in 1960 (Watson & Dark, 2012). Transplant surgery began with the successful transplantation of kidneys, which was later followed by the liver, the lungs and then the heart in 1968 (Watson and Dark, 2012). Since the inception of transplant surgery, a larger number of potential recipients was in need of an organ for transplantation that the number of organs available to transplant. Changes to the legal definitions of death, public education campaigns about the benefits of transplantation to the health of the recipient and the emergence of new technologies have been employed to increase the number of organs available. Simultaneously, patient for an organ had been increasing (Watson and Dark, 2012).

Legislation governing the retention of human material had been overhauled on several occasions to reflect changes in public and bioethical attitudes for the use of human organs and tissue for therapeutic purposes and research, but the specifics of a process for mandatory informed consent had not yet been specified (Bell, 2006).

In the late 1990s, the Organ Retention Scandal revealed that hospitals across the United Kingdom had retained the organs and tissues of patients for scientific research and education without the knowledge of the bereaved families (The National Archives, 2024a). The Organ Retention Scandal caused wide-ranging public outrage which was amplified by the knowledge that the organ retention had occurred across a large number of NHS trusts and damaged public trust in the country's medical institutions. The scandal laid bare the contrasting conceptions of human remains and the degree to which biological material retained relational ties and emotional significance in the minds of relatives, and the more scientific and utilitarian perspectives of clinicians and researchers who had conceptualised the material as a resource for the production of knowledge (Mchale, 2005). The government responded by drafting and introducing the Human Tissue Act of 2004, which overhauled the consent process around organ and tissue transplantation as well as the broader legal provisions surrounding the retention of human materials from living or deceased persons laid out in previous legislation (Mchale, 2005; Bell, 2006). The act was designed to better regulate the use, retention and disposal of human tissues and made the informed consent of the individuals or relatives they belonged to a requirement for research, educational and treatment purposes. The act required a greater degree of transparency around the handling of human biological material and was preceded by extensive consultation about the ethical principles that were agreed should govern organ and tissue donation. The primary consent source of the deceased's donation processes shifted to prioritising the donor's preference over the donation attitudes of the relatives (Simpkin *et al.*, 2009). Furthermore, the act predicated that in such cases where informed consent could not be obtained from the potential donor, consent needed to instead be obtained from a person in a "qualifying relationship" with the donor (Mchale, 2005). Competence was established as a pre-requisite for the provision of informed consent by a person and was defined under the principles of common law (The National Archives, 2024a, p. 4). The most recent change to the legislation of the consent process for organ donation in England occurred when the Organ Donation (Deemed Consent) Act 2019 was passed to make changes to the Human Tissue Act 2004 relating to the topic of organ and tissue donation (The National Archives, 2024b).

The passing of the so-called "*deemed consent law*" or "*Max and Keira's Law*", which came into effect in 2020, was intended to address the shortage of organs available for transplantation in England, by raising rates of consent to deceased organ donation. The law intended to reduce the concerns of those who hesitate to consent to donate their relative's organs because they are unsure of the donation preferences of the deceased. The new legislation was named after a young boy named Max whose life was changed because of the donation of a heart belonging to a young girl named Keira after her death following a car crash. The deemed consent law follows the so-called "*soft opt-out law*" about organ donation approach and is modelled after a law passed in 2017 to govern organ donation in Wales. "*Soft*" opt-out laws imply that unless a person has actively "*opted out*" of being an organ donor, they are deemed to have consented to organ donation after their death. However, this does not mean that organ donation can automatically go ahead. The law in England views everyone as a "*potential donor unless they chose to opt out[…]*", but the word "*potential*" underlines the legal requirement for specialist nurses to ask the relatives or nominated decision-maker to support the decision about the donation decision the deceased is deemed to have made (Bill Committee, 2018; Department of Health and Social Care, 2019). Families can refuse their consent – families can overrule the explicit decision of a potential donor who has opted-in for donation by registering themselves on the organ donor register (Bill Committee, 2018). The law seeks to reassure families who were asked about donations but did not know the deceased's preference following a situation where donation became possible. In these cases, the deceased is now legally assumed to have favoured donation unless they had actively opted out/ registered a preference to the contrary. The summary of the donation process I have provided here is not exhaustive and further details on how organ donation takes place in England under the current law can be found in Chapter 3.

To date, the new law has not achieved a significant increase in organ donation consent rates by the relatives of deceased-donors (O'Neill *et al.*, 2024). Because the deemed consent law became active during the COVID-19 pandemic, when information about the virus dominated the news, public discourses relating to the law change were overshadowed by the ongoing public health crisis of a global pandemic. This likely reduced the impact the law change had on public awareness of organ donation legislation, as did the fact that transplant services halted during this time (Parsons and Moorlock, 2020). Additionally, the statistics mentioned above indicate the continued need to increase donor numbers to help the people on the waiting list, even after introducing the new law. Consequently, it is a continued priority to better understand what drives relatives to agree to donate or to withhold their consent. Insights into this can arise from research into how organ donation is publicly and privately discussed as a result of the experiences of donor relatives. Because the new law places the need to make a decision about deceased donation on the surviving relatives or an individual nominated by the deceased, there is a need to better understand how the donation decision can impact donor relative experiences during and after their loss. Consequently, questions arise about how the decision-makers can best be prepared for making a decision in the contemporary English system, how the decision to consent may impact their own life after they experience their loss, and what sources of support and information are available to them.

Several disciplines have explored the reasons for donation attitudes and investigated the associated factors that are believed to relate to the likelihood of a person consenting to organ donation on behalf of a deceased relatives, or to express a willingness to donate their organs themselves.

The existing accounts on this matter fail to provide holistic contemporary insights into how the lives of relatives who consent to donation on behalf of a deceased relative are impacted by the decision to consent. Up to now, too little attention has been paid to how the experiences of others shape donation discourses. An experience that was characterised by the impression that appropriate care, support and information were provided may have positively impacted donor relatives' willingness to promote organ donation in their personal and private discourses. On the contrary, negative recollections about the donation process and its long-term effects may have led people who have experienced organ donation as donor relatives to share their negative impression of donation with others. Research to date has placed an overemphasis on the factors that are believed to drive the decision to consent and its impact on the number of organs available for transplant, with not enough attention being paid to how the lives of deceased-donor relatives who have agreed to organ donation are impacted after the loss. What does appropriate care for potential donor relatives look like in the hospital setting? What, if any, significance does donation have on the experience of loss in the minds of deceased-donor relatives in the long run? How do interactions with hospital staff shape the experience? What impact, if any, do interactions with organ recipients have on the donation attitudes of relatives who have consented to organ donation on behalf of a deceased donor?

Before I detail how my project has sought to address these issues, I will first expand on the themes that have dominated information campaigns, health interventions and research to date. This will help contextualise my research in the broader body of literature. I begin by discussing previous studies that have sought to identify deceased-donor relative characteristics that act as obstacles or advantages when assessing the likelihood of eliciting consent. Subsequently, I will explain how the trends that have emerged through this body of work have informed public health campaigns to educate the public about organ donation and to promote donation discourses. Following this, I will identify the limits of such campaigns and the complexities they are apt to overlook. Having situated my project in the existing body of work, I will outline how this doctoral thesis will be structured.

Research investigating the factors associated with hypothetical donation attitudes and influencing actual donation decisions have focused on a desire to understand what influences the provision of consent to donate some or all of the organs or tissue of eligible donors. Much of this work was historically linked to the mismatch between high-levels of public support to organ donation expressed in public opinion surveys but much lower levels of consent, with much interest being drawn to the causes of ethnic and religious sub-ground variability in willingness to consent in particular. A large number of studies drawing on both qualitative and quantitative research methods have been undertaken across several key disciplines and national context. Disciplines who sought to better understand donation attitudes and decisions include epidemiology, behavioural sciences, psychology, bioethics, public health, nursing, critical care medicine, sociology, anthropology and human geography, with subjects falling under the umbrella of the social sciences dominating the field. The vast majority of research to date has taken an attitudes and decision-based approach, with much less emphasis having been placed on the long-term implications of the donation decision on the relatives of deceased organ donors. The below discussion will summarise the insights and local contexts that have been explored quantitatively and qualitatively to date, before highlighting the limitations of these approaches using the example of rhetoric used in National Organ Donation information campaigns in England. The studies discussed here are not exhaustive but are intended to provide a methodological and thematic overview of what previous research into organ donation has focused on.

Quantitative research on donation attitudes has relied on insights from historical clinical data, surveys and questionnaires both administered over the phone and distributed electronically or via post, and analysis of demographic characteristics in relation to organ donation registration rates. The greatest number of quantitative studies investigating hypothetical donation attitudes was conducted in the US, with some additional insights available for the UK context and evidence from international contexts. One UK study identifies people from the Indian subcontinent as “reluctant donors” and investigates how donation information and guidance can better appeal to this statistically identified subgroup (Jindal, Joseph and Baines, 2003). Another UK study focuses on exploring the attitudes among South Asian Survey respondents with a high degree of internal variability in religious faith and cultural practices and concluded that Muslim respondents desired clearer guidance on religious implications of donations, whilst Hindus were reportedly more concerned with family approval (Karim, Jandu and Sharif, 2013). Studies in the US have analysed statistical data to determine whether more people having been declared brain dead would have increased the availability of organs (Webster and Markham, 2018); whether education campaigns highlighting self-interested benefits of organ donation can improve registration intentions (Siegel *et al.*, 2021); to what degree attitudes about organ donation relate to religious beliefs, race, and willingness to communicate about death (Shacham *et al.*, 2018; Carmack and DeGroot, 2020) and whether behaviour change interventions are effective in changing the willingness to discuss organ donation with one’s family among US students (Wang, 2012). In France, researchers have investigated whether donor card holders are influenced by superstitious beliefs, willingness to discuss death or other altruistic beliefs (Zouaghi, Chouk and Rieunier, 2015); document analysis in Japan has explored public views on brain death and its interpretation (Hayward & Madill, 2003); and in Pakistan, the impact of religious beliefs on willingness to discuss organ donation with relatives and to hold a donor card was assessed (Umair *et al.*, 2023).

More importantly, several quantitative studies have been conducted in the US and elsewhere to determine what impacted the actual donation decisions made by relatives. In the US, postal questionnaires have been used to investigate the donation decision (Exley, White and Martin, 2002); and telephone interviews have been quantitatively analysed to determine the impact of critical care nursing staff (Jacoby and Jaccard, 2010), interactions with staff in the hospital setting (Rodrigue, Cornell and Howard, 2006; Howard, Cornell and Koval, 2008; Jacoby and Jaccard, 2010), the level of understanding of the relevant clinical information (Stouder et al., 2009a; Jacoby and Jaccard, 2010), ethnicity (Rodrigue, Cornell and Howard, 2006), donation attitudes (Rodrigue, Cornell and Howard, 2006, 2008b), knowledge of the donation preference (Rodrigue, Cornell and Howard, 2006, 2008a; Hogan, Coolican and Schmidt, 2013), timing (Rodrigue, Cornell and Howard, 2006; Howard, Cornell and Koval, 2008), moral convictions (Hogan, Coolican and Schmidt, 2013) and levels of consensus (Rodrigue, Cornell and Howard, 2008a). Postal questionnaires were also used to quantitatively explore how relatives of donors in the US were affected by the donation experience in terms of the sources of support they drew on and whether they had outstanding questions or felt that their levels of stress or funeral arrangements were negatively impacted (Stouder *et al.*, 2009). Quantitative analysis was also utilised to explore the consequences of the loss as well as the motives behind the decision to consent (Hogan, Coolican and Schmidt, 2013; Hogan, Schmidt and Coolican, 2014). Furthermore, database analysis was used to determine the impact of staff interactions on consent rates (DuBay *et al.*, 2013); the impact of the creation of a ritual to honour donation in hospitals (15 minute silence) on consent have been explored (Neidlinger, Gleason and Cheng, 2013); and the impact of ceremonies to honour body donation for the study of anatomy was quantitatively assessed in terms of its effect on students and relatives (Greene, Collins and Rosen, 2018). Additionally, in Australia, survey research was conducted to evaluate the donation process in terms of its impact on donor relatives Douglass and Daly, 1995). The qualitative methods used often included large numbers of participants and pre-selected factors thought to be relevant to the donation decision and experience. Based on the research findings, they then went on to make recommendations on the basis of generalisations about the attitudes, needs and beliefs held by different subgroups. Quantitative studies are best suited to establish trends in reported aspects of donation that impact relatives' decisions and attitudes but unlikely to reveal previously overlooked factors or provide nuance and context to the information provided.

On the other hand, qualitative research methodologies often using interviews, focus group discussions and written correspondence have been employed and combined with qualitative data analysis methods (predominantly grounded theory, thematic analysis, document analysis, narrative analysis, qualitative phenomenology and psychosocial analysis). In the UK, attitudes on donation were explored through focus group discussions with Pakistani Muslims and white residents of the Northeast of England (Hayward and Madill, 2003), and Randhawa (2012) researched barriers of consent impacting different ethnic groups and members of religious faith, considering factors such as death rituals and methods of body disposal. Moreover, qualitative research has provided more nuanced insights into the experiences influencing the decision to consent among deceased-donor relatives. In the UK, qualitative research has engaged with healthcare providers in Scotland who detailed their experience of factors that were perceived to positively impact communication with donor relatives (Haddow, 2004a). Interviews have been used to explore the role understanding brain death played, as well as the relevance of staff interactions (Ormrod *et al.*, 2005) and overall procedural contexts (Ormrod *et al.*, 2005). The longer-term effects of the donation experience were explored through multivariate analysis to determine the relationship between donation views, believed donation attitude of the deceased, significance of donation in the context of death and overall processes on the relatives' grief (Sque, Long and Payne, 2005). A desire to protect the body of the deceased was explored (Sque *et al.*, 2018). An analysis of narrative interviews with hospital staff and donor relatives has explored factors such as timing and context-bound available resources in cases of donation after brain death and the challenges they can pose (Cooper, 2018, 2023). Qualitative interviews by Carey and Forbes (2003) further underlined the relationship between bereavement experience and the decision to consent and the benefits of familiarity with the donation preference of the potential donor. Internationally, the factors influencing the donation decision were qualitatively analysed in Switzerland (Kesselring, Kainz and Kiss, 2007), Spain (Martínez *et al.*, 2008), Sweden (Sanner, 2007), Greece (Bellali and Papadatou, 2007), Germany – albeit hypothetically - (Pfaller *et al.*, 2018), Canada (Manuel, Solberg and MacDonald, 2010), Brazil (Moraes and Massarollo, 2008), Australia (Marck *et al.*, 2016) and the United States (Siminoff, 2001; Frates and Bohrer, 2002; Ohler, 2007; Jacoby and Jaccard, 2010). In the US context, additional themes beyond the donation decision feature, such as document analysis exploring the phenomenon of a secondary loss sometimes experienced by donor relatives when the transplant fails (Corr *et al.*, 2011), and the impact of tissue donation on degrees of attachment and personal development for relatives of post-mortem donors (Hogan, Coolican and Schmidt, 2013) were investigated. In comparison to the quantitative evidence, the qualitative evidence relies on a much smaller sample size but provides a more in-depth, iterative exploration of influential factors. Due to the prevalence of less pre-structured and pre-classified categorisation of data in this form of analysis, unexpected themes and factors can emerge, and a greater degree of heterogeneity and complexity can be accommodated. However, both the quantitative and the qualitative explorations outlined above have sought to gather generalisable insights from the data that has been engaged with and frequently used semi-structured methods of exploration. Consequently, an opportunity to consider the interplay of the different factors and the personal dynamics that impacted the individuals involved was reduced and degrees to which subgroup trends have been co-constructed by the research design have been less well established. The majority of the studies above have not fully captured the complexity of the relational dynamics or the long-term effects of organ donation on families. Before I move on to highlight what ethnographic research has done to alleviate these limitations in the field to date, and how my research relates to these existing contributions, I will briefly outline the main emerging findings about factors influencing the donation experience to date. Additionally, I will indicate how trends in the research discussed above are reflected in the rhetoric that is predominantly used in NHS Organ Donation Information Campaigns in England.

Several systematic and narrative reviews have been undertaken to summarise the evidence on the factors that influence the donation experience of donor relatives. Doubts and limitations in understanding about the definition and reliable diagnosis of the donor's current brainstem or prospective circulatory death have been identified as a point of contention and possible reason for refusal (Long et al. 2008; Simpkin et al. 2009; Walker et al. 2013). The receipt of sufficient information and clear emphasis on the ability of relatives to make a choice, as well as clarity on implications on funeral plans made consent more likely (Long, Sque and Addington-Hall, 2008; Simpkin *et al.*, 2009; Walker, Broderick and Sque, 2013a). The phenomenon of dissonance and disharmony and harmony brought on by the news of the death coupled with the hope or search for meaning that may be associated with the possibility to donate has been discussed (Long, Sque and Addington-Hall, 2008), which also involved the identification of steps and sequences of experiences which the donation process gives rise to for relatives. Additionally, relatives have been described as feeling conflicting emotions towards the donor body which is often described as having ambiguous status (Long, Sque and Addington-Hall, 2008; Walker, Broderick and Sque, 2013a). Their contextual interaction with the hospital context, the timing of the request and the procedures relatives subsequently involved in (Long, Sque and Addington-Hall, 2008; Simpkin *et al.*, 2009; Walker, Broderick and Sque, 2013a), and their interactions with staff have been indicated to influence their experience (Long et al. 2008; Simpkin et al. 2009; Walker et al. 2013). Specifically, higher levels of perceived compassion and satisfaction that medical professionals had accommodated and recognised the family's needs positively influenced willingness to donate (Long, Sque and Addington-Hall, 2008; Walker, Broderick and Sque, 2013a). Religious beliefs and moral beliefs were also shown to sometimes play a role, in some cases making donor registration more likely and in others raising resistance and concerns about modifications to the body after death (Long, Sque and Addington-Hall, 2008; Walker, Broderick and Sque, 2013a). The potential donor's (sometimes presumed) donation attitude played a role (Long, Sque and Addington-Hall, 2008; Walker, Broderick and Sque, 2013a), with prior conversation or information on donor card carrying/donation registration making consent more likely and uncertainty acting as an inhibitor. A lack of consensus among relatives, a feeling of overwhelming emotional and physical stress and the idea of disturbing the body inhibited willingness to donate (Walker et al., 2013). Where there was a perceived moral duty or strong conviction that supported donation and the desire to help others in need, donation became more likely (Long, Sque and Addington-Hall, 2008; Simpkin *et al.*, 2009; Walker, Broderick and Sque, 2013a). A systematic review by Golding and Cropley (2017) highlights the positive impact community interventions can have on increasing levels of donor registration, frequently relying on strategies to modify behaviour and engaging with local leaders. Similarly, public health information community-based education campaigns as a means of addressing concerns about donation associated with religious beliefs about the afterlife or misconceptions about who can donate to target specific groups have been identified as a promising means of raising support for donation (Walker et al., 2013). Additionally, a systematic review by Molina-Perez and colleagues (2019) has determined that in Western countries with an opt-in system for organ donation, indicated knowledge of the consent process were higher than in opt-out countries, and that donation attitude conducted in opt-out countries worked with smaller samples and focused on societal subgroups rather than overall populations. The findings from these studies provide a robust overview of factors that can influence both hypothetical donation attitudes, the factors that can influence the decision to refuse or consent to donation in hospital settings, and the way these factors influence the donation experience overall. However, they often over-emphasise the relevance of reported donation attitudes and behavioural interventions for donation decisions and focus primarily on information intended to reveal how more relatives of potential donors can be persuaded to consent. This makes room for the creation of subgroups about which generalised statements are made in terms of donation preference, leading to the shaping of expectations of donation attitudes based on the physical characteristics of the donor and their relatives. Additionally, a binary distinction is often drawn between the experiences and aims of health professionals and those of deceased-donor relatives, largely omitting more complex relational exchanges that can come to influence their interactions. The importance of variable personal circumstances and long-term impacts of the decision to consent or not to consent are less frequently explored.

Despite this, public health campaigns have taken clues from previous research findings, drawing on insights from quantitative and qualitative research, as well as public and patient engagement work, they conduct themselves. Public Health Campaigns create narratives that aim to educate the public, share stories from individuals who were affected by organ donation, and create narratives designed to emphasise the good that organ donation can do and to promote conversations about organ donation and the registering of a donation decision among members of the public. NHSBT has developed information materials to educate the public and encourage conversations about donation preferences following the change to an opt-out system for organ donation in England. NHSBT campaigns seek to address disproportionately lower rates of consent among some religious groups and ethnic communities by providing information materials. Frequently, an emphasis is placed on the number of people waiting for an organ and the potential for a significant improvement in quality of life and chances of survival a transplant can offer. Additionally, the decision to donate is frequently presented as a rewarding way to remember a deceased relative by a positive choice, often described as "*the gift of life*" and "*heroic*". The social media pages run by NHSBT (Instagram: @nhsorgandonor) share stories about the successes of organ donation, emphasising the improvements in health and gratitude among recipients who received a donor organ and the pride and contentment about the decision to donate among donor relatives who consented to deceased donation (Figs 1 & 2).

Figure 1. (NHSBT, 2023)

Key messages on the NHS website describe organ donation as the "*gift of an organ to help someone who needs a transplant*" (NHSBT, 2023e). They provide information on the organs that can be donated, how many lives can be changed or improved, and that donation is a choice. Campaigns stress the great need for donation among those waiting for a transplant and highlight the need to increase donation rates among Black and Asian patients as a priority to reduce longer wait times for people with these ethnic backgrounds. Crucially, they emphasise the need for family consent and stress the importance of ensuring that the family knows a person's donation preference (Fig. 3).

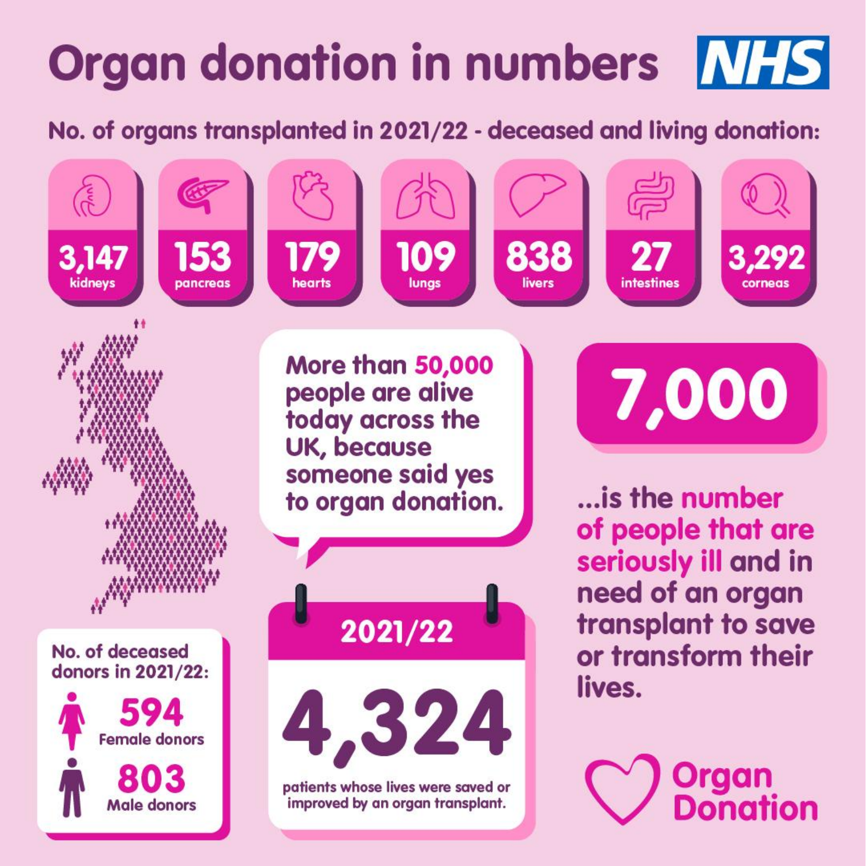

Figure 2: Public Information Statistic (NHSBT, 2023)

Figure 3: Poster campaign (NHSBT, 2023)

Furthermore, materials address possible concerns about the legal definition of death and combat fears that donation consent could lead to the cessation of life-saving treatment before the person has been declared dead. Individuals are told that medical professionals will continue to treat the body of the deceased with great care after consent to donate is given, and there is an emphasis on the possibility of recording additional requirements /requests for organ removal in line with personal beliefs.

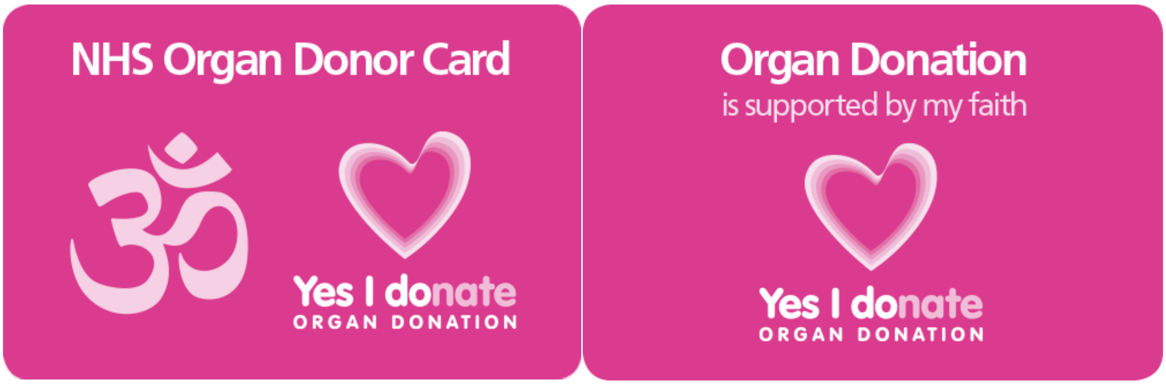

Figure 4: Faith-based organ donor card (NHSBT, 2023)

The NHSBT website includes information materials personalised for members of different faith groups, and faith-based organ donor cards are available to reflect this. For example, a number of leaflets disclose details on how a particular religion views organ donation and testimonies from religious figures of authority that explain their interpretation of the permissibility of organ donation in their faith (NHSBT, 2023a). Together with information emphasising the possibility of donating some, but not all, organs, these details address concerns about a loss of control over the donation process individuals may have after they consent to donation. The NHSBT website also includes links that allow people with a story about organ donation to get in touch and be represented on their social media channels but stress what risks the sharing of one's story might entail. Individuals are encouraged to share a personal story mainly because of the high impact personal stories can have on public opinion. Much of the focus of both research, public health interventions, and campaigns to date has been on preparing members of the public for the decision to donate. Notably, the driving factors believed to influence the decisions of individual persons are thought to be impacted by moral beliefs, religious beliefs, ethnic background, and degree of education on the topic. The narrative themes and symbols that the National Health Service draws on in its rhetoric about organ donation is discussed in greater depth in chapter 3.

To highlight the risks associated with an overly heavy focus on some of these themes, I draw on the following example: Organ donation information campaigns in recent years have focused on the question of how to achieve higher rates of consent from members of minority ethnic groups. The background to this is the higher likelihood of an organ being compatible for transplantation for a person of a similar ethnic background, and that the need for an organ transplant is greater for people from an ethnic minority background, whereas rates of consent are lower. As a consequence, there have been efforts from community groups and people at NHSBT calling on people belonging to these groups who are perceived to be reluctant towards organ donation but have a greater need for donor organs to mobilise their communities, to educate them on the need for organ transplantation, to offer education and discussion on perceived religious obstacles to organ transplantation, and to campaign to encourage conversations about organ donation (organdonation.nhs.uk, 2019, 2024). However, ethnographic research in England has indicated a need for caution around the classification of persons from a minority ethnic background as more likely to be opposed to organ donation and more difficult for specialist nurses to approach. In a recent ethnography exploring the UK context of hospital processes surrounding organ donation requests, Kierans and Cooper (2013) show that donor characteristics can influence staff expectations of how challenging the conversation about consent might be. Their research revealed that the notion of a problematic ethnic donor caused a bias and impacted how the donation approach was made. Kierans and Cooper were able to emphasise the role that biased interactions between hospital staff and donor relatives could play in the final donation decision (Cooper and Kierans, 2016). This example demonstrates what ethnographic research can add to the quantitative and qualitative literature discussed in this introduction to date and highlights ethnography's strengths in terms of revealing the unintended consequences of health services practice. Rather than seeking to categorise and simplify the circumstances and long-term effects of the donation decision, ethnographic research can better accommodate the complexity of the donation experience and articulate the nuanced tensions and the unexpected insights hidden within them. Ethnography allows for a deep, contextualized understanding of how organ donation is experienced and understood by families within their broader cultural, social, and familial contexts. It captures the day-to-day realities and emotional complexities that cannot be fully understood through surveys or structured interviews and reveals the relational dynamics between the donor, the donor's family, and the recipients, and the healthcare providers and third sector organisations involved. Ethnography, with its holistic and culturally sensitive approach, provides a more comprehensive and nuanced understanding of organ donor relatives' experiences, making it the most suitable methodological approach for researching this topic. By focusing on the lived experiences within specific social and cultural contexts, ethnography offers the potential to uncover the deeply personal and relational aspects of organ donation that are often overlooked in other research methods. To illustrate how the ethnography conducted for this study relates to previous ethnographic work on the experiences of organ donor relatives in the short and long-term, I will provide a brief overview of notable ethnographic contributions to the field.

Notable ethnographic insights into sociocultural attitudes and experiences in relation to organ donation have emerged in Australia (Zivkovic, 2022), Sri Lanka (Simpson, 2020), Iceland (Árnason, 2020), Japan (Lock, 2002), Spain (Bea, 2020), Denmark (Jensen, 2016), the United States (Jensen 2011; Lock 2002; Sharp 2006), Iran (Lalegani *et al.*, 2023) and the United Kingdom (Kierans and Cooper, 2013; Machin *et al.*, 2022). Zivkovic (Zivkovic, 2022) explores organ donation as in terms of various relational tensions brought about by definitions of death that coexist and yet contradict each other in the organ donation space in Australia, and that are being attempted to be navigated, in her field site, to better align with the faiths of Buddhists at a Melbourne temple. She unpacks how various symbols, including the notion of organ donation as a gift, are drawn on to characterise the death that occurs during the donation process in ways that amalgamate conflicting sociocultural understandings. It is the close attention to the nuances in beliefs and cultural groups and the dynamics at play at events designed to promote organ donation that Zivkovic interacted with during her fieldwork that allows her to provide an account of how this framing of organ donation is curated. Similarly, in his work on eye donation in Sri Lanka, Simpson (Simpson, 2020) reveals through an account of the process by which eye donation is promoted and carefully meaningfully orchestrated to align with Buddhist beliefs. Here, poignant familiar Buddhist stories about benevolent selfless giving are incorporated into charity narratives aimed at raising awareness and facilitating organ donation support. Cultural factors, knowledge about the donation process, powerful cultural narrative, social recognition and the incorporation of death rituals are revealed to produce much higher eye donation rates. Simpson's work analyses the use of powerful embedded donation narratives that have led for very widespread support for eye donation through the unique insights into the rhetoric at play in the practices surrounding death that have been mobilised by a donation charity that his ethnographic fieldwork could facilitate. Lock has conducted comparative sociomedical anthropological work in the United States and Japan (Lock, 2002). Her work reflects on the contrasting ways in which brain death is communicated in Japan and highlights the ways in which the biomedical definition contradicts local understandings of the less distinct boundaries between life and death. She unpacks how organ donation as the gift of life constitutes a less powerful metaphor in Japan, and problematises how the orchestration of brain death in ICU settings can feel less tangible or less real to people with different sociocultural understandings of death. In her ethnography, she draws on insights from participant observation and interviews in both countries and discusses them in the context of public debates on the topic to combine her multiple sources into a compelling and multi-facetted account. Ethnographic work by Anja Jensen in Denmark and the United States has explored how the way hospital staff interacted with the deceased body and the family members impacted the experience for relatives, particularly in terms of a sense of hope that is relevant throughout the process (Jensen, 2016). In her comparative work in America, Jensen outlines how donor-relative care organisations seek to help donor relatives process what happened during the donation through positive rhetoric, casting the promotion of organ donation as their secondary goal. Through combining observations in intensive care units with longer term follow-up interviews with deceased-donor relatives reflecting about the way consenting to organ donation affected their life, Jensen provides a long-term insight into the effects of the donation experience on the surviving relatives (Jensen, 2010, 2011, 2016). Similarly, ethnographic fieldwork work by Bea has provided additional insights into how the embeddedness of organ donation in everyday care procedures has made donation less of a separate moral choice and instead transformed it into a part of the care provision and treatment for potential donors (Bea, 2020). Bea emphasises how organ donation is contextualised and routinised through its increasing incorporation into hospital processes surrounding death in a Spanish hospital. These ethnographic contributions demonstrate a shift away from the simplistic accounts of donation that analyse the decision through an attitude-based or behaviouralist lens, instead inviting in more complex and holistic insights into context-bound experiences in different settings and with distinct personal circumstances. The piece of work that is most similar to what I present in this study is an ethnography on the long-term post donation experiences of deceased-donor relatives in the United States entitled “Strange Harvest: Organ Transplants, Denatured Bodies and the Transformed Self” (Sharp, 2006). In it, Sharp considers the ways in which non-profit organisations and interest groups constructed a National Donor Memorial, created ways to meaningfully contemplate the loss whilst framing donation as a positive and describing the impact of organ donation on the remembrance of the donor. Additionally, she draws on insights from participant observation to draw out the relational tensions, expectations and connections that exist between the surviving organ donor relatives and the recipients, and outlines how deceased-donor relatives embody their “organ-driven identities” (Sharp, 2006, p. 159) through their attendance at transplant sport events. Remembrance quilts and rose bushes in a garden for deceased-donor relatives are described alongside the rationale with which they were designed, and linked to transformative effects on the mourning process through the lens of organ donation outlined (Sharp, 2001). She links the long-term memorialisation of the deceased in the American Transplant Community to a sense of never-ending loss that connects to the frequent recounting of the death of the deceased through the narratives that connect to the donation events, tied into an ambiguous sense of distanced anonymity and imagined relatedness towards the recipient. Her work powerfully illustrates how ethnography is uniquely well-placed to capture the complex interplay of experiences, symbols, identities, memorialisation, narration and relational interactions through which post-donation deceased-donor relative experiences can be assembled. In contemporary England, the local context for this study, similar factors are at play in the provision of deceased-donor relative post-donation support and the production of meaningful donation narratives for public engagement and advocacy. The shift to the new deemed consent legislation places the responsibility to make a decision about organ donation on the nominated representatives or the surviving relatives of the deceased. However, no projects have examined donor relatives' involvement in shaping the transplant community, organ donation campaigns and donor-relative support groups in contemporary England. My aim in this research has been to use an ethnographic approach to help address these gaps in the literature. Although there have been several attempts to investigate how the decision to agree to organ donation influences the experiences of grief for donor relatives, the methods used to do so have often provided simplistic snapshot impressions rather than more nuanced accounts. The mechanism by which donor relatives in England access support services and receive communication following donation has seen little comprehensive evaluation. What is not yet clear is the impact that the reflections about the donation and its effect on the lives of surviving relatives have had on the local public's broader attitudes towards organ donation. Despite the long-standing involvement of deceased-donor relatives in educational campaigns, policy development and support provision, little is known about how they shape policy and practice. This hiatus points to a need to explore the different experiences and perspectives of the deceased-donor relatives affected and to understand the impact the donation decision can have on their lives post-transplant and their role in the current public education strategy in England. Therefore, the central aim of this thesis is to learn more about the recollected experiences of donor relatives in England both immediately before, during and after the donation – to better understand the situation they are put in by our current system and the actors that impact upon their experiences. Specifically, this thesis focuses on the experiences that occur after consent to donate has been obtained. In contrast to the existing literature, this ethnographic study focuses on the long-term impact of consenting to organ donation in England on the relatives of deceased organ donors. To achieve this, the thesis explores the different narratives that appear when organ donation is discussed from distinct perspectives and contextualises them with crucial contextual information about the post-donation support landscape. It is hoped that the emerging insights can indicate how deceased-donor relatives could be better supported at various stages of the donation process, how members of the public could be better prepared for the event of being asked to make a donation decision, and how past donation experiences and interactions with the transplant community might influence future donation attitudes. During this research, several questions and problems emerged, contributing to my understanding of deceased-donor relatives' lives following donation decision-making on behalf of a relative or friend. The explanation given below by one of my interlocutors underlines why this is the case. When speaking to me, Kathy, the mother of a deceased-donor, described how she felt about organ donation using a metaphor:

> *At the end of the day, we are all looking at something from different sides. It is like organ donation is a statue in the middle of the room and we are all looking at the statue from different angles.*

As Kathy suggests, there are multiple standpoints among those affected by organ donation. Consequently, my thesis comprises some of the different settings and activities that donor relatives may experience.

Each of the chapters in the thesis will address an important problematic that emerged in the research. In this thesis, I draw on several key anthropological concepts, including the gift (Mauss, 1954; Konrad, 2005; Bolt, 2012; Titmuss, 2018; Sprenger *et al.*, 2023), communitas (Turner, 1967, 1969, 2012), dividuality (Bird-David and Israeli, 2010; Appuhamilage, 2017; Mcintosh, 2018; Davies, 2020) and anonymity (Konrad, 2005; Baumann, 2017). During this discussion, a support and education network run by a number of proliferating intermediaries will emerge as what will be referred to as the bricolage that makes up the "*transplant community*" – the pieces that make up the figurative statue.

Consequently, each chapter of the thesis answers one of the central questions that emerged during my research. Chapter 2 provides information on the methods used throughout this project and sets the scene for the subsequent discussion of findings. Chapter 3 constitutes a background chapter and details how the services and initiatives that make up the deceased-donor relative support network are intended to affect the lives of deceased-donor relatives, drawing on both my findings and relevant background literature. The subsequent chapters are not findings chapters, but instead comprise the discussion of findings grouped by emerging key themes and combine them with the analysis of the date generated during fieldwork. Therefore, each chapter offers a discussion of how the findings from the research undertaken for this thesis can be understood in the context of the existing literature. Chapter 4 addresses how relationality in the hospital setting can influence the decision and how the relational status of the donor body in the relatives' minds affects interactions with hospital staff and procedures. Chapter 5 explores to what extent charities can provide a specialised support service to deceased-donor relatives and how the delivery of complex support by volunteers outside the professional sector is limited. Chapter 6 addresses how the notion of organ donation as a gift of life, that is, one that intimately links the donor and the recipient, can be reconciled with the legal requirement for anonymity. Chapter 7 discusses how charity organisations attempt to create spaces of belonging, memorialisation and solidarity and explains how these spaces can influence the self-understanding of donor relatives as parts of a wider transplant community. Finally, Chapter 8 expands on how donor relatives become volunteers, providing an educational workforce for the national health service and its efforts to promote organ donation. The chapter considers how the spaces for voices amplified in this way may shape public donation discourses. Throughout the thesis, the term "*grief*" is defined in line with the understanding posited by Corr & Coolican, who state that "*grief is the term that indicates one's reactions to loss*" and is "*experienced when one encounters a significant loss, which may or may not be a loss that is related to death*" (Corr and Coolican, 2010, p. 170). Therein, it is implied that the reactions and experiences characterised in this way can express themselves both physically and emotionally and may occur along different time periods, with varying intensity and individual contexts, circumstances and personal characteristics of my interlocutors. Consequently, the examples of the effect of organ donation and the impact the decision to consent had on their grief following their loss are intended to illustrate the significance organ donation attained for them. They are not intended to infer that the grief of others could predictably be shaped in the same way, given their unique contexts.

2. Methods

My primary aim in this research was to learn more about the recollected experiences of deceased-donor relatives in England both immediately before, during and after the decision to consent to organ donation. To achieve this, I wanted to better understand the situation deceased-donor relatives are put in by our current system and the actors that make up that system. Rather than prioritising an investigation of the factors that impacted the donation decision itself, this thesis considers the long-term impact of the donation on the life of the surviving relatives following the loss of the donor. I have sought to reflect on the different narratives that appear when organ donation is discussed from distinct perspectives, that donor relatives are exposed to through contact with the transplant community, and to investigate how these narratives are influenced by volunteers and support providers with lived experience of the donation process. Previous ethnographic studies on organ donation have demonstrated the need to employ qualitative methods that can accommodate the complexity and specificity of organ donation experiences. My work expands on these studies but takes place in the wake of the deemed consent law that has been enacted in England, which asks the deceased's relatives (or other individuals nominated by the deceased during their lifetime) to take the final donation decision. Therefore, the new law has intensified the need to better understand what deceased-donor relatives experience during and after the donation process to gain an understanding of what narratives and considerations can help prepare and educate members of the public for the possibility of being asked to decide about organ donation. During my research, I have spoken to relatives who consented to organ donation on behalf of the potential donor before and after the new law was enacted. I have endeavoured to find out more about what influenced their experience, what meaningful support they have themselves received or provided to others, what narratives and experiences brought them comfort, and what about the process following the donation they found challenging.

The underpinning methodology for this was chosen in the context of the existing literature and the circumstances surrounding my research summarised above. I conducted an anthropological ethnography which focused on thick description and drew on the ideas of patchwork ethnography and messiness in ethnographic research. The notion of "*thick description*" was most notably developed by Clifford Geertz (Geertz, 1973). According to thick description, it is the task of the ethnographer to help the reader make sense of the field site and the experiences of the subjects represented in their ethnographic account. In Geertz's own words, this requires the ethnographer to "*reduce the puzzlement [...] to which unfamiliar acts emerging out of unknown backgrounds naturally arise*" (Geertz, 1973, p. 16). In doing so, the ethnographer outlines relevant structures and shows how they come to life, interprets everyday ways of life and describes how cultural meanings manifest themselves and are produced. As Luhrmann articulates, ethnography consists of long-term participant observation and requires the author to try and capture the ways in which the sociocultural worlds of one's field site function (Luhrmann, 2001). The ethnographer tests their account through engagement with materials and documents produced by their interlocutors, through extensive self-reflective practice in relation to the insights gathered during their fieldwork and their own positionality, and through the peer-review of their work (Luhrmann, 2001). Thick description elevates an account from an anecdote to a piece of ethnographic research, by producing very detailed, well-reported notes that demonstrate an excellent understanding of the field. Social processes must be captured, and a persuasive interpretative account that is capable of making "*the foreign world comprehensible to the reader*" (Luhrmann, 2001) must be produced, and must not seek to verify a hypothesis at the outset, but instead allow the insights to emerge from their observations. In this study, the long-term, continuous observation of a stable field site was not possible for three main reasons: the research began during the global Covid-19 pandemic which prevented in-person contact, the research did not receive external funding which significantly limited the monetary resources available to support the work, and the interlocutors for this research do not cohabitate in a singular stable setting, but instead return to their everyday lives after becoming donor relatives. I draw on the idea of patchwork ethnography outlined by Günel & Watanabe (Günel and Wtanabe, 2024) to reconcile these circumstances of my work. Patchwork ethnography describes fieldwork that is non-continuous and interwoven with the personal responsibilities and various other roles the ethnographer has to accommodate during their research. In a nutshell, it describes the act of "*accommodating one's personal realities in fieldwork*", and makes the case that a more reflective and accurate ethnographic account can be produced if this is made explicit to the reader (Günel and Watanabe, 2024, p. 1). Rather than presenting a stable field site and the ethnography as an uninterrupted immersive observation, the process of exiting and re-visiting the field, reflecting on data slowly and in other contexts, and the relational entanglements of the researcher are better accounted for in this way (Law, 2004; Günel and Watanabe, 2024). In the ethnography at hand, I have done my best to reconcile the messiness and variability of my work with the truest account shaped by thick description I could produce with the sources of data that were available to me. In line with an argument made by Law, one could argue that the messiness of my drifting between my day-to-day life, interviews, document analysis and more immersive participant observation resembles the patterns of engagement with the topic of organ donation experiences by my interlocutors. Law posits that "*simple clear descriptions don't work if what they are describing is not itself very coherent*" (Law, 2004, p. 2). Therefore, to contextualise my research, I outline some of the uncertainties I faced during my work and how these influenced the direction of the insights I was able to gather (Boulus-Rødje, 2023). Consequently, rather than framing this variability as a problem, I present it as a feature that is indicative of the unpredictability of everyday life that was widespread during my work, seeking out opportunities for insights from each of the various spaces I encountered and welcoming heterogeneity in my materials rather than attempting to minimise it (Pappagallo and Semplici, 2020). One feature that has bound my interpretations of the observations I gathered together were the emerging narratives that were at play across the documents, interviews, symbols and sites I interacted with. By thinking carefully and closely about the ways in which these accounts were interwoven and how they came into play in the passive and active construction of the identities of people (Fikry, 2022) in their capacity as donor relatives, I arrived at the themes that now make up my thesis. Figure 5 illustrates how my research process and data collection strategy unfolded under conditions of variability in the context of these considerations and constraints.

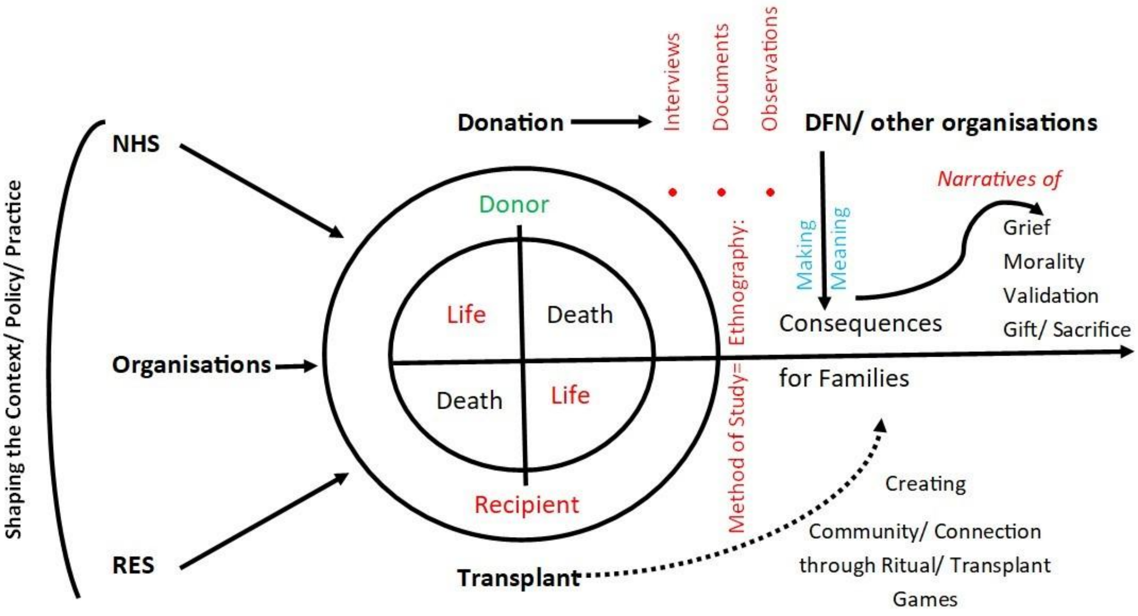

Figure 5: Research Process Graphic

I began the project in 2020, during the COVID-19 pandemic, as a self-funded student with little additional funds beyond the allocated department research allowance available to help finance travel and related activities. Consequently, the project was initially designed with a wide range of possible opportunities for qualitative data collection in mind, which could be adjusted depending on what was possible given my circumstances. A vital consideration of the original project was the different kinds of rhetoric used in public health campaigns to encourage members of the public to think about organ donation. I am originally from Germany and had noticed that German health campaigns appeared to place a greater emphasis on informing the public in a less emotive, matter-of-fact way about their responsibility to decide whether they wanted to donate an organ compared to the much more emotive public health campaigns in England that used much more expressive language. For example, the contrast between the German slogan "*Die Entscheidung zählt*" ("*The decision counts*") and the English slogan "*Leave them certain"* was notable in the way one emphasised a matter-of-fact personal duty to decide. In contrast, the other encouraged individuals to contemplate a situation in which one's relatives were asked to decide on organ donation and left uncertain about the donation preference of the deceased. There is a relational difference between these two slogans. While the German slogan emphasises individual responsibility, the English slogan draws in unspecified others, which can be read as a reference to the surviving relatives in the context of the law. Therefore, one starting point for the project lay in the qualitative analysis of rhetoric used in organ donation information and promotion campaigns in England.

Document analysis was used where participants or field sites could not be accessed directly. Additionally, I had noticed an exceptionally high willingness among private individuals to get involved in charitable activities and to speak publicly about causes that were important to them. This was happening in the UK on a grander scale and in a more personal way than I had observed in Germany. I was intrigued by the roles of volunteers and charities in the discourse around organ donation in England. I wanted to use narrative interviews and in-person participant observation/ethnographic fieldwork to learn more about their experiences of that work and their reasons for participating. Moreover, I wanted to join any in-person gatherings of deceased-donor relatives that would give me a better understanding of how they interacted among themselves and came to think of themselves as a transplant community.

Because less research was available on the experiences of donor relatives following the donation and how the decision they made impacted their lives, I wanted to speak to deceased--donor relatives. This was mainly those who put themselves suggesting they were comfortable with the idea of discussing the bereavement. The research undertaken for this PhD thesis has received ethical approval from the ethics committee of the Department of Anthropology at Durham University in autumn 2019. Due to the sensitive nature of the subjects discussed for this research, the ethics committee made the approval granted conditional on measures taken to ensure that the interlocutors for the research would not be asked to speak about a difficult event unexpectedly or be caused serious distress as a result of the research activity. Therefore, it was agreed that the subject of organ donation should be discussed with people who often speak about their experiences of organ donation publicly and who are accustomed to discussing the subject as part of their work in donation advocacy and support organisations. Additionally, it was agreed that such individuals could act as gatekeepers to potential participants by sharing the information about the research with their members and passing on the details of those who wished to be contacted to discuss the subject. The main gatekeeper that was engaged with for this research and the group who supported the recruitment of many of the interlocutors interviewed was the Donor Family Network.

As with all research involving gatekeepers, the readers of this thesis are asked to be aware that the views shared by many of my interlocutors are indicative of people who have had some contact with the transplant community in the UK, who have the capacity to engage in advocacy work and should not be considered hard to reach individuals in the transplant space. Instead, it can be said that their perspectives are among the more frequently shared views and heard voices in the transplant space. To ensure the project was conducted ethically, information and consent materials in accessible language and more detailed documents on data collection, anonymisation and storage were developed to be shared with participants. When discussing the inclusion of statements willingly quoted on information websites about organ donation that included photos or names of potential participants, there was an awareness that some information on participant characteristics and some direct quotes would need to be left out to minimise the risk of the anonymised recipients becoming identifiable.

Data was collected between November 2019 and August 2023, through in-person and remote interviews, document analysis, fieldwork was conducted at the British Transplant Games, the European Transplant Games, Donor Family Network Fundraising Events and the Donor Family Network Memorial Service. Data collection was impacted by the Covid-19 pandemic and the self-funded nature of the research, which limited the opportunity to travel and conduct in-person participant observation. The in-depth interviews conducted used an approach akin to that of narrative interviewing and were guided by the account of the donation experience that the participants wanted to share, allowing them to construct narratives that situate their experience in the context of the realities they inhabit (Riessmann, 2008). The aim was to enable interviewees to control the focus of the interview and to not feel a need to respond for pre-determined prompts (Riessmann, 2008). This method of interviewing focuses on narrative because it posits that narrative helps things present themselves more clearly in our understanding of the world (Bruner, 1986). While narrative can be defined differently in distinct disciplines, Riessmann emphasises that the term universally refers to a series of common factors. More specifically, attention to a recollected sequence of actions, choices of words and narrative style, a degree of concern with the audience’s response to the account, and, to some extent, the interpretation of one’s identity in a particular context (Riessmann, 2008). Consequently, exchanges with my interlocutors were narratively shaped by them as much as possible.

Once ethics approval for the research was obtained, I began to reach out to relevant charitable organisations. One notable organisation I had identified was the Donor Family Network. I sent them some general information materials about my project alongside an email requesting further information on the activities and functions of the charity. I soon received a reply and the opportunity to meet two representatives running the charity as they travelled through Durham. The first conversation with these two representatives significantly impacted the project's subsequent course because they could highlight suitable organisations. Furthermore, they offered to act as intermediaries between me and the people that the charity was in contact with to see if any of them could be approached for the project. Among other things, the conversation led to the identification of the Precious Gift Memorial Service and Transplant Sports as opportunities for data collection. These annual events, a memorial service and sports meetings, later proved to be opportunities to meet people from different parts of the transplant community. I also learned about the Organ Donation Ambassador initiative and became aware that speaking to the volunteers involved in that programme would be helpful.

Subsequently, several opportunities for further data collection were scheduled. Depending on the participant's preferences, I conducted several in-person interviews over the phone and on password-protected Zoom chats. In all cases, the participants were given my project and contact information and invited to indicate their interest in a conversation, with the Donor Family Network often facilitating the initial contact. Participants were informed of how their insights would be used, and care was taken to ensure no details were included in my account that participants did not want to be made public. At the beginning of the interviews, I briefly explained what research I was conducting and ensured that the interviewees were aware of the information in the privacy notice and information sheet and had given their verbal or written consent. In some cases, I requested permission to record the interview for transcription, in other cases, I relied on handwritten notes in a notebook, depending on the situation and the interviewees preference. The participant information sheet was shared in advance to give the interviewees some idea of what I wanted to find out more about. In most cases, once the opening question was asked, subsequent questions emerged as a reaction to the accounts shared by the interviewees. Frequently, interruptions were minimal and avoided questions that would re-direct the conversation, instead seeking to delve deeper into the information that the participants introduced to the conversation. After the interviews concluded, I would, depending on the setting, record a number of quick reflections on my dictation device or in my notebook to capture how the interview had felt for me, how the interviewee had seemed to feel about me and the information discussed, and any other immediate impressions that I may have forgotten had I not recorded them in the moment.

In total, 13 recipients were interviewed for this research, with many more informal chats taking place at the transplant sport events that were attended. In total, 24 donor relatives who consented to organ donation on behalf of a deceased relative were interviewed, as well as additional informal opportunities for conversation and participant observations and collection of fieldnotes taking place at the observed events. For 19 of the 24 donor relatives interviewed, the Donor Family Network acted as an initial point of contact. Additionally, 5 third party organisation support providers who work with recipients and deceased donor relatives were interviewed. Where requested, I shared a summary of my notes with the interviewees to allow them to confirm that I had understood them correctly and to ensure that they were happy for the information that they shared with me to be used in my text. Informed consent was obtained prior to the commencement of the interviews and the interviews lasted between 20 and 180 minutes. I contacted the individuals running the Organ Donation Ambassador programme and the Jewish Organ Donor Association via email. Following the phone calls with both organisations, I shared a summary of the notes I had taken for approval to ensure the organisations were happy for me to use the material I had gathered in my research. I conducted fieldwork at the British Transplant Games in 2022 in Leeds (four days) and in 2023 in Coventry (two days), where I worked as a volunteer in both cases. Each time, I indicated my role as a researcher on the registration and signed forms, which allowed me to take photos at the events. The event venues also included several signs informing participants that reporters and researchers were present and that pictures might be taken. The period of data collection was brief but intense in both cases. It allowed me to feel immersed in the world of transplant sports to such a degree that I hope to continue attending as a volunteer to support the event in future years.

The short time frame worked very well for me for two key reasons: first because my limited research budget could only stretch far enough to cover travel and transport, and second, because the experience of intense immersion followed by relative normality mirrored the experiences of the donor relatives, living donors, recipients and recipient relatives who were in attendance. I frequently used a recording device (Olympus Digital Voice Recorder, VN-713PC) to record observations spoken out loud. I rarely had time to write field notes immediately and needed to ensure the rich tapestry of observations and conversations I experienced did not escape my memory. "*Taking notes*" by speaking into the recorder after finishing my conversations with my interlocutors allowed me to stay more present in the moment and to blend into the surroundings more seamlessly. As highlighted by Laube, looking too much like a researcher can impact interactions and perceptions of the researcher in the field because it makes them look more noticeably different and constantly reminds participants of the reason for their presence (Laube, 2021). Therefore, this method of collecting field notes proved less disruptive, more time-efficient, and better suited to my active involvement in volunteer work during the event. Each day, I transcribed the recordings later in the evening to formulate field notes. Following the British Transplant Games, I attended the European Transplant Games in Oxford in 2022, consisting of organ recipient representatives for different national teams who had arrived to compete in competitions with higher proficiency. This event proved to be less decease-donor relative and less grief-focused. Few donor relatives attended the European Transplant Games. Instead, I sat down with several German Transplant Sports Charity Transdia members for an informal focus group discussion. We reflected on differences and similarities in rhetoric and public information on transplantation in England and my native Germany. Later in the year, I attended the Precious Gift Memorial Event, run annually by the Donor Family Network at the National Memorial Arboretum, also home to the Gift of Life Memorial for organ donation.

I attended as a quiet observer after the Donor Family Network invited me. I was anxious not to disrupt the event in any way for those in attendance who were there to commemorate a deceased relative. I greeted some of the donor relatives I had previously spoken to and thanked those who had supported my project by agreeing to be interviewed. I gave each of them a small hand-drawn thank-you card. In the background, I stayed quiet and took in the atmosphere at the event. I refrained from initiating conversations, opting to quietly gather field notes instead. Following the memorial service, coffee and cake were served, during which time members of the Donor Family Network who knew that some attendees were interested in speaking to me about their experiences approached me. I only spoke to donor relatives about the grief at the event after having been invited. Before I left, I visited the Gift of Life Memorial statue in the gardens to reflect on its significance for the people in attendance and to observe its design and message. The period of fieldwork was again very brief but rich in the insights it provided. The amount of help and support I received from the Donor Family Network placed me in a position where data collection on the factors influencing deceased-donor relative experiences further intensified my desire to ensure that my conclusions were useful to the organisation and its members.

The process used to produce an analysis of the interview data and of my fieldwork took inspiration from the process of thematic analysis (Terry *et al.*, 2017; Braun and Clarke, 2022). The aim of the analysis was the identification of themes in the qualitative data that was being analysed. A method akin to thematic analysis was used as a tool to engage reflexively with the data in the synthesis of this thesis. In doing so, the theory facilitated the critical engagement with the experiential accounts of the participants with an analytical gaze. Throughout the engagement with the data for this thesis, I have prioritised depth of engagement. The version of thematic analysis that inspired this thesis is a qualitative one, which can accommodate the positionality of the researcher by moving from a process of immersion through familiarisation with the data to iteratively emerging themes through subjective interpretation (Terry *et al.*, 2017; Terry and Hayfield, 2021). Therein, the depth and complexity of the data emerge as a means of enhancing reliability in the data, which interplays with the researcher's positionality through an inductive approach. In this method, theory and meanings emerge from the themes through semantic analysis and conceptual structuring of the data, producing a reflexive account through deep engagement (Terry et al., 2017; Braun and Clarke, 2022). Consequently, when I began to produce the interview recording transcript or to look at my detailed handwritten notes of what was said, I relied on the contextual information I had captured in my situational notes taken before, during and immediately after the conversations. These notes served as a reminder of my own state of mind and of the flow of the interview, pauses, objects that were shown, or facial expression that I believed gave me a sense of the interviewees emotional state. The material supplemented and completed the details I was able to recall from memory, in order to ground the process of transcription at a later date in my interpretation of the conversation in the moment, rather than just my interpretation of the transcript amid re-engagement with what was said. I found it helpful to transcribe my interview recordings myself instead of using software because it allowed me to maintain a more personal connection with the material and familiarise myself with it more intimately. I allowed myself a great deal of methodological freedom in the way in which I explored connections between different pieces of information and looked to identify emerging themes, frequently relying on mind maps, schematic drawings and conversations with others to reflect on the connections between the breadth of material and topics this thesis combines. To begin the analysis of all interviews, I would firstly re-read my "*situational notes*" to remind myself of the way the interview had felt, before subsequently working on the transcription of the recording or reading through my notes. Whenever I encountered notable statements, anecdotes or themes that I had questions about or that had been highlighted as a particularly important aspect of the donation experience, I would use coloured pens to highlight them in the text. I would add any questions, impressions or symbols either on the printed text itself or on a piece of paper next to me. At the end of each interview, I compiled these colourful thematic notes into a summary account and highlighted the parts of the interview that they corresponded to. Once I had produced these synthesised versions of the interviews, I had usually read over the details enough times to remember the accounts in great detail. To draw out cross-cutting themes as well as diversities of experience, I assigned all of my interlocutors' pseudonyms for the purposes of this research and omitted additional personal details where they could have compromised the anonymity of the participants. The documents analysis was used to help me contextualise the wider context around my findings and to evidence supplementary information that I became aware of during my fieldwork. My PhD is an interdisciplinary study and my first experience of working independently with qualitative data collection methods. I studied Philosophy, Politics and Economics for my BA degree and completed an MSc in Public Health which covered an introduction into qualitative methods for health research before commencing my PhD project in Anthropology.

Throughout my work on this thesis, managing my own positionality as a researcher was a primary concern, particularly because I was working as a volunteer and with gatekeepers (although they did not frame themselves as such) during much of my ethnography. In doing so, the considerations posited in relation to the idea of a "*stranger*" entering a new setting brought forward by Schuetz (Schuetz, 1944) helped me reflect critically on my interactions with my interlocutors. Since I was a German student studying a group of people in England whose personal experiences I had no prior connection to, like the stranger Schuetz described. I went through a process of questioning my interactions, reflecting on what was meant by behavioural and semantic queues and tried to uncover unfamiliar group dynamics and symbolic and sociocultural patterns. Since I had lived in England for four years by the time I began my PhD research, I was not entirely unfamiliar with the customs of the country, especially since they did not differ drastically from the rules for social interactions in my hometown of Hanover. However, the Covid-19 pandemic amplified the sense of unfamiliarity with what was and was not appropriate, with both my interlocutors and I finding our way back into physical meetings with others, speaking with new people for the first time, and attending large events in a post-Covid world after lockdown.

Like the stranger, through the process of entering into contact with a group of interlocutors who I had up to this point only read about, I underwent a process of beginning to compare my interactions with the people I was meeting with the expectations I had for the meetings based on my previous experiences. I began to encounter disjuncture in the accounts of the experiences and perspectives of deceased-donor relatives that were being shared to me, and saw similarities and differences between the rhetoric that was being used to drive the promotion of organ donation and the symbols and perspectives drawn into narrative recollections of what it felt like to become a donor relative. I tried to lean into these differences and nuances because they were indicative of an unpredictability and a complexity that I was unfamiliar with after reading the literature. In fact, one of the most significant findings that emerged for me through my analysis was the greater heterogeneity in perspectives than the literature reflected, even in a group that was relatively homogenous in terms of its demographic characteristics. I drew on the official legislation and policy on the donation process to compare the accounts of what donation was like and the understandings of the processes and rules that were being shared with me with the best practice, standardised description of organ donation processes in the healthcare processes. I compared the official intentions behind symbols and honorary ceremonies with the ways in which they were being received. Since I am not a native English speaker, I drew on definitions of terms and noticed unfamiliar language patterns, and I reflected often about the ways in which my interlocutors phrased their accounts of their experiences. While this does by no means make me an objective observer, it did help me maintain a degree of curiosity that made me feel like an enthusiastic outsider looking into a new social context. Rather than looking for things that demonstrate what donation might be like for every deceased-donor relative, I tried to better understand the full extent to which it affected the different people I spoke to, and the independent meanings that it assumed for them. I used tools like frequent note-taking and cross-comparing of different people with different perspectives to try to prevent myself from generalising too much and from alienating the perspectives that were being shared with me not just from my own positionality, but also from that of the person I was speaking to. At times, I found the act of critical reflection on the things that hard-working volunteer organisations and individuals advancing altruistic causes in their free time challenging. The anthropological approach I took in my research involved entering into an actual relationship with my interlocutors, which helped me better understand their accounts. It was challenging that I was often seen as someone who was asking for help with a piece of work rather than someone who was trying to be helpful. I tried to work around this by making myself useful in other ways, for example by volunteering at events or by offering to help with organisational things. Despite my brief periods of fieldwork, I found myself adopting phrasing similar to that used by my participants about the roles of individuals in the transplant community. I found myself becoming native in the sense that my way of speaking and thinking about the different groups of people involved began to involve terminology commonly used by different members of the transplant community. To write this thesis, I had to carefully separate that "*native*" terminology from more etic language appropriate for this thesis (Mostowlansky and Rota, 2020).

My attitude to organ donation is that I am in favour of donation but believe that donation should be an educated personal choice. My opinion has not changed during this study. Throughout the research, I have tried to be mindful of my positionality to prevent it from influencing my evaluation of what others have said. I have felt reluctant to exclude significant sections because I believe the under-researched information is relevant despite the breadth of emerging areas of interest. The breadth of the topics covered results from my willingness to be guided by my informants' accounts. Indeed, the ethnographic approach revealed a high degree of flexibility and iterative potential in the material I encountered. This enabled me to access field sites in roles that felt appropriate (such as an event volunteer) and kept conversations more organic and natural, placing control over the content of the exchanges with the participants rather than with me as a researcher

The terminology used throughout the thesis differentiates between that used by participants and organisations included in the research and analytical descriptions for this research. To achieve this, terms like "*donor family*" and "*donor dad/mum/sister/etc*." will only be used when they arise in participants' accounts. Similarly, deceased donors will only be referred to as "*loved ones*" if participants use this language. Identifying these ways of speaking enabled me to highlight how a new vocabulary to describe emergent relations was coming into being. The distinction differentiates participant rhetoric and analytic terminology to maintain clarity throughout the text. Sometimes, my research included conversations with groups who were themselves reflecting on or developing policy and campaign rhetoric, at times approaching what Holmes and Marcus (2020) call para-ethnographic[1] trajectories of conceptualising and interpreting the material I was also researching. In these cases, the distinction between participant and organisational language and my analytical terminology became more challenging to maintain.

I am aware that the project I had hoped to undertake was impacted by the Covid-19 pandemic and limitations in funding. The research I summarise in this thesis covers a wide range of factors that influence the relatives of deceased donors and reflects on their perspectives on the current organ donation strategy in England. Because the participants I have spoken to were often connected to similar organisations and came from relatively similar backgrounds and age ranges, making for a group of people that was not very geographically, socio-culturally, ethnically or religiously diverse. The majority of the participants were between the ages of 40 and 80 and from a middle class white British background. Notably, the organisations and initiatives I discuss as examples of voluntary or self-initiated engagement do not cover every possible activity or community with which donor relatives can engage but include all the widest-reaching national initiatives currently operating. Thus, some of the events that donor relatives can engage in here are examples of a wider web of regional services and organisations of differing sizes and objectives. Additionally, I relied on recollected experiences in the hospital that may be subject to recall bias because my informants often thought back to an experience that was not only highly emotional but that happened a long time ago. However, since this thesis seeks to determine the long-term impact of the donation decision, the element that matters is, to some degree, what stands out in memories and is revisited later on. Despite these limitations, I believe that my research has produced results that are conclusive and well-supported by the materials gathered. There has been little ethnographic research into transplantation in England to date. My experience from this project highlights the flexibility and appropriateness of this method for research into topics with this degree of complexity. The insights from research that could be expanded on will become apparent throughout the main body of the text. My cost of living was supported by small grants from the Funds for Women Graduates, the Sir Richard Stapley Trust, and Grey College at Durham University; none caused a conflict of interest in my research.

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[1] The term "para-ethnographic" refers to ethnographic research with interlocutors who themselves have analytical perspectives on the work they do and their surroundings similar to that of the ethnographer.

3. Understanding the System: Existing Deceased-Donor Relative Resources in England

3.1 Introduction

When the question of organ donation arises for a relative, it does so within a complex arrangement of institutions and processes. I describe these processes and their effect on donor relatives in this chapter. The journey begins at the moment at which organ donation is transformed from a hypothetical possibility to an acute and often unexpected reality. Consequently, this chapter provides an overview of processes and procedures surrounding the organ request, the information and support provided to donor relatives in hospitals, the remembrance and support resources that are offered to relatives after they leave the hospital, and some of the organisations and events donor relatives can attend to begin to interact with as part of the broader transplant community. This chapter sets the scene for the rest of the thesis in that it familiarises the reader with the current culture of care in England. Neither the academic literature nor the NHSBT information resources currently include a comprehensive overview of the different actors and initiatives available to deceased-donor relatives and what they aim to do. Indeed, the most comprehensive assembly of links and references to different deceased-donor relative memorials and support organisations and links to NHS services and transplant community events I am currently aware of is provided on the website of the Donor Family Network. The Donor Family Network is one of the organisations this chapter introduces. For this introduction, I want to introduce the different settings and perspectives involved in the research settings as a "*bricolage*", as coined by Claude Lévi-Strauss (1962) for the purposes of this chapter.

Claude Lévi-Strauss introduced the term "*bricolage*" as part of his description of how people construct meaning and systems of classification by creatively reusing and reinterpreting existing cultural elements. He likens this process to the way a builder (the bricoleur) uses the materials available to them to construct something. In doing so, new configurations emerge, and several existing parts are combined and creatively adapted to form a new whole, such as an emerging idea of a cultural system (Levi-Strauss, 1964). In the account of the different guidelines and provisions for deceased-donor relatives, I also describe several factors that influence the deceased-donor relative "*care culture*" post-transplantation that currently exists in England – this is what I mean when I describe my account as a bricolage. The institutions and groups whose role I draw on are set up with specific desired impacts on deceased-donor relatives in mind. Institutions as objects of research for part-whole relations studies have long been sights of interest. Ideas about social worlds have long inspired research approaches that emphasise the interconnectedness of behaviours and institutional structures, underlining the need to look to the parts that make up a cultural system to draw conclusions about the broader cultural context. This opportunity for synecdoche drives me to explore the contributions made by the different organisations discussed in this chapter and how they relate to each other. While the account does not cover all of the smaller charities and local community initiatives, focusing on the ones that had the most significant impact on my interlocutors within this project provides an overview of the groups and processes that intend to shape deceased-donor relative experiences.

This overview is necessary to establish the organisational and cultural context of the accounts and spaces discussed in the subsequent chapters. Notably, the organ donation system in England is governed by a so-called "*soft opt-out*" or "*deemed consent*" law (Shepherd, O'Carroll and Ferguson, 2014; Parsons and Moorlock, 2020). This legal requirement places the final responsibility for the decision about organ donation on relatives (or nominated decision-makers) known to the deceased. In some cases, those decision-makers know of a general preference for or against organ donation that the potential donor had. This may have come from a conversation they or somebody else had with the person or because of a decision recorded on the organ donor register. The deemed consent law about organ donation has been put in place to indicate that the potential donor was in favour of becoming an organ donor after their death, if they did not register to opt-out or say otherwise during their lifetime. Contrary to organ donation in "*hard*" opt-out systems, people deemed to have consented to organ donation by not registering a decision against becoming an organ donor cannot donate unless their relatives or the nominated decision-makers have consented. The decision-making responsibility about what happens with the body of the potential donor remains with the relatives; organ donation cannot go ahead without their consent. The existence of novel transplant technologies that allow for the secondary use of organs has created a profoundly social choice a person might make. Various contextual, moral, spiritual and personal factors may impact that choice. This decision is indirectly available to the potential donor during their lifetime, as they may choose to express it to take steps to ensure their body is donated after their death. For example, they may communicate their preference to their relatives and ask them to uphold their choice in the event of their death. However, in the English organ donation system, the law is most directly targeted at the surviving relatives, who are the only party able to approve a donation preference after a person has died. The choice they must make is about a body other than their own. They have to rely on the medical information disclosed to them by the health professionals present, the things they know about the potential donor and other contextual information that may be relevant under conditions of severe time constraint. At the time when consent to donation is given, they cannot anticipate the likely outcome of the donation attempt, as additional biomedical factors will ultimately determine the success of the transplantation and whether the organs can be used at all.

3.2 Guidelines for deceased-donor relative care provision in the hospital

Whether or not one would consent to becoming an organ donor is a hypothetical question for most people. It is not expected to become a real possibility in most people's lives. When an individual is declared brain dead, circulatory death is deemed medically inevitable following the assessment of a patient in the hospital. In other words, it is established that an individual has either already died or will die, once the mechanical support of bodily functions by a ventilator is removed.

Deceased organ donation in the UK can occur following the declaration of brain death (DBD) or following the circulatory death of the donor (DCD). The management of controlled DCD in the hospital setting was re-introduced in England in 2008 to raise donation rates and has been the subject of bioethical debate in recent years. Donation after Circulatory Death, abbreviated as DCD, can occur in a managed or "*controlled*" clinical environment, in which life-sustaining treatments have been withdrawn because they were deemed as being "of no further benefit to a critically ill patient" in emergency or intensive care (ODT Clinical, 2023a). In some cases, DCD is also possible following an unexpected cardiac arrest after which the patient was not successfully resuscitated (ODT Clinical, 2023a). Several points of contention can arise in the context of DCD because the inevitability of the death of the patient and the conversation about the possibility of organ donation with the relatives take place prior to the point where circulatory death has occurred (Cooper, 2018; Gardiner *et al.*, 2020; Zivkovic, 2022). Bioethicists have contested whether the definition of DCD has been the question of whether it violates the dead donor rule. Specifically, given that at the time the anticipated possibility of organ donation is brought up in conversation with the relatives the patient continues to be alive but is expected to die, the ethics of changes to the care administered to the patient given the possibility of donation have been debated (Cooper, 2018). Furthermore, recent work in England by Cooper ((2023) has indicated practical challenges that relate to the available resources to support DCD in clinical settings and the impact the timing of the donor's death can have on the donation hopes of the relatives. Additionally, the disjuncture between strict time frames governing DCD and complex context-bound clinical realities (Machin *et al.*, 2022), as well as the prolonged wait it can entail for relatives and the disappointment the inability to donate because of these challenges can have on them has been highlighted (Prescott *et al.*, 2019; O'Neill *et al.*, 2024). Finally, the procedures surrounding DCD in the hospital setting for the purposes of organ donation and the impact uncertainties about donation can have on relatives in this context have been explored in recent research (O'Neill *et al.*, 2024).

Donation after Brainstem Death, abbreviated as DBD, becomes possible in circumstances where brain injury has caused "*irreversible loss of the capacity for consciousness*" and neurological tests have been performed on a patient on mechanical ventilation that have confirmed the diagnosis (ODT Clinical, 2024). When brainstem death has occurred in the hospital setting, the patient is on mechanical ventilation and continues to have a beating heart, feel warm to the touch and appears as though they are breathing until the withdrawal of treatment is performed (Lock, 2002). As a result, tension often arises between the biomedical declaration of death and the socially accepted image of death that relatives expect. Cultural definitions and understandings of the moment of death, the reality of death and a limited degree of certainty among relatives that no treatment would be of further benefit to the patient can cause the relatives of the received to struggle to accept the reality of the death or to contemplate the removal of organs from the body (Lock, 2002; Zivkovic, 2022). For example, Lock has detailed public opposition to brain death in Japan and Germany in her work (Lock, 2002, p. 308), and Zivkovic unpacks the ways in which Buddhist imaginaries of death may clash with the notion of brain death. Indeed, the continuation of visible signs of life in contrast with the declaration of irreversible death continues to be the subject of biomedical debate. In the face of this, multiple attempts have been made to homogenise the definition of death and to counteract the notion that brain death is socially constructed rather than biomedically verifiable and several studies have explored the definition of brain death on the experiences of donor relatives in the ICU (Ormrod *et al.*, 2005; Long, Sque and Addington-Hall, 2008; Shah, Kasper and Miller, 2015; Ahmadian, Rahimi and Khaleghi, 2019; Ahmadian *et al.*, 2020; Greer *et al.*, 2020; Zivkovic, 2022; Lalegani *et al.*, 2023).

In England, both donation after brain death (DBD) and donation after circulatory death (DCD) are possible, with 46% of deceased donors having donated after circulatory death in the 2022-2023 period (ODT Clinical, 2023a). The care provision pathway that governs the process for a possible organ donation approach requires that the news of the death of the relative is disclosed, and the inevitability of the death has been fully understood and accepted by the relatives or responsible representatives present in all cases before the possibility of organ donation is raised. This is required because raising the possibility of donation before the confirmation of the likely death of the potential donor could cause relatives to fear that the desire to transplant the potential donor's organs could negatively affect ongoing medical efforts to care for the body or improve the condition of the potential donor. However, while braindead donors have already been declared dead legally before organ donation is proposed/requested, individuals who are expected to die of a controlled circulatory death continue to be supported and kept alive mechanically when the donation request is made – although their ultimate death is also medically inevitable.

To avoid confusion or suspicions about the motives of medical professionals during the conversation about the possibility of donation, the bad news about the death is usually communicated by a person from the treating medical team. In contrast, a specialist nurse handles the subsequent conversation about organ donation. This is intended to alleviate fears over a premature declaration of death to press on with organ donation among relatives (NHSBT, 2023b). Specialist nurses must also educate themselves on the organ donor register status of the deceased before the conversation with the surviving relatives. The specialist nurses are trained for situations in consultations that may be particularly difficult, which, according to the Family Care Policy Document valid on 24.11.23, includes situations where nurses speak to a person whose relatives are from an "*ethnic minority*" and situations where the potential donor is a child (NHSBT, 2023b). Language interpretation services are made available as needed, and specific policies are in place for cases in which there is a need to incorporate language services into the donation discussion. Consent and authorisation forms (appendix 1, appendix 2) continue to refer to the donor as "*the patient*" throughout the donation process, and materials on the NHS website stress that the degree of care that is taken when handling the patient during and after the donation is not negatively affected by the decision to donate.

These policies are in place to make the experience as positive for the relatives present as the circumstances allow. Although the process is heavily embedded in routine practices, it involves opportunities where relatives must be granted time alone with the donor before or after organ retrieval, takes place. During these times, they can keep a keepsake if they so wish, such as a lock of hair or hand or footprints from the donor. The wait for donation can be a lengthy process, and many relatives spend long periods in hospitals while the necessary tests and preparations are undertaken. Sometimes, the wait can exceed 24 hours. According to the NHSBT, they must be supported with "*any religious or spiritual needs*" during this time (NHSBT, 2023b). Relatives should be granted this time alone because this period is likely to be the last opportunity for them to interact with the physical body of the potential donor as they were when they were alive. Even when the person has already been legally declared dead because brain death has been established, and although the potential donor does not have the capacity for consciousness in these moments, the idea of "*spending time*" implies that both the donor and the relatives/representatives present are still there together. The Family Care Policy Document's additional requirement to support religious or spiritual needs is relatively unspecific. It indicates a desire to respect the additional needs of relatives without going into detail on how this should occur. The policy requires that organ donation be framed in favourable terms. However, an emphasis is placed on setting realistic expectations about recipient contact. The relatives are provided with information materials and informed about support options; they are also allowed to state whether they want to hear from the NHSBT programme about donation outcomes.

Another symbolic aspect of the NHSBT's programme is how the specialist nurses inform relatives of a gold heart pin and a certificate of recognition sent to the relatives of all organ or tissue donor relatives who wish to receive it, usually within two days of donation. Multiple badges can be sent to the people present for the consultation, but there is an upper limit of 10 badges per donor (NHSBT, 2023b). The need to frame donation in positive terms is linked to the need to increase consent rates by presenting donation as a positive step and alleviating any fears that relatives may have about the decision they face. The simultaneous object to set realistic medical and social expectations about donation outcomes and contact regulations with future recipients indicates that the consequences of donation are complex and often difficult to anticipate. Although the donation often intends to make a positive decision to help a recipient in need of an organ transplant, the real-world outcomes in terms of the lives of the relatives and the organs of the donor cannot easily be predicted. The number of organs consented for donation from donors whose relatives have consented to organ donation and the number of organs offered for donation can differ. This is because consent may have been obtained in cases where the donor's condition worsens or where the donor organs are later deemed unsuitable for donation (NORS, 2023). For the 2022-23 transplant period, the number of consented deceased donors was 1902. Out of this group, the number of donors from whom at least one offered organ was retrieved for transplantation was 1429, and 1353 cases were donors for whom at least one of the organs retrieved for transplantation was utilised. This means that out of the donors whose relatives consented to donation, 71% had at least one of the organs utilised for transplantation. Additionally, the long-term outcomes from donation can vary, and it is difficult to anticipate how long the donor organ will be used. Specialist nurses and medical staff are tasked with indicating these areas of uncertainty to facilitate informed consent. When relatives are informed about the donation process and what to expect after it occurs, they may also be handed additional information about charities and other volunteer services that they can contact later for transplant-related support. This information can include NHSBT materials, pin badges, flyers and other branded materials.

One of the charities that provides pin badges to new donor relatives to be handed out by specialist nurses in local hospital units is the Donor Family Network. This is the largest UK charity offering support, information, advocacy and community by and for "*donor families*". The materials are provided in the hospital to enable donor relatives to refer back to them later should they want to access support or engage in memorial activities. The experience of the network and its members has shown that deceased-donor relatives often wonder about the outcomes of the donation following organ removal. The NHSBT Donor Family Care Policy (2023) recognises this by mandating that relatives must be offered a phone call at the end of the donation process to be informed about this information, as well as an official outcome letter or a thank you letter that is usually sent within 15 working days after the organ donation. Relatives can refuse further contact if they wish; in such cases, this preference is documented when it is first expressed (NHSBT, 2023b). Some procedures ensure that the medical details of the letters to deceased-donor relatives are checked before they are sent. The specialist nurse who supported the relatives can personalise letters where desired, using a blank greeting card in the care package (*Donor Family Care Policy*, 2004). Relatives can request further follow-up information on the transplant through contact with the Donor Family Care Service (DFCS). The DFCS sends a card on the day of the death of the donor after one year to thank the relatives again. The health service sends information letters and documents honouring the donor and the relatives to acknowledge the organ donation and to give the relatives some closure about the outcome of their decision. Should relatives not be informed of outcomes, they may wonder whether transplantation took place at all and feel unsure about the consequences of their decision. The documents expressing gratitude or appreciation of the support for organ donation indicate that the health service members are grateful for the relatives' decision to donate and continue to value the support decision.

In addition to the initial outcome information about the transplant, relatives often hope to receive an anonymous letter from the recipients or decide to write a letter to the recipient themselves. If they wish to do so, they must go through a standardised and carefully monitored process to ensure anonymity. Content that is considered appropriate is shared. A leaflet is sometimes sent to guide communication between recipients and donor relatives. The leaflet contains instructions on how to write to recipients, including a reminder that the Donor Family Care Service reads the letters that have been written. A request to include information such as the donor's first name, their hobbies and interests and the relationship the author had with the deceased and a reminder not to share information that could enable the addressee to determine the donor's identity also feature. Additionally, the Donor Family Care Service Website features written tips from two relatives of deceased-donors to provide tips on what to include and video testimonies from three recipients who outline some of their reasons for and against initiating contact. Such provisions are in place to ensure that the anonymity of the donor and recipient is maintained and that both parties desire any communication. While many donor relatives hope to receive a letter from recipients, both the information leaflet and the initial conversation outlining how donation takes place stress that there is no guarantee that recipient contact will occur. The Donor Family Care Policy anticipates that the relatives of the deceased will likely take an interest in the outcome of the donation in terms of the utilisation of the organ, but also the potential desire of the surviving relatives to communicate with the recipient that received the organ. When the donation approach is made, and throughout much of the donation campaign messaging, the great need for donor organs among recipients is emphasised as a primary reason relatives should consider the donation request. Stories of the good that donation can do and the difference it can make to recipients are frequently emphasised along the notion that the decision to consent to organ donation is the act of "*giving the gift of life*". While any potential communication between the surviving relatives and the organ recipients is carefully monitored and kept anonymous in most cases, the notion of the gift of life that is repeatedly used to recognise the significance of the donation emphasises a sense of intimate connection between the two parties.

3.3 Rhetoric to honour deceased-donor relatives

Organ donation in England (and abroad) is frequently referred to as "*giving the gift of life*". In its guidelines, the Nuffield Bioethics Council states that organ donation must occur in line with the definition of gifting or donating advanced by Titmuss in his influential work discussing arguments against monetary incentives for blood donation. Titmuss requires that the donation decision be made altruistically and without expectation of reciprocal action (Titmuss, 2018). With the organ donor shortage in the United Kingdom increasingly leading to an emphasis on organ procurement in public health messaging to the population, the Titmussian definition for procurement of bodily material in the absence of expected remuneration for the benefit of strangers has been favoured by the Nuffield Council of Bioethics, rejecting the possibility of any commodification of human tissue (NCoB 2012, Simpson & Douglas-Jones, 2017). The implication of deceased organ donation in the UK is an altruistic act, a voluntarily extended gift with no further promise of receiving something in return. This narrative opens the possibility of casting donation following a problematic death into a more positive, even heroic light. Invoking the gift carries a transformational power that can make the invasive organ removal process easier to think about for a donor's relatives (Hogle, 1996; Sharp, 2006; Bea, 2020).

The giving of the "*gift of life*" in the sense of the physical removal of the organs from the donor marks the end of life for the donor in terms of physical appearance in this instance (Lock, 2002). Indeed, the description of organ donation as giving the gift of life has a long history in organ donation rhetoric and research on donation experiences, which will be explored in greater depth in Chapter 6. To understand how donation as the "*gift of life*" is utilised to offer deceased-donor relatives comfort and support, I will describe highlight cultural events and acts of recognition that acknowledge the act of consenting to organ donation. The NHS, the Donor Family Network charity, and the Order of St. John all offer pin badges to the relatives of deceased donors and acknowledge and recognise the donation. The Donor Family Network is a charity run by donor relatives who seek to offer support and remembrance to others who have also consented to organ donation following the loss of a relative (Donor Family Network, 2019b). The Order of St. John is a royal order of Chivalry founded in England which is involved in the provision of healthcare and healthcare-related support services internationally and offers an award to deceased-donor relatives for their willingness to help others and to highlight and promote the positive impact organ donation can have (Order of St. John, 2023). In the design of the pin badges each of the organisations hands out, the positive significance of the decision to donate and the commitment in support of donation made by the family is recognised.

The NHS itself launched its gold heart pin initiative in 2018, wherein the relatives of deceased-donors are sent a pin badge that has the shape of a gold heart with the word "*Yes*" written on it, alongside a certificate in which the chief nurse for organ donation expresses their gratitude in the month after the transplant (SMC, 2023). The campaign and marketing bulletin launched by NHSBT explained that the badges had been modelled after the Gold Star Label Pins that the families of people who lost their lives in military service in the United States receive. (NHSBT, 2018).

Reflecting on this symbol, the bulletin explains that "*Gold Star Families are respected and honoured for their sacrifice and are proud to wear their pins. The ambition is that over time the Gold Heart Pin will become recognised in the UK and donor families will wear their pins with pride as recognition of their part in saving lives."* (NHSBT, 2018, p. 7). The heart is the existing symbol of organ donation used by the NHS. It is usually worn in pink by supporters of organ donation - the larger size of the pins given to deceased-donor relatives was chosen to acknowledge the greater significance of their contribution to organ donation (NHSBT, 2018).

Figure 6: Gold Heart Pins (NHBST, 2018)

To understand how an existing symbol of national gratitude for the sacrifice of military personnel has been adapted for the context of organ donation here, it is helpful to reflect on the notion of sacrifice. In the Cambridge Dictionary, sacrifice is defined as "the act of giving up something that is valuable to you in order to help someone else" (British English) or as "the act of giving up something for something else considered more important" (American English) (Cambridge Dictionary, 2024b). When discussing sacrifice in the context of organ donation, Sque and colleagues adapt the definition for personal sacrifice to mean "*good deeds or […] gifts to other humans that are usually wrought at great individual expense*" (Sque et al., 2008b, p. 135). Durkheim discusses sacrifice in the context of rituals using symbolic gestures generate means of expressing reverence, gratitude, and remembrance towards the deceased while simultaneously reinforcing community values and establishing the moral values of a given society (Durkheim, 1912). The notion of sacrifice is often analysed to determine how a society conceptualises death and mourning. Rituals surrounding the acknowledgement of sacrifice have been theorised as opportunities to encode values held by members of the community and to affirm social hierarchies (Geertz, 1973). In work by David Graeber, new arguments about sacrifice have emerged in the context of re-evaluating the concept's relevance for modern societies in which individuals often engage in acts of sacrifice and exchange that are not consistently recognised (Graeber, 2001). He draws on historical ethnographic work and contrasts it with examinations of contemporary capitalist systems in which indebtedness and a sense of obligation can drive people to modern forms of sacrifice (Graeber, 2001).

Ann Mongoven discusses organ donation as a sacrifice in her work, arguing that it meets the requirements of "*Christian notions*" of sacrifice and that it provides a means of acknowledging the additional strain the decision to donate might place on relatives who are in an already difficult situation (Mongoven, 2003). She identifies a concern that organ donation in the United States is at risk of becoming "*over-glorified*" and that there is a trend towards "*a dangerous routinisation of sacrifice*" that exists in this context (Mongoven, 2003, p. 89). Sque and colleagues interpret the element of sacrifice that is involved in the process of agreeing to donate an organ in the decision of the deceased-donor relatives because they "*must relinquish the guardianship and protection of the corpse and allow the cutting up of the body and the removal of organs (…) for the benefit of an unknown recipient*" (Sque et al., 2008, p. 135). In this context, the gold heart pins produced by NHSBT invoke an explicit acknowledgement of the relatives' role in allowing the donation to go ahead. Implied in honouring the relatives' contribution is the implication that the relatives agreed to donate in part because they felt generally supportive of the transplant service and favouring organ donation more broadly. In this sense, the gold heart pin is also intended as an item that signals the moral virtue of consenting the organ donation to others, inadvertently turning the recognition of the "*sacrifice*" for those who already made it into something that might "*inspire others to do the same*" (NHSBT, 2018). The symbol of respect and gratitude for the nation's health service is invoked to reinforce the moral virtue of support for that organisation and serve as a powerful opportunity for donation promotion.

A similar dual intention exists behind the Organ Donation Award that the Order of St. John has launched in collaboration with NHSBT in 2013. The award seeks to "*honour donors for their gift, but it also raises awareness of the successes of organ donation and inspires other families to follow in the* *donors' footsteps*" (Order of St. John, 2023). The award is handed out posthumously to the surviving relatives. It represents the recognition of the King to "*people of all faith and people of no faith*", although the order itself is Christian (NHSBT & Order of St. John, 2018). Relatives can receive the award at regional ceremonies or in the post alongside the accompanying certificate. The ceremonies are often attended by a representative from the local government or a local religious figure from the church of England who is present to honour the donors (NHSBT & Order of St. John, 2018).

Figure 7: Order of St. John Award Pin (Order of St. John, 2018)

The box the pin is presented in bears the royal crest, as seen in Figure 6, and the order itself displays a symbol of a heart stylised to signify the secondary use of the organ. Below the heart is a banner with the words "*Add Life. Give Hope*" to emphasise the significance of organ donation for the lives of others. The badge also incorporates the symbol of the order itself. The modern royal Order of St. John shares its symbol with the historical charity it is associated with, which dates back over 1000 years and began as a Catholic order which has now been involved in the delivery of health aid for centuries (Museum of the Order of St. John, 2023). The "*white eight-pointed cross on a black background is an international symbol of first aid. It is known as the logo of St John Ambulance, emblazoned on the sides of ambulances and on the uniforms of its highly trained volunteers*"– the wearer explicitly signals their association with humanitarian care (Museum of the Order of St. John, 2023). St. John's purpose, beyond honouring the donation decision, is to advocate for and raise awareness of organ donation. The honour and recognition of the act of donating by a representative of the king and in a high-profile venue are intended to inspire other individuals to donate in support of a stranger who needs help – the ceremony helps characterise organ donations as a socially admirable and morally desirable choice. The intention behind the award is similar to that distributed through NHSBT. However, the primary emphasis for the award from the Order is on the donor's contribution to the well-being of members of society who are in need. In contrast, the NHS pin is intended to demonstrate recognition for the relatives' role in making the donation possible.

The Donor Family Network charity is the third organisation that offers a pin badge to all deceased-donor relatives as an act of recognition. The Donor Family Network aims to provide high-quality support to all donor families that need their help regardless of ethnic group, religious beliefs, sexuality, ability and background. The charity is run by donor relatives who have themselves experienced a need for support and acknowledgement of the donation decision and have made it their mission to ensure that "*no donor is forgotten*" (Donor Family Network, 2023). In line with this goal, the network draws on symbolism that emphasises the donor's essential role in allowing the recipient to benefit from the transplant and assures deceased-donor relatives that the network members will always remember the donor for "*giving the gift of life*". The network's logo is also the motive on their pin badges and incorporates a "*butterfly and a forget-me-not. The butterfly represents hope and new life; the forget-me-not means no donor will ever be forgotten"* (Donor Family Network, 2023).

Figure 8: Donor Family Network Logo (Donor Family Network, 2023)

The donor is represented by the forget-me-not, which feeds the butterfly and helps it live. The butterfly represents the recipient and hopes for a new or improved life following the support from the deceased donor and their family through organ donation. The support for organ recipients is built into the Donor Family Network charity logo, situating its identity within a group of deceased donor family members and as a wider part of the transplant community, whose activities are centred around the desire to help recipients as well. The Donor Family Network has also drawn heavily on the Gift of Live imagery in creating its commissioned memorial. The charity commissioned and funded the building of a memorial that would serve as a national site, recognising the transplant community because they became aware that all previously constructed memorial sites were usually built by smaller local organisations. The network commissioned artist Julia Hennessey-Priest, who designed a National Organ Donation Memorial to be constructed at the National Memorial Arboretum. The Memorial was completed in 2016 and unveiled to over 450 attendees (Donor Family Network, 2016). I visited the Memorial during my fieldwork in 2022 and experienced it sitting in the arboretum's quiet and carefully landscaped surroundings. The Donor Family Network website features photos of the memorial and a testimony to its intended message:

Figure 9: The Gift of Life Memorial (Donor Family Network, 2016)

Life. The most amazing gift of all.

Every year, hundreds of lives are saved as a direct result of organ donation. Hundreds more lives are changed and enhanced through tissue donation. To pay tribute to the donors and their families who made the gift of life possible, The Donor Family Network have created a National Organ Donor Memorial. The Gift of Life Memorial is situated at the National Memorial Arboretum in Alrewas, Staffordshire and encompasses 3 main themes:

Reflection – a place of quiet and natural beauty for reflection and contemplation. For all those whose lives have been touched by organ donation:

- *Those people for whom the call never came, those who died waiting for a transplant because of the tragic shortage of organs available.*
- *Those who have received organs and tissue for whom gratitude and thanks are simply inadequate.*
- *Those who work in the field of organ donation and transplantation.*
- *For all those who support organ donation*

> *Recognition – where the precious gift of life is recognised as an altruistic, life affirming, life changing act of kindness and generosity.*
>
> *Remembrance – where all are remembered, and they are remembered by all. Those who wished to be donors but whose wishes could not be fulfilled are also remembered with gratitude. The project includes an on-line Book of Remembrance where tributes may have been written in memory of donors by their families and anonymously by their recipients.* (Donor Family Network, 2016)

The dedication expresses that the network decided to build the national organ donor memorial "*to pay tribute to the donors and their families who made the gift of life possible*" but further explains the three greater themes represented. These themes – reflection, recognition, and remembrance - are inscribed in writing on the metal circle surrounding the butterfly's central mosaic statue and forget-me-not.

The dedication to the first theme, reflection, explains that the memorial is intended to offer reflection to all who have been affected by organ donation, including those recipients who did not receive the transplant they needed in time, those recipients who do not know how to thank the donors for what they were given, people who work in organ donation and people who support donation. All these people are invited to be inspired to quietly reflect while standing before the memorial and thinking about what organ donation means to themselves and others. The emphasis therein is positive – the dedication does not indicate a person's possible struggle with having received a transplanted organ, for example, in terms of their own identity or ongoing health issues. However, it does seek to offer support to those who lost a recipient who could not be saved by transplantation. The memorial contains elements intended to promote organ donation. The promotion of organ donation is implied in how the Donor Family Network chooses to express its own identity, taking the stance that donor relatives collectively support organ donation. The recognition theme clarifies how the network views organ donation and believes it should be recognised nationally, namely as a "*precious gift of life*" that is altruistic, life-affirming, life-changing as well as kind and generous. The story of organ donation is told here using the language of a "*gift*" – a Titmussian gift that was given altruistically and whose significance, in light of the formulation from the first theme, could never be adequately reciprocated because "*gratitude and thanks are simply inadequate*". The Donor Family Network tells the story of organ donation as a selfless, boundless gift in their memorial. This notion can be linked to the idea of perpetual indebtedness following sacrifice outlined in connection to the work of David Graeber (Graeber, 2001). Although the network does not mention sacrifice in its inscription, the statue establishes that the choice they made implies a right to gratitude in perpetuity and a lingering social obligation to recognise and value that contribution. The main point made about remembrance in the dedication is one of inclusion. It stresses that all donors and their families are remembered, not just those whose offer resulted in a transplant. The Donor Family Network often stresses that all donor families, including those whose relatives could not become organ donors for medical or logistical reasons despite the family consenting, must be remembered. This is in line with their view of donation as a generous and selfless act – altruism is expressed in the agreement to offer organs for donation, and it does not become less selfless or significant if an obstacle later emerges, preventing the transplant from going ahead. Notably, this is the case because the trustees of the network are aware that the decision to agree to offer the organs for donation is the factor that deceased-donor relatives have in common, independent of the medical outcome of the procedure.

Drawing on the literature on memorialisation is helpful in understanding the imagery of the memorial and the unveiling ceremony. Previous research has explored the significance of memorials to express gratitude to individuals who donated and to define an aspect of the death of a person (Bolt, 2012). A memorial in a quiet and peaceful setting can give the affected individuals additional time to contemplate the meaning of their donation decision. Notably, the Gift of Life Memorial attempts to create a field of relations. This field is figuratively represented by the mosaic stones covering the statue. These form a patchwork of representation and recognition for every party involved in transplantation. The Gift of Life Memorial utilises imagery akin to war memorials, commemorating sacrifices made for a national cause by soldiers and their families. War memorials have the potential to engage onlookers, causing them to reflect on the significance of the lives they represent. Consequently, memorials often promote desirable behaviours and values and comfort those who reflect upon them (Beckstead *et al.*, 2011). The Gift of Life Memorial affirms a place for "*donor families*" in the broader transplant community and a place for the transplant community at the National Memorial Arboretum. This place can help individuals determine who they are as donor family members and what they might mean to others affected by transplantation. Crucially, the Gift of Life Memorial serves a further purpose for the Donor Family Network: It is a chance to publicly express and celebrate its values and support for donation. Like the other two organisations, the Donor Family Network draws on familiar cultural imagery and symbols that hold significance to produce a rhetoric of the social significance of organ donation.

In this context, Sherry Ortner's work can provide valuable insights. She argues that cultural symbols are not only representations of meaning but also active agents in shaping social reality. By analysing the meanings and functions of cultural symbols, the underlying structures and dynamics that govern social life can be uncovered (Ortner, 2006). Ortner's approach emphasises the role of symbols in mediating social relations and constructing collective identities. For example, the pin badges suggest that deceased-donor relatives and donors are, in a sense, heroic. Simultaneously, the ceremonies' symbolism turns the identity of deceased-donor relatives into a source of pride and a positive role model who supports organ donation publicly to motivate others. Symbols come together and form a powerful pro-donation rhetoric embedded in the routine processes that deceased-donor relatives encounter.

Michael Carrithers argues that in rhetoric, there are compelling ways of seeing the world and advocates close attention to the work of rhetoric (Carrithers, 2005). He highlights that in some instances, "*master strokes*" in rhetoric are achieved when humans use recognisable symbols in novel ways that have the power to shape the understandings and actions of the people exposed to them. Cultural symbols come to be used as the "*tools of culture (…) to persuade and convince, and so to move the social situation from one state to another*" (Carrithers, 2005, p. 581). In the butterfly and forget-me-not flower logo by the Donor Family Network and the gift of life memorial, a novel arrangement of symbols casts the role of deceased-donor relatives as part of the process as understood by the network into the minds of onlookers. How these symbols have been assembled indicates how the network thinks organ donation should be considered. Conversely, in the badges used by the NHS and the order of St. John, meaningful and recognisable symbols of remembrance that already have a familiar cultural significance are adapted. This is done to create a cultural push that can lend itself well to simultaneously honouring deceased-donor relatives and donors and promoting organ donation.

Acts of memorialisation bring together rhetoric and memory. Mary Carruthers explores this connection in her work on rhetoric techniques used in medieval times to shape memories and facilitate knowledge transmission (Carruthers, 2008). Before the majority of society became literate, rhetoric is said to have played an essential role in the organisation and dissemination of information, using the example of so-called memory techniques, strategies which helped a person better remember things, for example by purposefully introducing an element of reasoning (ibid.). According to her, pieces of information were often memorialised by strongly associating them with vivid images that would be easily remembered. This example shows how the memorialisation of important information has long been connected to fitting symbols. In organ donation, recognition and remembrance ceremonies, there is a tendency to invoke imagery associated with war memorials to underscore the importance of not forgetting what the donors and their relatives did. In his work, Victor Turner showed how ritual processes associated with collective memorialisation also hold a transformative power in which the deceased is given a new social significance and, in some instances, become associated with a sense of purpose in the loss (Turner, 1967). Margaret Gibson observed that in Western societies, memorials often create spaces in which public mourning can be facilitated, and others can participate in the grieving process and publicly share emotions and reflect on the meaning of loss in ways that are not expected in most other social spaces encountered in daily life (Gibson, 1970). In this sense, war memorials in modern Britain bring meaning to tragic loss; they cast the deaths they commemorate in a more heroic and sacrificial light, one that invites acknowledgement and commemoration from community members within the memorial space. The Gift of Life Memorial, built by the Donor Family Network, sits amid many such memorials at the National Memorial Arboretum partly because the Network believes that the death of deceased-organ donors deserves a similar kind of public recognition. Powerful stories of organ donors and organ recipients, coupled with the imagery of the butterfly and the forget-me-not flower, are intended to generate a new form of social recognition for the members of the transplant community.

3.4 The Donor Family Network: Support for deceased-donor relatives

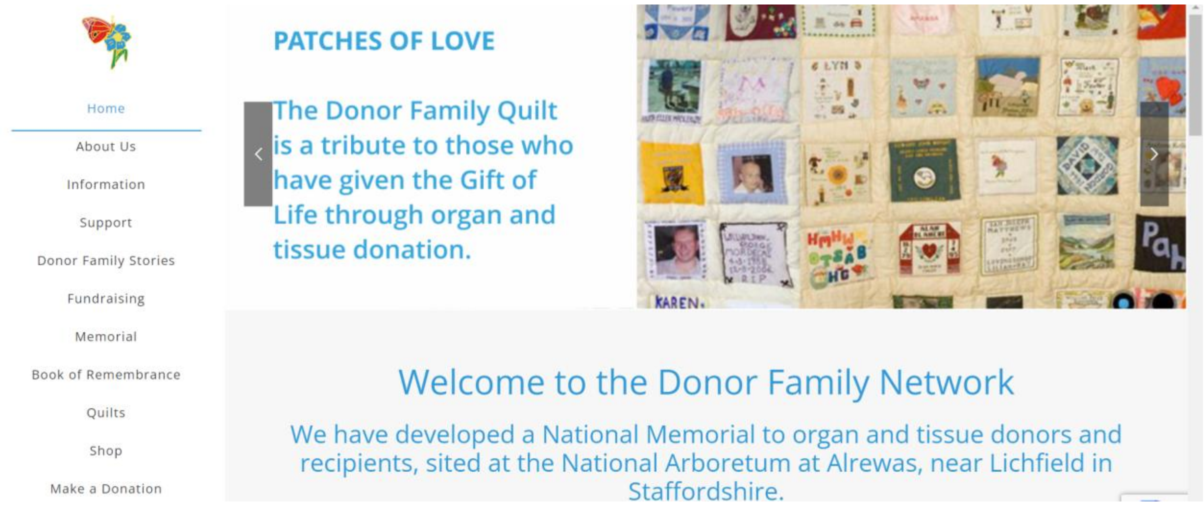
The Donor Family Network was created in part because the one-to-one care and support provided to deceased-donor relatives by the specialist nurses in the hospital came to an end when the transplantation process had been completed. While relatives are informed of donation outcomes, as detailed earlier, the more personal care and support provision frequently terminates at this stage. The Donor Family Care Service Website includes contact information where relatives with additional questions can contact the transplant service and links to charities offering general or specialised bereavement support. However, many relatives are preoccupied with the legal and organisational consequences of the death as well as its consequences for their lives in the time immediately after the transplant. Relatives must register the death, inform the government that the person has died and organise the funeral. Additionally, they may need to deal with financial matters, including pensions, benefits and taxes, as well as deal with the estate of the deceased and access bereavement and support services as needed (Gov.uk, 2023). For these reasons, they may not seek out do additional donation information immediately after the death. However, many relatives reflect on the donation decision afterwards. Having had time to reflect, they may ask themselves whether they made the right choice, if the decision was appropriately recognised, contemplate additional procedural they might have had or begin to wonder about the possibility of hearing from the recipient. The Donor Family Network wants to respond to these needs and prevent relatives from feeling isolated or forgotten once the organ retrieval phase had passed.

The desire to create an organisation that would acknowledge these needs first arose when an English couple lost their daughter in an accident in America. The daughter became a multiple organ and tissue donor, helping over 74 people. Her parents were sent a letter and other materials from an American charity, offering recognition of the donation and sharing in the remembrance of their daughter. This outreach was very positively received by the grieving parents, who hoped there might be a similar support organisation they could contact in England. They approached their local transplant coordinator to see if such a charity existed and were told that no such charity existed apart from occasional meetings between local donor relatives. They were encouraged to set one up themselves. The two parents drew on their shared experience and the blueprint of the support they had received from the American organisation to take appropriate steps to create a support group for others in England. They named the initial group "*Donor Family Support Group*", a local group serving the Midlands. The organisation's name was changed to "*Donor Family Network*" a year after the group was founded. As their community grew, they expanded it to make it a national organisation, and their charity was officially registered in 2003. When I asked the founders why they chose to establish the Donor Family Network, they stressed that they "*acted on a need*". Namely, a need to ensure that support was offered to donor families and their interests and that they were represented in the world of transplantation. The charity was set up to avoid donor relatives and deceased donors who passed away being "*forgotten*" in the process of organ donation once the transplantation was complete. They also began participating in various activities and events into the broader transplant community to ensure that deceased-donor relatives became a formally included presence. To guarantee that "*no donor is ever forgotten*", the Donor Family Network set up several opportunities for collective remembrance. Nine Trustees run the charity; some additional volunteers and members have been directly affected by organ donation and are donor relatives. Their activities are modelled after their own needs after their relative's death, some of the activities of the American Donor Family Association that influenced the idea of a dedicated support group initially, and the things that helped them create a sense of meaning and identity following organ donation for themselves. The setting up of a charity and the task of determining how it should provide support and where deceased organ donors should be remembered also allowed donor relatives to reflect on what would have been of benefit to them.

The Donor Family Network's activities cover three main areas. First, the network allows deceased-donor relatives to remember the donors and extends its appreciation for the relatives' donation decisions. Second, it offers support to "*donor families"*, for example, by way of a support phone line or by advocating for the needs of donor families in discussions on NHSBT donation procedures and policies and by offering comforting blankets as gifts to families who are experiencing the organ donation process in the extensive care unit. Third, it seeks to represent donor families as a part of the transplant community, ensuring they are remembered and present in public spaces, such as the National Memorial Arboretum, the British Transplant Games, and political discussions, such as those held by the Organ Donation Taskforce. All of these activities will be considered in more detail in due course.

The charity's primary aim is to support any family whose relatives' donated organs in England and who wished to hear from the network. One of the remembrance initiatives that the founding parents began, was to create personalised cards on the day of donation and send these to donor families who were members of the charity. They did this to let them know that they were not alone and that someone was thinking about them. Later, other trustees who helped run the network supported them in this endeavour. The focus on remembrance of the donor within the donor family community extends beyond the letters. The American Organ Donor Association and the Donor Family Network have "*Quilts of Remembrance*" made with "*patches of love*". The quilts consist of hand-sewn commemorative patches in memory of a deceased family member that were submitted to the donor family network. The quilts are often taken to and displayed at the events in which the Donor Family Network participates. On these quilts (see Fig. 9), the patches are sewn by hand and include personalised motives chosen by family members; some include photos or symbols of the various activities the person used to enjoy, others resemble a memorial plaque or are made with a piece of fabric that once belonged to the deceased donor.

Figure 10: Quilts of remembrance (Donor Family Network, 2023)



PATCHES OF LOVE

The Donor Family Quilt is a tribute to those who have given the Gift of Life through organ and tissue donation.

Welcome to the Donor Family Network

We have developed a National Memorial to organ and tissue donors and recipients, sited at the National Arboretum at Alrewas, near Lichfield in Staffordshire.

Figure 11: Donor Family Network Website (2023)

Photos of the patches of love on the quilt can be found online, and some of the pieces can be clicked on to reveal a personal message by the family about the person commemorated. The website the Donor Family Network created also includes a book of remembrance, where families share their stories, usually in the month the donor passed away. These allow network members to see who donated during which months and to think about them. Many of the memorial activities offered by the network make the private experience of donor families public – they can be understood as both an expression of personal grief and as a need to represent the person who has passed away. They provide an ongoing testimony to the surviving relative's relationship with the deceased person and to their personality. Finlay and Krueger (2011) have explored the use of online memorial pages and argue that memorial websites act as a public representation of the identity of a person after their death, allowing families to keep a lasting reminder about the person and the life they lived in an online space alive (Finlay and Krueger, 2011)**.** By doing so, the person's memory is immortalised, and the relationship with the deceased continues to be reflected on and expressed in a digital social community. However, this possibility depends on the policies enforced by the used platform provider, and the preservation and accessibility of immortalised presences are spurious in that sense.

The network's activities pursue similar goals, allowing the members of the charity to support one another, remember the deceased-donor relatives collectively, and help members of the network reflect on the meaning of organ donation. Furthermore, the Donor Family Network provides links to various resources for support, including books on grief and relevant Bible psalms, that can be accessed through the webpage. A newsletter informing members of the network of the latest activities of the charity, is produced every quarter and sent to those families who are registered members of the charity or friends of the network. Stories from other events in the transplant community and personal testimonies from donor families and recipients are also covered. Additionally, the Donor Family Network holds an annual remembrance event, sometimes called the "*Precious Gift*" event, at the National Memorial Arboretum, which will be discussed in greater depth in Chapter 7. The Precious Gift event is held on a Sunday in September. Deceased-donor relatives are invited to the event to remember their relatives, followed by cake, refreshments, and the opportunity to socialise with others. This event collectively celebrates those who passed away. Attendees are given a chance to light a candle for their deceased relative as part of the event and to have representatives involved in different parts of the transplant process[2] speak about their experiences. Typically, speakers might include a deceased-donor relative, an organ recipient, a representative from the Donor Family Network and a

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[2] The term "transplant process" is deliberately chosen throughout the text over a description of a "donation process". This is because my work draws on different perspectives that emerge at different times in the context of transplantation and is not limited to a discussion of the donation process alone.

medical professional representing the health service. The annual gatherings acknowledge a painful loss and encourage collective remembrance and grieving. The event presents the donation decision as a positive thing for the community. Once the formal aspect of the event is over and the group moves into a different room, peer support is provided to those who need it. In particular, representatives of the Donor Family Network can be seen offering advice and comfort to those who attended. They take great care to offer a listening ear, especially to those who have come for the first time or experienced a recent loss. The support arm of the network is also available outside the event in the form of a phone line, which the trustees operate. Here, donor relatives can ask questions about aspects of donation they struggle to understand or about feelings, emotions, and memories they grapple with. The Donor Family Network trustees often spend a long time answering questions and sharing their experiences and knowledge about organ donation and its consequences. In this sense, the Donor Family Network positions itself as the point of contact where further support can be accessed once formal contact with the hospital is over. The qualifications of the trustees and other volunteer providers rely on the assumption that the needs of all donor relatives can be responded to in a somewhat generalised way to some extent. The network has designed its activities based on their best assessment of the needs of relatives in terms of how they need to be supported in their grief, usually also influenced by their own experience of grief. Their position of authority is ambivalent; they have insight and unique authority because they went through the experience themselves. However, they are limited by how their own experiences influence their assessments of how others might likely feel and what they may need. The network's assessment of what is likely needed by deceased-donor relatives is communicated outward in a somewhat generalised way. Because this form of counselling is volunteer-run and relies on personal experience, it is not comparable with professional care provision; instead, it offers something different. For example, the Donor Family Network Support Phone Line is a service intended to complement the needs of relatives when they stop being under the care of specialist nurses in the NHS.

Volunteers are in what is often characterised by the health service as a *"boundary position*" (Morris *et al.*, 2017). They become an asset when communicating information about health procedures to the general public and can be viewed as semi-professional health support providers. In attempts to frame the need for private citizens to provide a service not provided by the health system, this is characterised as an opportunity to realise the potential of communities to care for individuals (Morris *et al.*, 2017). However, Morris et al. (2017) noted that there is often a false assumption that volunteers in such a boundary position can accurately represent the diversity of their society. The prevalence of volunteer and charity incorporation into the health service is increasing. In 2015, Public Health England called *"for public health and healthcare to become more person and community-centred, enabling* *individuals to realise their potential and to contribute to building healthier, more resilient communities*"(Public Health England, 2015, p.1). This move to more community-based models for healthcare provision includes the notion that community-centred care would allow for greater representation of individuals within the health service. It shifts the responsibility for care delivery onto care and peer support delivered by the community and requires personal initiative from individuals to be accessed. To highlight the historical context for this recent shift back to community-based care in England, I will briefly outline its history in England.

Community-based models of care were common in England before the welfare state was founded, with care for the elderly, sick and poor largely being provided by religious institutions, charities, and local communities on an informal basis. Industrialisation at the beginning of the 20th century highlighted the need to provide a more structured approach to care, due to increasing population growth brought on by industrialisation. The first and second World War exposed the fragility and the limitations of community care systems and led to the commissioning of a report that would form the foundation of the welfare state. The Beveridge Report of 1942 first formally addressed the possibility of providing social insurance and allied services, framing the abolition of five great emails characterised as want, disease, ignorance, squalor and idleness as the responsibility of the government (The National Archives, 2024c). This contributed to the later creation of the National Health Service in 1948, which placed the government as the central provider of care and health service provision and established government-run social services. Throughout this period, voluntary organisations continued to provide support and helped deliver care, often working alongside local authorities (Wiener & Cuellar, 1999). In the lead up to the 1970s, economic pressures were mounting and contributed to the spread of more neoliberal economic policies, which increasingly began to reshape public services when Margaret Thatcher became prime minister (Freeman, 2018; Scambler, 2023). Thatcher's economic policy focused on a reduction of public expenditure and an increased reliance on free market solutions, laying the groundwork for a shift towards welfare responsibilisation of individuals, private sector and community organisations, and voluntary organisations. These proposed cuts to state care provision were subject to significant public resistance (Scambler, 2023). The Community Care Act passed in 1990 brought on a shift from institutional care in residential homes towards community-based models of care that tasked local authorities with helping people live independently and which led to a heightened contribution to care by third-sector organisations (Scambler, 2023; Turner, 2004; Wiener & Cuellar, 1999). This effect was further amplified by increasing measures to increase privatisation, efforts to support people in their homes were subject to cuts to local government funding, and a reduction of public sector investment, with volunteer labour which was framed as allowing for greater tailoring of services to local needs being drawn on to fill the gaps.

In the 2000s, the government began to promote the concept of personalisation in care services, allowing individuals to manage their care budgets themselves and attempting to push maintenance costs for building and facilities onto private contractors (Scambler, 2023). This reflected market-driven decision-making, but it also placed more responsibility on individuals and families. The austerity policies following the 2008 financial crisis further weakened the public sector's ability to fund social care. With the Health and Social Care Act of 2012, partnerships with private providers and efforts to cut government spending further increased but were accompanied by a greater bureaucractic burden on the government and reliance on volunteers (Scambler, 2023). As part of this trend, the devolution of state power to the different regional governments of the United Kingdom has needed to take into account inequalities in service delivery due to differences in local resources and capabilities (Pemberton et al., 2015). The long-standing challenges of community care lack of funding, reliance on unpaid workers and risks of inequality and exploitation by for profit private sector providers that have been integrated into the public service were becoming more widespread as a result. To modernise the health service and to give people accessing healthcare a choice, for profit companies have started to be subcontracted by the National Health Service, in the wake of structural shifts introduced in the Health and Social Care Act of 2022 (Scambler, 2023). The reliance on volunteer labour has compounded issues such as staff shortages and low wages in the formal care sector. There is an increasing demand for care services, but the sector remains underfunded and increasingly reliant on volunteers or poorly paid staff. While volunteers play an essential role, the increasing dependence on them in the face of shrinking state provision raises questions about the long-term sustainability and equity of care systems. The matter of volunteer-run support services will be critically explored in greater depth in Chapter 5. One notable role the Donor Family Network takes on is a point of entry and contact for deceased-donor relatives who want to learn more about the transplant community. Donor relatives who have not heard from some or all of the recipients of the donated organs can struggle to get a sense of the impact their decision to donate might have had. Because of this, the trustees of the network encourage donor relatives to attend events where organ recipients and donor relatives are each represented to celebrate the positive impact transplantation had on recipients' lives. One of the best opportunities for deceased-donor relatives to interact with recipients is at the annual British Transplant Games.

3.5 The British Transplant Games- a Mini-Olympics for organ recipients

The British Transplant Games are an event where organ recipients participate in various sporting competitions to represent their hospital's transplant team. The Games are held in different cities every year, and competitions are usually hosted in facilities belonging to a university in the host city, providing the necessary infrastructure for the sporting events. The British Transplant Games are organised by the charity "*Transplant Sport*". The first games, then entitled the "*Transplant Olympics*", occurred in Plymouth in 1978. Subsequently, the Games grew in scale and were hosted in a different city every year. In recent years, more than a thousand competitors of all ages have competed in more than twenty-five sporting events (British Transplant Games, 2023). They participate in sporting competitions ranging from cup-stacking[3] and obstacle course races for the younger competitors to track and field events, such as archery, darts, football, badminton, bowls, tennis, table tennis, squash, snooker, swimming, ten-pin bowling, volleyball, golf and cycling. All the competitions are part of the "*active transplant concept*" – an approach encouraging recipients to be active after the transplant and to look after their physical health (Greig, 2023). The recipient unit teams were often accompanied by family members and, in some cases, medical professionals. When I attended the British Transplant Games as part of my fieldwork, I registered as an events volunteer to actively contribute to the event while doing my research. After spending some time at the event, I could quickly appreciate how it had a powerful rhetorical effect on the participants. The events include an opening ceremony and medal ceremonies, which serve as opportunities for the event organisers to express their aims and promote their values in practice. During these opportunities, care is taken to emphasise recipient appreciation for and remembrance of "*donors and their families*". The intentions behind the Games, run by the are explicitly outlined on their website.

> *Running for over 40 years, the Westfield Health British Transplant Games are a celebration of life. (…) The Games are organised on behalf of Transplant Sport. They aim to raise awareness of the need for organ donation, encourage transplant recipients to lead active lifestyles and show appreciation for and remember donors and their families*. (Transplant Sport, 2023)

The British Transplant Games create small and large spaces for deceased-donor relatives to be represented as an essential part of the broader transplant community throughout the event schedule. The opening ceremony on the evening of the first day of competitions, usually held in the centre of the host city, includes annual practices of collective recognition, appreciation, representation and expressions of gratitude. Here, organ donors are honoured as those who enabled the competitors in attendance to participate. I will describe the most notable examples of this in what follows.

At the British Transplant Games, the acts of remembrance are for all deceased organ donors who, rather than being named individually, are represented through several symbolic objects during the

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[3] Cup-stacking is a sport where cups are stacked in different formations against a timer – the fastest competitor wins. At the Games, the number of cups and the shapes that needed to be achieved got harder with increasing competitor age and both recipient children and other children attending were permitted to compete.

ceremony. The ceremony always begins with the arrival of the competing teams, consisting of the recipients from the different transplant units and their families. The recipients arrive at the opening ceremony in their transplant unit team's uniform; they march in together, holding signs cheering on their teams, sometimes chanting as they are cheered on by the supporters and bystanders in attendance, as they make their way to the area in front of the main stage where the ceremony takes place.

Once all recipients have arrived, the groups of live donors and deceased-donor relatives are announced; they are welcomed last to give the recipients presents to applaud them as they walk by, providing donor relatives with a show of gratitude and appreciation and allowing recipients to express their respect and recognition as well. Additionally, there are multiple instances during the opening ceremony where the subject of suffering on both the recipient and the donor side is brought up and where organ donation is framed as a positive and, in some cases, a solution to end or improve that suffering. The Opening Ceremony, which I attended twice, once in the centre of Leeds in 2022 and once in the centre of Coventry in 2023, included two poignant moments of explicit symbolic

Figure 13: Tom's Baton (British Transplant Games, 2023)

remembrance: the handing over of “*Tom’s Baton*” and the lighting of the Transplant Flame. Tom’s Baton, pictured above, symbolises the handing over of the “*gift of life*” from deceased donors to transplant athletes and was created in memory of sport-loving deceased donor Tom after his passing. It is handed over to representatives of the host team from the city in which the Games are held each year as a handing-over of a baton to all recipient athletes present at that year's Games on behalf of deceased-donor relatives. It is both a symbol of remembrance for the deceased donors and a symbol of support and encouragement for the athletes who have arrived to compete (British Transplant Games, 2022). Additionally, a second sculpture was created by the Donor Family Network to remember deceased donors explicitly: the Transplant Flame. The flame is also intended to offer recipients hope and support on the donor relatives' behalf. It was created using the symbols used in the network’s logo: A butterfly and a forget-me-not flower to symbolise the remembrance of the donor and hope for the recipient. Both are surrounded by two hands that securely cradle the flame and the flowers and butterflies at its centre. The flame is lit every year by one of the donor relatives in attendance in remembrance of the deceased donors who enabled the recipients to compete.

Figure 12: The Transplant Flame

Additionally, the flame expresses support for the transplant athletes in attendance, a blessing from donor relatives to reassure and encourage them during the event.

Both the baton and the flame are reminiscent of the imagery used at the Olympics as a sporting competition that celebrates athletic excellence in various disciplines, with athletes competing on behalf of their country. Here, it is adapted to recognise the recipients' achievements in overcoming adversity and being strong in the face of health challenges in the context of a sense of belonging and pride for the transplant teams (instead of countries) they compete for. The athlete's oath, which is also read out on behalf of all the athletes present at the event, responds to these gestures with a further grateful acknowledgement of the contribution of the donors. One of the recipients reads the words and promises on behalf of the recipients that they will "*strive to give our best in the spirit of sport, for the honour of our teams, and in thanksgiving to our donors and families*" (British Transplant Games, 2023). The oath poignantly incorporates a familiar sentiment of a promise of fair competition often heard at sporting events. It can be understood as a demonstration of "*sportsmanship*", but beyond that, it continues with an acknowledgement of the support that recipients received to be able to be there. While the focus is heavily on gratitude for deceased-donor relatives and donor support[4], there is also an acknowledgement of the suffering that recipients have endured and the challenges they continue to face.

Much like the rhetoric outlined in the previous section, the British Transplant Games adapt familiar cultural symbols and consciously incorporate these into the event to invoke a particular kind of social recognition. Here, organisers borrow imagery from the Olympic Games to creatively assemble existing powerful symbolism to form a kind of pastiche. In this pastiche, elements that work well in other contexts, such as the Olympic Flame, are adapted into new contexts. This phenomenon can indicate a flow of ideas, practices, and symbols that lead to the creation of a new multifaceted cultural landscape (Clifford, 1988). The event and the identities incorporated within it have been constructed like a bricolage, that is, using familiar cultural images that have new meanings in the organ donation context (also see Fischer and Marcus, 1996). One of the Olympic Games symbols brought into the transplant sport context is the Transplant Flame, modelled after the Olympic Flame used in the opening ceremony. Historically, the Olympic Flame is connected to the moral values of Olympism, namely excellence, friendship and respect, and coincides with philosophies of international understanding and peaceful coexistence (Maguire, Black and Darlington, 2015). These values are reminiscent of those expressed by the transplant oath, which similarly emphasises the importance of mutual respect, gratitude and understanding. However, the oath athletes at the Transplant Games compete in

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[4] In the context of the British Transplant Games, this always incorporates both living and deceased-donors

coherence with also requires that athletes compete in the spirit of thanksgiving to their donors and relatives, who are presented as essential to enable their participation at the event. The imagery of the Olympic Flame is connected to the origins of the Olympic Games in ancient Greece. It is traditionally lit “in front of the ruins of the Temple of Hera in Olympia using the sun’s rays to ensure its purity”(Maguire, Black and Darlington, 2015, p. 118). Conversely, the Transplant Flame is lit at the Games as part of the Opening Ceremony by a deceased-donor relative as a representative of all donors and deceased-donor relatives. The powerful ritual performance of the Olympic Flame Relay, in which the flame is carried by hand across different parts of the world and passes through the hands of different groups of people while always being kept alive as a symbol of cooperation and connection, is less relevant for the Transplant Games at first glance (MacAloon, 2012). However, the connection between the donor organ and the recipient body that is represented by the Transplant Flame can be understood in this context – rather than cooperation between different groups of people that work together to keep the flame lit, the flame here can be understood as a symbol for the donor organ and its role in supporting the recipient so that they can compete. Cooperation then exists between deceased and living donors, their relatives and the recipients in attendance.

Where the Olympic Flame has in modern times been presented as a symbol for the moral virtues of the Games and its noble mission to facilitate international understanding and cooperation (Maguire, Black and Darlington, 2015), the Transplant Games have a moral message too that can serve the production of a public understanding of organ donation as a moral virtue. Indeed, the Paralympic Games for people living with disabilities have borrowed much of the same Olympic symbolism a few years earlier than the Transplant Sports events. Here, the idea is to allow people who cannot compete in the Olympic sporting competitions due to their disability to access an alternative space for competition, where sporting achievements can be celebrated and recognised similarly. However, organ recipients too are physically impacted by the donation. They must remain on heavy medication for the organ transplant that they have received, which prevents them from participating at the Olympic level. Crucially, the Paralympic Games do not have a category for transplant athletes, as transplant recipients are not generally classed as disabled as a result of the organ transplant (BBC, 2023). Because the Transplant Games concept was developed specifically for the needs of organ recipients, they create a space in which symbolism is invoked with an added sensitivity for the questions that may linger in the minds of recipients (Slapak, 2022). Initiatives like Tom’s Baton that create a “*blessing*” from donor relatives, therefore, do not exclusively exist to respond to the deceased-donor relatives' desire to demonstrate their part in the Games but also to reassure recipients who may feel guilty about having received an organ from a living or deceased donor.

Furthermore, the Transplant Games create a space for deceased-donor memorialisation as part of the opening ceremony and throughout the Games. Those in attendance will receive the call for collective remembrance in this context since sporting event ceremonies in modern society have frequently become a source of opportunities for collective mourning (Herzog, 2015). Football stadium spaces often provide the proper arena for a passionate community of supporters to mourn one of their own or to support a mourning community member (Herzog, 2015). For example, places and things may be named after a deceased community member to leave a permanent legacy and a symbol of remembrance at the heart of the community – in many cases, within or near the stadium facilities. One poignant example such example from recent years was the show of support from fans at Sunderland AFC, who stood in solidarity with the family of Bradley Lowery, a young fan who was a keen supporter of the club who died from cancer when he was only six years old. Fans later started a petition to name a stand at the stadium after the young boy, who received over 50.000 signatures. Similarly, one-off remembrance events, including minutes of silence, are often held in the wake of the death of prominent figures at sports clubs before the start of matches. The British Transplant Games recognition for the loss of the deceased-donor relatives is different because the organs donated by the deceased-donors and their relatives play a role at every transplant sport event; the deceased-donors are repeatedly remembered as part of the annual tradition. Additionally, there is rarely recognition for one person; instead, the commemoration at the Games adopts symbols and practices that can facilitate remembrance of a group of anonymous people as a sign of gratitude and respect. This point will be explored in greater depth in Chapter 7. Overall, the rituals and symbols used throughout the event are not new; they draw on familiar sporting and cultural imagery. Throughout the event, care has been taken to ensure recognition for deceased-donor relatives is included, making the event a powerful space for many deceased-donor relatives who struggle to get a sense of the impact their donation might have had.

Figure 14: Recipient teams and supporters watch the opening ceremony at the British Transplant Games in Leeds (2022)

According to the Donor Family Network, the Games can provide a space where donor relatives can better understand what their decision to donate has meant for recipients' lives. Often, members of the network who attend have the opportunity to reinforce their support for recipients. For example, they indirectly help enable recipients in attendance to participate by handing out some of the medals to the competitors during the different medal ceremonies. The members of the Donor Family Network who attend usually find time for a small network gathering for the donor relatives in the city where the games are hosted, which generally takes the form of a shared meal. Donor relatives do not need to rely on the Donor Family Network if they want to attend the event. Anyone can sign up through the online event organising system or come along as a spectator without registering. NHSBT usually also have representatives present. Many deceased-donor relatives and transplant athletes who attend enjoy being an active part of the transplant community and personally involving themselves in the world of transplantation in their free time. The Games can be one of many events that spark a desire to become more active in volunteer, advocacy or educational work.

3.6 Donation education and the Organ Donation Ambassador Programme

Some deceased-donor relatives draw on their experiences to create artwork, public information materials or memorials; others attend transplant-themed events like those outlined above or respond to calls for focus group members or charity supporters. NHSBT representatives do not just work alongside these kinds of activities; they have also created a space that semi-formally incorporates a select few deceased-donor relatives into their efforts to educate members of the public about organ donation. The next chapter introduces how this is done in the form of a volunteer workforce named the "*Organ Donation Ambassador Programme*". The Organ Donation Ambassador Programme is a programme run by NHSBT to educate the public about organ donation with the help of people who can share personal stories known to have more traction on modern media platforms.

The Organ Donation Ambassador Programme is an example of a volunteer-based semi-professional public health messaging and education service which blurs the lines between statutory and volunteer-run service provision. Volunteers have long worked within the NHS and acted as a source of support for the health service, but this trend has been further amplified following the recent Covid-19 pandemic. Approximately 12 million people are thought to have supported the NHS in volunteer roles during this time (NHS, 2023). Plans from the NHS Volunteering Taskforce intend to improve the usefulness of volunteers, including in "*operational roles*", to build efficiency and effectiveness but also want to ensure that volunteer well-being and skill development are looked after (NHS, 2023). Additionally, research in the NHS on both patient conditions and patient experiences is frequently supported by "*altruistic*" volunteers who put themselves forward to support research that could help others within a national health service that collectively looks after the community (Adams and McKevitt, 2015). Adams and McKevitt (2015) discuss how participation in clinical research and feedback provision has been framed as an "*entitlement*" by the Department of Health that is part of a right to have one's experiences recognised. However, such work is presented as providing patients with a voluntary opportunity to share their experiences and, perhaps, to improve those of others in a similar position. However, in doing so, the health service must also recognise the demands on patients in terms of time and money that arise as a result. Additionally, the privatisation of the health service through outsourcing and sub-contracting amid funding cuts has seen an increased risk of high levels of inequality in terms of care provision as some communities have a greater capacity to work as volunteers to support one another than others (Prato, 2023). In the context of these developments, I present the outline of the Organ Donation Ambassador Programme, which recruits people who have been personally affected by and involved with organ donation to act as a public health education task force instead of recruiting patients for research.

The programme was proposed as part of the move to a soft opt-out law for organ donation in England. The initiative relies on volunteers who want to help alleviate pressure on health services by using their personal experiences and donation stories to help educate the public and promote organ donation on behalf of NHSBT. The information on the Ambassador Programme I have gathered here relies on an interview with a representative for the programme and programme planning reports, which stress the intended value of the proposed programme to volunteers, to the NHS and cost-effectiveness in an increasingly resource-constrained health system.

The programme has 65 ambassadors who have all volunteered to share their stories of organ donation to help educate the public on the topic. In doing so, they have agreed to help promote some key messages on behalf of NHSBT, including the need for organ donation discussions with one's family. Making sure these messages are shared with the public is a crucial condition for the new opt-out law to work the way it is intended, to spread its intended message of deemed consent. The opportunity to be an ambassador for NHSBT is framed as a chance for people who are ready to "*think about what happened and process everything*". The representative emphasised how helpful and "*almost therapeutic*" such an experience could be and that it could be "*a celebration of the gift of life*". A key message of the programme is to emphasise the importance of discussing one's donation preferences with one's family to prepare members of the public for the possibility of organ donation should the situation arise. The programme planning report placed a greater emphasis on the potential benefits to the NHS than on the ambassadors but covered similar points:

> *The benefits and added value of volunteers include (1) increased reach of the organ donation message and capacity to cover requests for organ donation promotion stands, speaking engagements, and school presentations, (2) groups of trained representatives to localise and implement high-level marketing strategies, (3) lightening the current pressures placed on SN-ODs [Specialist Nurse – Organ Donation] to cover such events, (4) inspiring, personal testimonies which increase the impact of the donation message, and (5) the value of a volunteer can also be financially measured by calculating the number of hours of volunteer time multiplied by the current national minimum wage.*

The volunteers can provide a potentially higher impact message following training and alleviate the pressure on the current employees, such as specialist nurses, who already grapple with a high degree of responsibility. Moreover, while the role of the ambassador coordinator is paid, the team of volunteer ambassadors consisting of donor families, live donors, recipients and healthcare professionals provide a free workforce which can be specialised and trained to present the message on organ donation in a wide range of suitable environments, including those they identify themselves.

> *There are several channels through which the Co-ordinator will recruit potential Ambassadors to the new programme, which are minimal- to no-cost, yet effective. These include direct referrals from the SN-ODs of donor family members, recipients, living donors, etc., who are already active in the local community. Recruitment can also be achieved by working closely with the Lead Nurse Recipient Coordinator and collaborating with the Donor Record Department (DRD), Lead Nurse Family Aftercare, Donor Family Network, and the existing partnership with the Order of St. John. Ambassadors can also be recruited via social media platforms and the NHSBT website (Source 2018 NHSBT Report)*

The recruitment process is exceptionally cost-effective, primarily relying on organisations like the charities discussed in previous chapters, healthcare professionals, and individuals who reach out and register an interest online. This has the advantage that the people coming forward are likely to be already knowledgeable and familiar with some aspects of the transplant process or have prior experience attending organ donation talks. Recruiters assess whether a potential candidate would be suitable for the programme, and volunteers are trained before they become active. There is a limited number of available volunteer spaces, meaning only a tiny portion of deceased-donor relatives have taken on this formal role. The unique personal perspective from personal experience the volunteers can offer is viewed as highly valuable, and the workforce wants to use volunteers because "*The families are the only ones able to describe and communicate that feeling"*. The programme explains that:

> *If you have never had the experience of it, you would not be able to share it. Right now, people are just meant to speak about it. The programme works with diverse communities and provides education on what could happen and how it could affect them. It stresses the fact that donation comes down to personal choice. You always meet some individuals who do not want to donate, which is their choice; the choice is very important and speaking to the family is so important.*

In this sense, the programme is intended to educate the public in the first instance. Still, the objective of increasing rates of consent to deceased donation with the help of people who share their positive donation stories is clear. Because the programme does not want to risk reducing consent rates, training and guidance are available for volunteers and scrutiny in recruiting. Like the donation decision, the willingness to support the programme as an ambassador is rewarded with gratitude and "*recognition*".

> *Recognition: A key element of volunteer engagement is to ensure the Ambassadors feel valued and are having a fulfilling volunteer experience. (…) However, Ambassadors will also be asked upon recruitment and in an annual survey how they like to be recognised to ensure volunteers*

> *are receiving thanks from the organisation in a way that is meaningful to them. (Source 2018 NHSBT Report)*

The intended management of the volunteers in the programme speaks to the long history of volunteer workers within the NHS. NHS volunteers often use NHS-branded materials when engaging in advocacy work, and their activities are subject to state-centric objectives. The altruistic motivations of volunteers and their state-centric role in delivering information and support as deemed appropriate and where needed usually coexist in formalised volunteer schemes. As indicated earlier, England has been described as a "*nation of volunteers*", and the recent COVID-19 pandemic has acted as a recruitment opportunity for people who want to become active in public support opportunities for the country and health service (Stewart, 2023). The degree of reliance on volunteer support becomes evident when comparing the English health education model to that in Germany, where the responsibility to answer questions about organ donation for members of the public is usually placed within official institutions or as part of professional roles. For example, general practitioners have recently been asked to act as a point of contact for queries about organ donation. In England, volunteer programmes are viewed as a chance to increase the representation of people privately affected in public messaging. In doing so, a chance to incorporate and represent diverse perspectives is intended to be created (NHS, 2023). Event requests and the appropriate selection of ambassadors to speak in specific settings are something the ambassador programme wants to "*carefully manage*".

> *Working alongside the ODT Lead Nurse for Diversity, a specific element of the Organ Donation Ambassador Programme strategy will be the engagement of Black, Asian and minority community volunteer Ambassadors who are willing to represent NHSBT and the positive message of organ donation within their communities.* (Source 2018 NHSBT Report)

The programme wants to maximise the impact of a positive message and experiences thought to represent the specific needs of "*diverse*" groups by remaining closely involved in team selection and message delivery, not least because they want the ambassadors to feel *"safe*" and *"comfortable"*. While the NHS encourages volunteers to share their stories, they do not want them to do so to the detriment of their "*wellbeing*"; instead, they need to make sure *"people feel ready to speak about their personal loss"* and can "*be engaged about it*". With some aspects of volunteer selection, there is limited transparency, and there is a desire to send ambassadors who have appropriate "*personal characteristics*" for different settings, with the ethnic or religious background of audiences at specific events acting as a factor that can influence the choice of volunteer/s who is/are sent. There are different age ranges within the volunteers, and there is some acceptance that the same messaging might not work for everybody. The programme coordinator explains that:

> *It is often essential to respect the venue and the culture – it is about creating a really good impression, and the whole experience is difficult because losing someone is stressful and challenging in and of itself. Talking about donation can impact how we talk about that person in a positive way. There are certain key policies and procedures, but it depends on who you speak to some degree, and you try to fit everything into the right niche as much as possible*".

The training for ambassadors responds to this need to ensure the donation message is "*consistent and accurate*" and prepares the ambassadors for things to bear in mind for specific settings, not least to avoid damaging messages that negatively impact donation numbers or spread misinformation.

To help volunteers do this, information materials and a sense of "*humbleness and care*" are offered in exchange for the hard work they do *"in the spirit of engagement"* and on a mission to promote "*real true facts"* and "*alleviate misconceptions"*. Thus, the ambassador programme draws on a select group of deceased-donor relatives and their experiences, as well as NHS guidelines and information materials, to help prepare potential future donor relatives for a situation where organ donation could be possible. The two main reasons why volunteers can step into a formal role where they do this for the NHS is to save costs and time for paid NHS staff, to ensure the accuracy of accounts of the donation experience for deceased-donor relatives, and to make the message as persuasive as possible, by bringing (positive) private stories into public spaces. For those deceased-donor relatives who cannot be official NHSBT Ambassadors, a host of other opportunities to engage in volunteer or advocacy work around organ donation that allows them to share their personal experiences can be found online and in person. Such alternative opportunities, especially when done independently of a larger organisation, may qualify for a greater degree of freedom in the way the personal story is shared. Sharing a deceased-donation story is almost always an exercise of reflection on the decision to donate itself, the hospital process, what it has meant for the legacy of the deceased, and the rest of the lives of the surviving relatives. A small number of representatives indicates what organ donation is like for deceased-donor relatives (and other people affected by donation) based on their personal experiences. These first-hand experiences are what causes them to be recruited as "*experts*". However, the members of the semi-professional volunteer ambassador workforce are also encouraged to utilise NHS materials and to be mindful of NHS guidelines. In this context, questions can be raised regarding the representativeness of the perspectives shared by this smaller group for the whole spectrum of people involved. This point will be developed in greater depth in Chapter 8.

3.7 Conclusion

This chapter has outlined how the spaces and experiences deceased-donor relatives might encounter impact upon their lives after the experience of a loss which was accompanied by the decision to consent to organ donation. In doing so, it has assembled a preliminary bricolage of the different contexts and pieces of information that are encountered. In summary, public health campaigns and information materials seek to prepare deceased-donor relatives for a new kind of moral choice that they can make in the event of a relative's death that renders their relative a potential organ donor. They seek to provide contextual information relevant to the donation decision. Service guidelines take steps to ensure that relatives are well-supported and that the difficult situation they are in when asked to consent is acknowledged, with specialist staff available to help guide them through the process. After the donation, materials intended to honour the deceased's memory and express gratitude to deceased-donor relatives are sent out, often to emphasise the positive impact the decision to donate had. The idea of organ donation as the gift of life is frequently part of this message, and the positive impact that donation can have on the lives of recipients is emphasised. Many materials designed to honour donation can also be worn to demonstrate support for organ donation publicly. They rely on familiar cultural symbols that have been adapted for the context of donation and employ specific rhetoric to influence the donor relative experience.

Where donor relatives need further support or information, they can reach out to charities like the Donor Family Network and become a part of their community of "*donor families*". The Donor Family Network facilitates collective remembrance and advocates for the "*donor family perspective*" in various capacities to the best of their ability. Other events emphasising transplantation's positive impact on recipients' lives, like the British Transplant Games, also have space for donor relatives to attend and recognise the role of relatives and living and deceased donors in promoting and championing recipient health. The many volunteer and charity-run initiatives in the transplant community in England can be contributed to and supported by deceased-donor relatives who want to share their story. There is a push within the transplant service to include volunteer perspectives and experiences in the discourse designed to educate the public about organ donation. Deceased-donor relatives are thought to have unique insights into how the transplant process feels for other relatives and to be able to provide engaging and authentic personal accounts of donation. Raising awareness of donation and telling their "*donation story*" is also thought to be beneficial for donor relatives who are given a chance to reflect on the donation and to remember their relatives. However, little research has been done to describe how these various processes and initiatives are received and experienced by deceased-donor relatives. This will be the subject of the next chapter.

4. Unravelling Relational Tensions in Donation Service Interactions

4.1 Introduction

The body's ontology in medical settings has long been identified as a matter of great complexity in the anthropological literature. During organ donation request and retrieval processes in hospitals, the presence of relatives grieving their loss coincides with the legally and medically complex process of organ removal. This chapter reveals the potential organ donor's body as a profoundly relational entity. The different ways in which relatives and medical professionals understand and treat the body in the hospital setting and how these can contribute to shaping deceased-donor relatives' donation experiences will be discussed in-depth. Before I form the main themes from my conversations with deceased-donor relatives, it is necessary to set the scene by drawing on a vignette. The below vignette has been compiled as an account of how I imagine it feels to sit in a hospital room being asked to make a decision about organ donation. The vignette is based on the recollected accounts of my interlocutors, and serves both as an illustration of the context for the main arguments in this chapter and as a tool to reveal my positionality to the reader – in other words, it is grounded in the data.

Imagine you are sitting in a room in a hospital, in the middle of the night. You are with a number of other members of your family. You have just received terrible news from the doctors who have been caring for someone you love. The doctors have informed you that they have conducted a neurological test to determine if there is any remaining detectable brain stem activity. Sadly, the test led the medical team to confirm brainstem death – you have been told there is no remaining chance of recovery and that several machines are being used to administer care artificially to maintain your relative's vital functions. You are in shock, you feel overwhelmed by the news, struggling to come to terms with the reality of the information you have just received from the medical team. Slowly, you begin to accept the death of your relative. The clinician who informed you of the outcome of the neurological test that confirmed your relative's death leaves. A specialist nurse for organ donation enters the room.

The specialist nurse explains that because your relative did not record a wish to opt out of organ donation, it is believed that it was their wish to donate their organs after their death to help somebody waiting for a transplant. The nurse asks you whether you want to honor their decision and agree to organ donation on their behalf. Suddenly, you have been asked to make a decision – a decision about your relatives' body that you never expected to be asked to make. Questions begin to rush through your head. You try to reconcile the image of your relative in the hospital bed with the way you used to see them every day. You think about the way they looked before they suddenly fell ill, you think about what *they mean to you. You look at them and you still see the person you love, and you try to grasp the reality of their death. You think about the memories that you share together, and the kind of person that they are. You wonder what they would have wanted, and whether the fact that they did not opt out of organ donation really means that they would have wanted to become an organ donor. You recall the many times your relative helped others, how kind they are, and you try to remember whether you ever spoke to them about organ donation. Despite knowing that brain death has been confirmed, you feel protective of them, you want to spend time near their body, for one last time. The decision you are being asked to make feels like a new opportunity, but the environment you are in and the prospect of donating feel entirely unfamiliar. After speaking to your family, you agree to consent to organ donation on behalf of your relative – you all believe that they would have wanted to become an organ donor if it meant improving the lives of others.*

After sharing your decision and intention to donate with the specialist nurse, you are given a donation consent form which lists the different organs that your relative can donate. The nurse explains which of their organs are eligible for donation based on the condition that your relative's body is in. The list of organs is long – your eyes rush over the page: Kidneys, Liver, Pancreas, Heart, Lungs, Bowel, Skin, Eyes, Bone, Meniscus – you read about cells, you see boxes asking you to tick the options which apply – you read questions asking about the possibility of transferring the body to facilitate organ removal. The nurse reassures you that you can take some time to decide. Together with your family, you speak about what donation would mean in practice for the first time – should you consent to donating everything you can? Should you donate your relative's eyes, or their heart? Are there any organs that you would want to bury them with, are there organs that you think you cannot agree to give? You wonder what will happen to the organs once they are removed, you try to imagine who they might go to. You think a million unfamiliar thoughts for the first time.

The analysis in this chapter draws on the idea of multiple ontologies of the body that appear in the organ donation context in a hospital setting, and argues that greater consideration for these multiple coexisting realities is conducive to better understanding the experiences of donor relatives in this context. The term "*ontology*" refers to "*the part of philosophy that studies what it means to exist*" (Cambridge Dictionary, 2024). The idea of multiple ontologies, taking inspiration from Mol's work, has previously been applied to the donation context by Zivkovic (Zivkovic, 2022). She uses it in her discussion of how multiple realities of death can coexist and conflict in the context of organ donation when comparing Buddhist beliefs about death with the biomedical definition of brain death in Australia. Multiple ontologies of the body are relevant to organ donation, because they are concerned with the way problems and opportunities are framed, the body and its functions are being interpreted and contextualised, and the different lived realities that are being impacted and shaped by the possibility of organ donation. The idea of multiple ontologies articulates the way in which human bodies are "*intertwined*" and "*in tension*", "*shaped by our technologies*", the classification and manipulation of our bodily functions and the identities that are assigned to our bodies by ourselves and others in- and outside the context of medical settings (Mol, 2003, pp. 6–7). In her book on the different ways the bodies of people with atherosclerosis in Dutch hospitals are understood by medical and healthcare professionals, patients, and their relatives, Annemarie Mol highlights the different ways of understanding the body that coexist in the clinical setting. Mol's study proposes the concept of an ontological pluralism of the body (Mol, 2003). In this approach, the body is understood as simultaneously existing in multiple different forms, depending on the context in which it is situated. For example, she discusses the treatment of a patient's body with a heart condition to emphasise that cardiologists, nurses and surgeons each applied their own "*ontological frameworks*" to the body, in line with their respective disciplinary perspectives. Additionally, she added "*perspectives*" from non-human actors to the factors shaping ontological assumptions by highlighting how new medical technologies could cause changes to the clinical routines chosen to treat patients. Her discussion highlights how material medical technologies can play an active role in how patients' bodies are understood. The data analysed in this chapter details the way in which deceased-donor relatives have described the way they felt when they learned that their relative had been declared braindead or that they were expected to die. They discuss what it was like to hear about the possibility to donate, to try to determine what the right decision would be, how it felt to spend time in the hospital setting and to interact with medical staff, and what considerations influenced their decision when it came to deciding what organs to give. I outline how many of the relatives I spoke to recounted being told the necessary clinical information, interacting with the specialist teams, seeing the donor undergo various checks, waiting for organ removal to take place, saying goodbye, trying to cope with the reality of their loss whilst completing the necessary legal steps for donation to ahead. I discuss how for most donor relatives, their identities had become interconnected with their relationship to the donor, and their own realities dramatically changed as a result of the donor's death, but how they could not immediately grasp this shift, often still perceiving the donor's ventilated body as synonymous with the person. I posit that the process of organ donation asks the relatives, over a relatively short period of time, to comprehend a double transformation of the donor's body: first, when they learn that the donor has died or is expected to die and that organ donation has become a practical possibility, and second, when they are given the consent form and asked to indicate which of the donor's organ they consent to donate. The analysis in this chapter consults personal accounts of how the time and interaction in the hospital impact the overall experiences of organ donation for the relatives who had given their consent to donation. Here, isolated parts and supplementary materials come together to create an emerging notion of the donor body as one entangled within a web of relational ties that influence every part of the process. Before I move on to the discussion of these insights, I want to indicate how its content connects to the existing literature. The unfamiliarity of most with the notion that a body is not being cared for to survive and to be kept from dying but instead to ensure that the organs inside can be used to help another has been aptly discussed by Lesley Sharp (2006). In her ethnography on the experiences of deceased-donor relatives following donation in America, she emphasises that people living in the West have come to see death as a failure of the health service to prolong the life of the patient. Commenting on her idea, Arnar Árnason (2020) has described how, in Iceland, organ donation campaigns surrounding a deemed consent law similar to that in the UK show that a particular rhetorical effort is being made. According to him, this effort seeks to transform the understanding of organ donation as something that follows a bad death in the minds of members of the population through donation campaigns and debates. Instead, the great need for donor organs to improve or to save the lives of relatives is emphasised as something that can make a bad death good to some extent. Namely because the circumstances of a "*bad*" death – something that the medical service could not avoid, is constructed into a new opportunity to enhance the lives of others in need (Árnason, 2020). However, this narrative of organ donation as a process that has transformative power for how relatives later think of the death can be challenged or jeopardised during interactions in the hospital setting. Even though care provided to the donor's body during preparation for organ retrieval is no longer intended to save the life of the donor, the literature has emphasised the need to ensure that the relative's potential protectiveness and continued emotional attachment to the body is taken into consideration (Sque et al., 2008). For example, ideas around the continuing social processes that influence how the donor should be cared for are described by Sara Bea in her work in Spain, which describes the donor as a "*relational person*" whose relatives are tasked with "*transferring or inferring*" the donation preference. In contrast, the donor is first treated as a patient and later as a deceased body (Bea, 2020, p.1935). The idea of the organ donor as a patient who is embedded in the hospital processes becomes challenged in the context of the recipient simultaneously, as well as being a patient, rendering the donor's presence relevant, particularly in light of organ procurement (Bea, 2020). Consequently, friction can arise between the healthcare professionals who are tasked with ensuring that the transplant is as successful as possible, and the family members present. To some extent, professionals need to perceive the donor regarding vital functions from a biomedical perspective, in which the body is no longer thought of as a relational person but instead fragmented and thought of in terms of the health of the organs that are inside of it. These contexts in which biomedical processes and terminology work to "*disassemble*" the body and how practices of memorialisation and forms of acknowledgement for the dead body that is being worked with can be re-assembled are explored in the context of body dissection in medical school in the academic literature (Hallam, 2020). The phenomenon that Hallam terms "*relational anatomy*" is very relevant to the discussion in this chapter. After all, the concept of organ donation as an abstract opportunity to enact a moral good because of a bad death and to make that death less wasteful is more difficult to evoke in the minds of relatives amid the highly medicalised processes required to prepare the donor body for organ retrieval.

In her work on the experiences of Danish donor relatives in ICU settings, Anja Jensen has highlighted the conflicting experiences of Danish donor families who are in the presence of a braindead relative in hospital prior to organ retrieval, who seems to be "*simultaneously dead and alive*" (Jensen, 2011, p.131). In this instance, the author is referring to the seemingly alive, brain-dead donor bodies whose vital functions are being kept alive prior to organ removal. Jensen describes the difficulty of families trying to "*find the privacy and peace needed to say goodbye*" and feeling "*clearly uncomfortable in the surroundings of intensive care units*" (Jensen, 2011, p.131-132) as ways to emphasise that the biomedical process needed to facilitate donation can interrupt newly bereaved relatives grappling with the reality of the death. This is because deaths disrupt the social realities of the surviving relatives that are situated within the relationships between the living and the newly deceased, the state and legal system's understanding of the deceased person and their assets, as well as broader societal obligations and expectations (Simpson, 2020). The death of a person, followed by the act of giving consent to organ donation among relatives, can have an even more complex effect. This is because the relational status of the body and the organs within it, as well as obligations associated with the loss experienced by the relatives for the healthcare system and expectations held by the surviving relatives, cause ambiguity and sometimes tension. Consequently, the discussion in this chapter begins in the hospital setting as experienced by deceased-donor relatives in England in the context of the reaction to the news of the donor's imminent death and the possibility of organ donation.

Unravelling how relations between the different people and materials that influence the donation decision and subsequent donation experience for deceased-donor relatives in England can provide insights, allowing us to better understand the complexities of the factors that impact the construction of distinct ontologies of the body that exist in the hospital system. This includes the discovery of factors influencing the decision that are embedded in the individual circumstances of the loss and the processes that are experienced by relatives, as well as interactions with hospital staff and, therefore, difficult to predict. Learning of the inevitability of a relative's death is often a profound shock which often permanently reshapes the reality of the surviving relatives. Although the inevitability of the death must have been "*accepted*" by the donor relatives at the point when the possibility of organ donation is raised, the relative will not always perceive the donor's body as deceased when looking at it in the hospital. The different teams involved in the organ donation process who work for the health service must recognise and acknowledge such relational tensions whilst simultaneously ensuring the organs are as carefully prepared as possible to maximise the likelihood of donation success for the benefit of the recipient/s. The existence of specialist teams who work with the donor relatives and who are not also part of the team administering treatment for the donor preceding confirmation of the inevitability of the death nor part of the team caring for recipients is one attempt in which the health service has recognised the different ontologies of the body outlined above (NHSBT, 2023b). However, as briefly indicated above, the health service continues to require deceased-donor relatives to engage in a swift and ambiguous reimaging of the donor body in which it is no longer understood as simply synonymous with the person who they have a close relationship with. The donation process requires that deceased-donor relatives begin to think of the donor's body no longer as a living person and are being asked to understand a body that will inevitably be dead or is already dead before the question of donation can be raised. Then, in a second transformation, the donor's body must begin to be thought of as a collection of organs with the potential for helping others, which could be removed and given to someone else (ODT Clinical, 2023b). This double-transformation outlines the legal requirement for consent to organ donation, and the considerations that influence whether deceased-donor relatives give consent is the subject with which our exploration will begin.

4.2 Speaking for the deceased

The new soft opt-out law about organ donation in England was intended to alleviate one area of confusion that had been identified as a primary reason for relative's reluctance to consent to organ donation (Neades, 2009). This was dependent on whether the surviving relatives tasked with deciding about organ donation believed that donation is what the deceased would have wanted to do in cases where the deceased did not register their decision nor speak to their family about their preference before their death. The new law was intended to reassure relatives by letting them know that if their relative did not "opt-out" of organ donation, they could be deemed to have consented to it. However, according to the experiences of many of the people working to educate members of the public about organ donation, it seems to have created much confusion. According to conversations that some Organ Donation advocates I spoke to had with members of the public, some people no longer thought it was necessary to register their decision online or speak to their families about their donation preference because they took the new law to mean that they had automatically been added to the register. Among those who already registered themselves as organ donors, there was little awareness of the fact that surviving relatives could still overwrite the deceased's decision and decline to donate the dead person's organs. In my personal experience, many members of the public are still entirely unaware of the law change. This phenomenon has been linked to the COVID-19 pandemic-related public health information that was discussed just as the law change was due to come into effect (Parsons and Moorlock, 2020). Conclusively, evidence about whether the new law has reassured more people to consent to donation is not yet available. The impact of the law is difficult to assess because the factors influencing the discussion can be multiple and are not always entirely rationalised by the relatives until much later. The disconnect that has puzzled researchers and governments across the world is the higher levels of willingness to donate indicated by public opinion surveys about organ donation compared to the much lower rates of consent obtained in real-world settings. The setting in which the donation has a powerful influence on the decision that is taken. There is a difference between organ donation as a hypothetical step - asking someone to decide what they would hypothetically want to do - and the genuine circumstances under which relatives find themselves asked to determine what should happen to the body of the deceased.

Many public education and advocacy initiatives push donation promotion and education rhetoric to address possible religious, moral or trust-based concerns that could prevent donation that members of the public may have. Such campaigns frequently address religious beliefs about what happens to the body in death. In some cases, such beliefs about the imagined connection between the body and its organs and the soul or essence of the person can play a role in the decision that is made. For example, research by Ben Kasstan has emphasised the importance of burying a dead body whole among members of a Haredi Jewish community in England (Kasstan, 2017). In his account, he emphasises that the community has developed specific rituals of how to prepare dead bodies for burial in which all biological material connected to the body, including blood that was lost during an autopsy or possible accident, are collected, and buried with the body where possible (Kasstan, 2017). Organ donation in this context would mean that much biological material would be missing when the body is buried – it would be incomplete, which would likely act as a powerful obstacle to donation—on the other hand, tying powerful religious stories about the virtuous act of donating one's eyes to the promotion of cornea donation in Sri Lanka. A combination of detailed information as to what to expect from the cornea donation process has been shown to cause great willingness to donate among Sinhala Buddhists in the country (Simpson, 2020). Here, religious symbols were carefully adapted to give a rhetorical push to a story about the moral and religious virtues of eye donation. In England, many people who are from a minority ethnic background in England are disproportionately more likely to need an organ transplant and less likely to donate their organs (organdonation.nhs.uk, 2019). This disconnect is believed to be partially routed in concerns that organ donation may not be permissible as part of a person's religion and confusion about whether donation would comply with its teachings. This has prompted the inclusion of specific guidelines for specialist nurses that explain why people from minority backgrounds may need to be approached differently when the donation request is made. Ethnographic work conducted by Ciara Kierans and Jessie Cooper has revealed this practice to be highly problematic because concerns over attitudes among the relatives of "*minority*" or "*ethnic*" donors contribute to a change of behaviour among medical staff, resulting in differential treatment, which was believed to respond to the different care needs (Kierans and Cooper, 2013; Cooper and Kierans, 2016). The authors raise their concern that additional pressure on people perceived to be potentially "*problematic*" based on their religion or ethnicity contributes to a projection of a disproportionately high responsibility to donate and a culturalisation and racialisation of the donation decision itself (p. 221). Their work highlights the possibility that there can be a false assumption about the relevance of religious beliefs and ethnic background for the donation decision that is ultimately taken and underlines the importance of looking for the recollected donation decision influenced by relatives who have decided about organ donation on behalf of a relative.

Indeed, ethnographic research by Sara Bea on how organ donation is deeply embedded and routinised in the running of a Spanish transplant hospital suggests that abstract cultural and moral beliefs could be less important than is often assumed (Bea, 2020). My insights from conversations with deceased-donor relatives, similarly, point to more reactive decisions born out of the context relatives found themselves in and not primarily bound by the factors surveys about transplant attitudes and health education campaigns frequently focus on.

I asked donor relatives about what they believed made them decide to consent to organ donation. Tina, a mother whose son died as a teenager and who is a very active part of the Donor Family Network, has had many opportunities to reflect on her decision.

> *For me, we were at the point where there was no choice, our son died very suddenly, but we still had the option of organ donation, and when that moment comes, we still had a choice, and that is very important to me, to be able to make a decision about something. And I always say, we made that decision, because it was the only decision we had left to make, you know, after everything else was taken away.*

Tina experienced the death of her son as something that left her powerless, something that put her in a position where she felt she was no longer able to help with further treatment options. Being asked about organ donation presented her with a final chance to be proactive and to decide. She felt that the staff in the hospital needed to ask her about donation because had she not been asked, she would not have had a final chance to choose. She said she felt glad that the staff had not been too scared that the question might upset her further and explained that nothing could have upset her more than the death of her child. In that instance, the context of the decision and the timing of the news of the death and the possibility of organ donation influenced her and her husband.

A second mother, Scarlett, whose daughter had died similarly unexpectedly when she was a toddler, said that being able to donate her daughter's organs had been a luxury. She felt she had been lucky because she had a chance to donate. When she learnt that her daughter would not recover, Scarlett had an almost visceral desire to donate; donation suddenly became essential to her. She was unsure why she felt this way, describing the decision as more of a reaction at the time. Scarlett later began to rationalise what might have caused her to feel this way but emphasised that organ donation had initially been a reaction. She also recalled feeling strongly that if she could spare someone else from going through the things she was experiencing, namely the mother of a recipient whose child may die without a donated organ, then she wanted to help. What she felt was almost unbearable, and she wanted to take the opportunity to try to prevent similar feelings in another mother who lost her child. Tina, on the other hand, explained that her knowledge of her child's character had played an important part in her decision – she thought that by consenting, she and her husband took the decision that their child would have made had they still been alive.

> *We truly believe it would have been his decision; he wanted to be a nurse, so we used that as our logic if you like. And the whole family, we all felt it is what he would have wanted, which is very important. But at the end of the day, we have to acknowledge that we made the decision, not him. So we were the ones who were put in that decision [sic].*

The recollection of the personal preferences and interests Tina's son had when he was alive and his aspirations for the future meant that Tina and her husband thought her son would have decided to donate. Still, ultimately, they could not be entirely sure. To take a decision, they had to draw on their memories of past exchanges that they had with their son and think about the kind of person they remembered him as – ultimately, the idea that they too were "*put*" in that decision indicates that the decision to donate was made together in an ambiguous sense. Within that ambiguity, Tina was keen to emphasise that she and her husband were responsible for the decision, taking a kind of moral ownership of the consequences of the decision. A different family, the Ibbingtons, another couple who lost their son when he was in his early teens, had a similar reason to donate but felt conflicted when they needed to decide.

> *You don't just discuss it in the home, not over the dinner table or outside the home with friends – most people do not want to talk about (organ donation). The decision to donate in our case was taken because we thought that is what he would have wanted, the kind of boy he was, although we did not know what his wishes were, he was only young. We kept being unsure,*

> *the hardest thing was when we were left alone in a room, where we waited, and I kept thinking, I might have changed my mind about it, and it was difficult to have a really long wait. It was just really hard to sit there thinking about everything, and they (the transplant nurses) did come in to check on us, but I just found it really hard.*

Mrs Ibbington chose to donate her son's organs together with her husband because they felt that it matched the character of their son – "*the kind of boy he was*". However, it was not a decision they were certain of and never questioned – they experienced doubts as they waited, particularly when left alone to reflect. Waiting for the transplant to be prepared proved challenging, leading them to go over the decision again and again. Once again, both parents drew on their interactions with their son, the time they spent together and how they viewed his personality to enable them to determine what he would have been most likely to choose had he been able to choose for himself. Because in doing so, there was no way to be 100% certain, the waiting caused them to doubt themselves and to go through much turmoil regarding the decision while they waited. The recollection of this moment was still upsetting for Mrs Ibbington, who came close to tears and was comforted by her husband.

Kathy, a mother who consented to donate the organs of her son, who died when he was a young adult, felt more confident that her son would have chosen to donate had he been able to make the decision himself.

> *It is always the families who have to decide. I know that he would have wanted it. I knew he would never breathe on his own.*

Kathy also reflected on what her son would have said had he been able to speak for himself, and because he could not, she spoke on his behalf. She was so sure that this was what he would have wanted that she decided to go through the lengthy process of waiting for organ removal in the hospital and stayed by his side the whole time – she was there because he needed her to speak for her, she was there on his behalf. Reflecting, Kathy recalled a very challenging time in the hospital, but changing her mind was not something she considered doing because making sure she went along with the donation process was her way of being there for her son. She stepped in as the closest thing to a representative for her son. Her account, along with the other accounts discussed here, indicates that doing what the deceased would have decided to do if they had been able to decide is often something relatives are anxious to ensure, and the deemed consent law is intended to make this process easier. However, sometimes even in cases where the potential donor officially registered a decision to donate, and the relatives are aware of this, they decide to overrule the deceased's wishes. This can be due to multiple reasons, but it indicates that honouring the deceased's preferences is not universally an objective that determines whether consent is given.

In my conversations, I found that deciding to donate was viewed as a matter of general moral principle and rationality. This question was thought of as separate from the death and the grief associated with it. The family that stood out with the most "*practical*" reasons was the Davies family, whose middle-aged son became an organ donor.

> *Within the 24 hours we all agreed on the spot that we would consent to donation. The main reasons for agreeing to donation was practicality, we think the agreement should happen by default and we had agreed earlier as a family. We personally have now experienced it through one family member.*

In our conversation, both parents frequently pointed to the values and ways of dealing with grief they had discussed "*as a family*". They had their own way of doing things and did not like to be overly emotional – their decision did not greatly influence the way they remembered their son; instead, it was almost viewed as a formality – an opportunity to do what was right and what made sense. In part, this desire was explained by their conviction that their son's organs would no longer be needed by him but were greatly needed by recipients waiting for a transplant. They did not recall the consent process as particularly strenuous or as having made the situation worse nor better. Overall, I was struck by the degree of distance they had created between the death, their memory of their son and the matter of organ donation. Their openness to contributing to my project pointed to a similar pragmatism – I needed people who had experienced the donation process to speak to for my research; this was something they could help with, which is why they were open to sharing their accounts with me. Their attitude overall pointed to a high baseline level of solidarity with suffering members of society who needed organs from deceased donors to improve their condition.

A similar kind of motivation to donate was described as a point of emphasis in Finnish organ donation campaigns, in which national solidarity and a willingness to "*give back*" were identified as common beliefs held by citizens who felt that they lived in a welfare state (Ådahl, 2020). However, participants did not believe that donations should go ahead automatically – the Finnish participants saw an important difference between their willingness to consent to donation to help others in a spirit of solidarity and the state taking automatic ownership over their bodies when they died. In this point, the prevailing narrative differs from the opinion held by the Davies family that "*the agreement should happen by default*". This points to the difference between organ donation as an opportunity to make an individual decision or a decision on behalf of an individual to help others (Árnason, 2020) and an obligation to meet a resource problem that exists in a country facing a "*shortage*" of organs offered for transplantation. Indeed, while a similar resource problem has not led to the adaptation of new opt-out legislation, my native Germany has, much like Finland in recent years, endeavoured to reframe the decision about organ donation as one of the big decisions in life that every person must take as a routine matter – simply because "*the decision counts*" ("*Die Entscheidung zählt")*. The reference to something that matters in the form of a numerical phrase (namely *"zählen"*- "*to count*") reminiscent of economic terminology seems like a strange coincidence in this context. It places the responsibility to think about donation outside of the responsibility of the state and into the personal affairs of private individuals who are part of a broader collective. If the state should not assume that someone was happy to donate if they did not opt-out as per the proposed and rejected German "hard" opt-out law, then private citizens who insisted on retaining the need for explicit consent ought to follow through and decide for themselves in life. The English donation law is a law that aims to nudge the decision by way of a more emotional appeal – the notion that donation is likely what the deceased wanted if the deceased did not opt-out. As shown by the discussion of factors influencing the decision earlier, the likely preferences of the deceased did seem to influence the decision that was taken. Most of the deceased-donor relatives I spoke to said that they desire to do what the person would have wanted influenced the decision. This gives rise to the hope that relatives who believe that the deceased knew the law and chose because they believed that the deceased could reasonably be deemed to have consented would effectively feel reassured. Many of the campaigns that NHSBT initiated recently have pushed members of the public to discuss their donation preference with their relatives to make it more likely that relatives felt certain about the potential donor's preference. This is the message that the words "*leave them certain*" is meant to communicate – the rhetoric powerfully invokes the idea of relatives being uncertain about what to do in the face of a loss as a situation to be avoided.

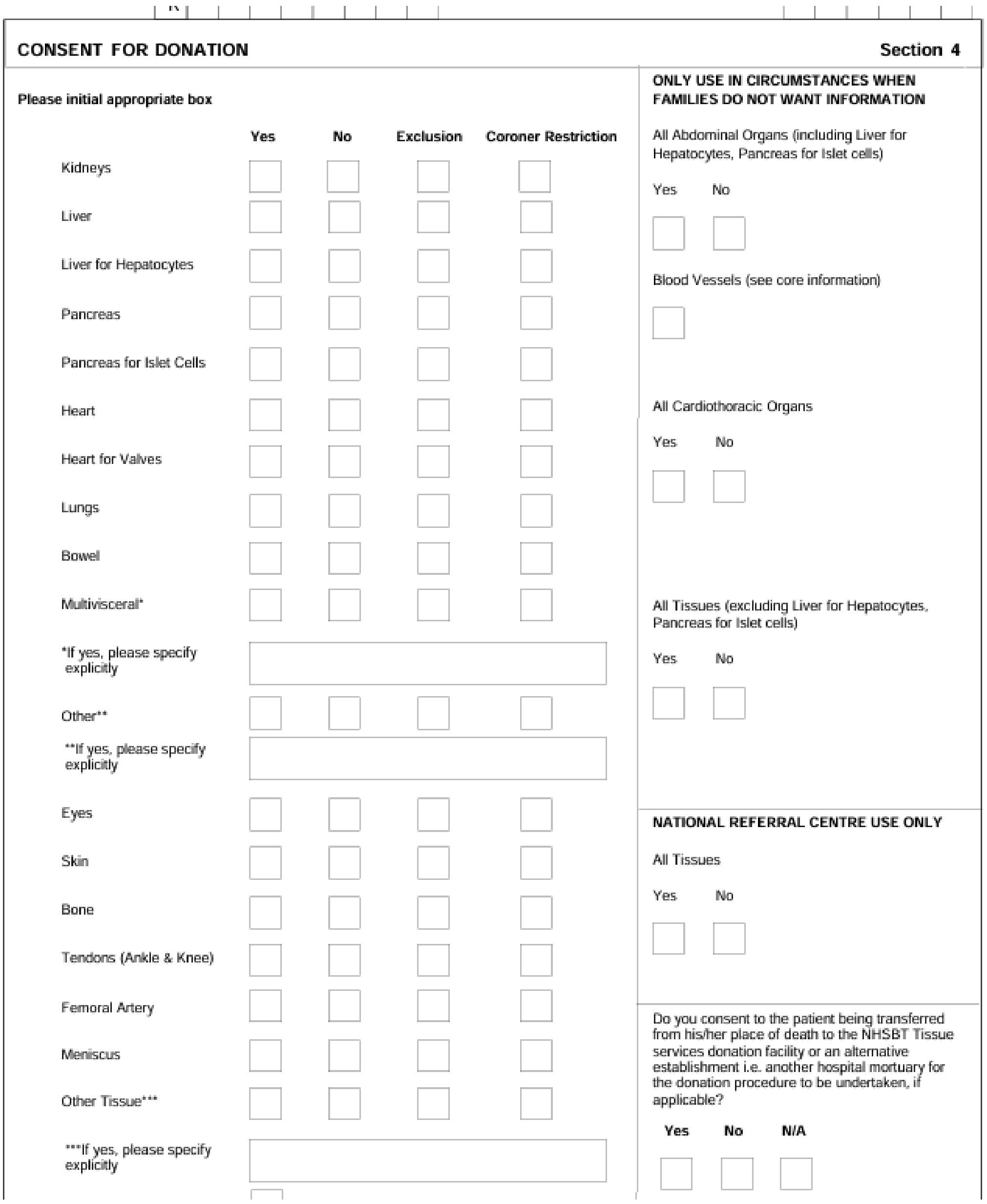
However, many of the relatives I spoke to also recalled that their decision to consent was at least partially reactive, indicating that there are remaining complexities in the process that are very difficult to prepare for. Scarlett had a visceral desire to consent before she took the time to think about why she felt that way – she experienced what can best be described as a "*need*" to donate. Similarly, Tina's initial response was that of having been left with a final decision that gave her some power over what would happen to her son when "*everything*" else had been taken away. Some part of her decision was an act of agency when faced with a very limited set of options. For Kathy, it took strength to stay by her son's side and to enable him to donate – she recalled the ICU environment as having been very difficult to be in. Similarly, needing to wait and being left to think about the decision and experiencing lingering uncertainty, imagining what organ removal would entail continued to be difficult for Mrs. Ibbington. She repeatedly considered "*changing her mind*" because she found everything very difficult to live through. Lastly, when a donation preference is discussed, the people affected rarely know whether they will ever be in a situation where they can become a donor. Even if a conversation with one's family was had, it can be difficult to have complete certainty that the deceased would have had the same preference had they known the decision would have an acute real-world impact. Organ donation campaigns seeking to change levels of consent and to start conversations about organ donation and its potential to help recipients in need cannot entirely do away with the ontological, emotional and procedural complexities that are involved in transplantation.

The recollected experiences and questions of my interlocutors presented in this chapter indicate that there are questions about the relationality between the donor as a person, their body, their organs and their relatives that are "*put in the decision*" of whether to donate. To better grasp these complexities, I want to move away from Western notions of self that conventionally see persons as individuals in more material terms and as bounded by flesh and blood (Farman, 2013). The secular institutions involved in organ donation conceptualise the person as synonymous with the material body up until the moment of death or, for the purposes of organ donation, the certainty of imminent circulatory death (Farman, 2013). Mind and body are understood as entangled, and the self is understood as bound to the tissues that make up the parts of the body. At the moment a person dies, this entanglement can, in some religions, shift. For example, the Sinhala Buddhist beliefs discussed in relation to eye donation at the beginning of this section are underpinned by a belief that the energy [vinnana] of a person leaves their body when they die, leaving the body as a husk. Here, a disconnect upon the moment of death between mind and body is imagined (Simpson, 2020). In contrast, the Haredi Jewish beliefs outlined earlier posit a continued connection between mind and body that necessitates the completeness of the body after death (Kasstan, 2017). The NHS website contains materials, including faith-based leaflets, that clarify what religious figures of authority have said about the permissibility of organ donation for several different faiths and help alleviate any faith-based concerns. However, in organ donation, the multiple ontologies of the body that exist during the consent process, together with the ambiguities that come from the legal definition of the person's death in the case of braindead donors, juxtaposed against the continued vital signs of bodies biomedically kept "alive" can cause further confusion. The donor relatives I spoke to described how they thought of their time in the hospital with the donor's body preceding organ removal as their final moments with the donor, while at the same time, they had just signed a legal document that confirmed they understood the donor had died/would die and consented to donate their organs, and medical professionals were interacting with the donor's body to prepare them for theatre. Although the death of the person must have been confirmed as inevitable for the donation conversation to take place, clinical guidance for donor care continues to refer to the deceased donor as a "*patient*"(NHSBT, 2023b). Simultaneously, reports on organ utilisation refer to the donor "*quality*" during this period, applying a classification that is more apt to describe a dead body rather than that of a "*patient*" (NHSBT, 2023d). For the relatives of donors who are in attendance in the hospital, being by the side of the donor's body can often feel as though they are still spending time with the person. At the same time, they must draw on their memories from past interactions with the person and any information they may have about the person's donor registration status to determine "*what they would have wanted*". The bounded definition of personhood and self, outlined above, has analytical limitations when one tries to capture the complexities involved in the donation decision and experience.

My conversations with donor relatives suggest that the decision by relatives is often born out of the affective state that they are in when suddenly asked to decide what happens with a relative's body after death. For many, the best way to respond is to do what they believe the donor would have chosen. Relatives would often explain their decision to consent as rooted in the knowledge that donation was an expression of the deceased's wishes and an expression of their desire to help others. Sometimes, they can think back to actual conversations with the deceased on the question of organ donation. In other cases, they had to look for reassurance or be informed that the deceased had registered to be an organ donor. Frequently, the memory of the deceased is, as a person, is often invoked in the decision. One justification for asking the relatives to decide on organ donation from a perspective of dividual personhood is that more of the potential donor is likely a part of them than of anybody else. Simultaneously, it calls to mind how significant the news of the inevitability of the death of the potential donor is likely to be for the sense of self and lived reality of the surviving relatives who begin to grapple with the reality of the loss whilst being asked to make a decision that has profound effects on what happens to the body next.

4.3 Relationality: The body as a collection of organs

During the organ donation consent process in the UK, deceased-donor relatives are given a form that asks them not only whether they consent to donation but also which of the organs and tissue of the donor they want to offer for donation. Figure 13 shows one of the pages on the form on which relatives are asked to indicate which parts of the body are offered for donation.



CONSENT FOR DONATION **Section 4**

Please initial appropriate box

	Yes	**No**	**Exclusion**	**Coroner Restriction**
Kidneys	☐	☐	☐	☐
Liver	☐	☐	☐	☐
Liver for Hepatocytes	☐	☐	☐	☐
Pancreas	☐	☐	☐	☐
Pancreas for Islet Cells	☐	☐	☐	☐
Heart	☐	☐	☐	☐
Heart for Valves	☐	☐	☐	☐
Lungs	☐	☐	☐	☐
Bowel	☐	☐	☐	☐
Multivisceral*	☐	☐	☐	☐
*If yes, please specify explicitly				
Other**	☐	☐	☐	☐
**If yes, please specify explicitly				
Eyes	☐	☐	☐	☐
Skin	☐	☐	☐	☐
Bone	☐	☐	☐	☐
Tendons (Ankle & Knee)	☐	☐	☐	☐
Femoral Artery	☐	☐	☐	☐
Meniscus	☐	☐	☐	☐
Other Tissue***	☐	☐	☐	☐
***If yes, please specify explicitly				

ONLY USE IN CIRCUMSTANCES WHEN FAMILIES DO NOT WANT INFORMATION

All Abdominal Organs (including Liver for Hepatocytes, Pancreas for Islet cells)

Yes ☐ No ☐

Blood Vessels (see core information)

☐

All Cardiothoracic Organs

Yes ☐ No ☐

All Tissues (excluding Liver for Hepatocytes, Pancreas for Islet cells)

Yes ☐ No ☐

NATIONAL REFERRAL CENTRE USE ONLY

All Tissues

Yes ☐ No ☐

Do you consent to the patient being transferred from his/her place of death to the NHSBT Tissue services donation facility or an alternative establishment i.e. another hospital mortuary for the donation procedure to be undertaken, if applicable?

Yes ☐ **No** ☐ **N/A** ☐

Figure 15: Excerpt from the Donation Consent Form (ODT Clinical, 2023b)

The form, in effect, asks relatives, shortly after they have learned that the potential donor will die or has already been declared brain dead, to begin to understand their body as a collection of organs and tissue that could be removed and used to help somebody else. As highlighted in my discussion on dividual personhood in the previous section, during this time relatives may still perceive the body as synonymous with the person and grapple with the task of comprehending the reality of the loss. Because organ donation is a very time-sensitive process, relatives usually need to make a choice quite quickly. The selection of which organs to donate can be further complicated by which of the donor's organs are suitable for organ donation and which are not – information that is usually communicated by the attending health professionals and may change as the potential donor's condition is further monitored. Ideas about the significance of specific organs for the memory of the deceased donor can come to influence both whether consent is given and how the consequences of the donation in terms of something of the donor having been left behind are thought of.

Scarlett, whose young daughter became a heart donor, felt strongly that her daughter's heart needed to be donated. When the possibility of donation arose, she was adamant that donating the heart would be a positive thing.

> *When families say "no" to donation, they will not get a special closure. It isn't 'Oh my god, you have done such a wonderful thing'. When you agree to donate, you are not trying to do a wonderful thing. When the question about organ donation was asked, it was not a decision; it was just an answer, and I would have overruled everybody in the family who spoke against it.*

As outlined earlier, Scarlett had no doubts about her decision; to the contrary, she felt a compelling need to donate, which she recollects was particularly pronounced at the thought of donating her daughter's heart. The chance to know that her daughter's heart would survive was the special kind of closure Scarlett felt she needed. She attributed special significance to this organ but did not explain precisely why. In Western mainstream belief, the heart is conventionally thought of as a symbol for the seat of feelings and emotions, playing a central role in shaping cultural understandings of love, passion, and empathy (Lutz, 1988). For instance, Sarah Ahmed's work on the politics of emotions reveals the heart as a metaphorical reservoir of emotions, embodying love, desire, and longing (Ahmed, 2014). Ahmed's research illustrates how cultural practices and discourses construct the heart as a symbol of emotional intimacy and connection. Moreover, Anne Fadiman, in her exploration of the cultural significance of heartbreak and longing experienced in different ways by Americans and a Hmong family of refugees, sheds light on the emotional resonances of the heart within different interpersonal relationships and cultural practices (Fadiman, 1997). The association of the heart as an anchor point for love and kinship can mean that relatives are particularly keen to donate the heart and that the donation of this body part is deemed a preservation of the person to some degree.

For example, the Lakefield family, comprising of a mother and three adult daughters, one of whom had died suddenly in middle age, had hoped that the heart of the daughter who died could be donated. They felt that essential parts of her would live on to some degree in a donated heart.

> *When we decided to donate, we did not all sit down in the hospital together; we just decided. We just said, what can we do next, and I wanted her to be an organ donor. I think I would have been really sad if she would not have been able to donate anything. Unfortunately, the heart was not quite in good enough condition to donate, but the heart is the same organ that carries those memories, the love…. You kind of think of it like that.*

While the heart could not be donated in the end, the act of deciding what organs to donate for the Lakefields included the deliberation of the significance of different organs for their relationship with their daughter/sister in life, the person that their daughter/sister was. The notion that the heart "*carries those memories, the love…"* indicates powerfully that relatives, in this instance, come to think of the organ as a part of the person that has an association with the shared experience and memories that connected them with their family in life. A continuation of the heart as "*living*", continuing to beat, is thought of as a chance for something of the person associated with the human connection to the surviving relatives to be preserved (Simpson and Douglas-Jones, 2017).

Similarly, the Hewett family, two parents whose teenage daughter became an organ donor after her death, found themselves trying to decide what organs they felt comfortable donating and which could not be donated for some time in the hospital. They experienced a process of learning about "*how much you could give*" in the hospital. Contrary to the requirements of communication guidelines, the possibility of donation had been informally raised at a point when they still believed their daughter might survive, which prolonged the time available for consideration.

> *Two hours after we got to the hospital was the first time, someone brought up the donation. We had never thought about donation until we got to (the hospital). We were still in shock, so we could not really think, but the organ donation consultants were lovely. On the third day we heard somebody say "we will try to bring her around" to one of the nurses, but of course they had to see how serious the situation was, but we thought she might make it. In the end we agreed to giving all of her major organs, although they could not take all of them. The donor programme there was great, they can speak to you and explain everything, they were excellent nurses and they kept reiterating that we could change our mind at any point, even at the last minute we could have still said no.*

While they waited for new information, they had a lot of time to think. They deliberated about the different organs as they waited. They wanted to avoid giving too much, as this would have meant that "*there would be nothing left"* of their daughter.

> *We did not even know how much you could give, things like the skin and everything and they asked us how much we wanted to give. We said if we give everything then there will be nothing left of her. We did not want to give her eyes. Later on, we were asked why we did not want to give the eyes and we said she needed to be able to see where she was going, and they said to us that a lot of people had said that.*

Both parents had initially said that they wanted their daughter to become an organ donor because their daughter no longer needed her body after her death. However, when they were asked by the donation consent form to think about their daughter's body as a series of parts, they encountered ideas about the function of physical remains like their daughter's eyes might have for her in the afterlife. They thought that if they donated her eyes, she would not be able to see "*where she was going*". Although they gave their informed consent to donation and acknowledged their daughter's death, they did not immediately see her physical remains as separate from her as a person. They thought that for some organs, a connection could persist. The decision about which organs to donate can emerge as complex and heavily influenced by ideas that begin to form during deliberation about which parts of the person's body could continue to hold a particularly powerful connection to the deceased and which might not. The concerns of the Hewett family existed in contrast with the research into the willingness to donate eyes in Sri Lanka, where, because of Buddhist beliefs about the afterlife and virtuous acts, eye donation benefits the deceased in the afterlife (Simpson, 2020). Contrasts like these suggest that ideas about the afterlife, which can be influenced by religious beliefs and concerns about the dead in the afterlife, do play into donation considerations for some. Moreover, the accounts about the imagined significance of certain body parts, coupled with the consent form that asks relatives to make a specific decision about each body part, provoke a need in relatives to contemplate the relative significance of individual organs.

In the considerations outlined above, organs must undergo a transformation whereby they cease to be viewed as part of a person and come to be thought of as independent entities. As relatives decide what to donate, they engage in an act of reflection about the emotional significance of organs, how they interplay with the potential donor's identity in life and death, and how they are dividually connected to their own social identities through shared memories and emotional or biological bonds. Mol's concept of ontological pluralism can be fruitfully applied to capture the moments of tension that can arise in this context. Here, the pluralism is amplified by the presence of grieving relatives and the fact that health professionals are dealing with a "*patient*" whose body is no longer being treated to be cured. Instead, the body of the donor is now being prepared and interacted with to help treat that of a stranger, the prospective organ recipient, making the picture more complex. The different pluralist perspectives and identities of the donor body are produced by the interactions between healthcare staff, the donor care team, the donor body, the relatives and the legal materials that need to be consulted as part of the donation process (Sharp, 2001).

My conversations with my interlocutors suggest that in the instance of deciding what to donate using the Consent Forms in use in England, a process that is less related to commodification and more to the imagined significance of the organ for the memory of the person leads me to develop the terminology in a different direction. In a sense, some donor relatives find themselves reflecting on organs as simultaneously connected to the donor in life and potentially in death. For some, this contributes to the perception of the ambiguous status of a donor organ in which the organ continues to "*live*" in a new body. Part of the inherent complexity of the donation process arises because organs, in the eyes of many, have more than mere biomedical value that has often not been thought about in detail by relatives until they are asked to make a decision about organ donation. At this point, they can find themselves faced with an unexpected set of hopes and fears associated with the implication of donating particular kinds of organs. However, the imagined sociocultural significance of individual organs is not always a decision driver.

Isabel, one mother who agreed to donate her adult daughter's organs, had come to think of them not as elements of her daughter's body that preserved some of her as a person but as biological material that had come from her own body since she was the one who gave birth to her daughter. Isabel was the first to enquire about the option of donating her daughter's organs after she was declared brain dead. When Isabel had needed an operation earlier in her life, she had been saved by blood transfusions from blood donors. She felt she had been a recipient in some way and that organ donation would be a means of helping others in the way she had been helped. Once the possibility was raised, it was discovered that her daughter had been a registered organ donor as well; the donation preferences of mother and daughter aligned. Isabel felt content that her daughter had become a donor because she also felt that while the donation did not preserve her daughter in the sense that she lived on through organ donation, it did provide a chance to use her potential.

> *I feel like my daughter's organs; I think she would be pleased with this. Because she was quite, not spendthrift [sic] but you know you have to be careful with your money, don't you? She used to buy a lot of second-hand and recycled materials. To donate an organ is the absolute, absolute, absolute ultimate in recycling. You cannot get any more pure or higher than recycling an organ, can you? It's like the, it's, it's at the top of the pyramid, isn't it? Yeah, I think it's helped me because had she not… had I said no, I feel like it would have been a waste. The waste of her, the waste of her potential*

For Isabel, the thought that her daughter would have liked being an organ donor is a source of comfort. She feels that having "recycled" her organs, a death that would have otherwise been a complete waste, had now resulted in the preservation of some of her daughter's potential, which she believed continued to have a positive impact on the lives of others, much like the donated blood had had on hers. A similar account of donation as a form of recycling potential or avoiding the waste of organs is also mentioned by Ådahl in her work of messages encouraging organ donation in Finland's welfare state approach to healthcare (Ådahl, 2020).

The father of a different organ donor, whose son also died in his early twenties, felt similarly about the decision to donate his son's organs. To him, a proud father whose son had always been very athletic and who derived great pride from his son's sporting achievements when he was alive, not donating his organs would have been "*a terrible waste*" because all of his organs had been in "*tip-top shape*". Here, the possibility of organ donation was accompanied by the hope that what was otherwise wasteful could result in the hope that some part of the person could be saved from being wasted or preserved in some way. As previously mentioned, the potential problem with this resort to hope as a reason to consent to donation is that there can be logistical, medical, or other procedural complications, which mean that the organ is not transplanted as planned. The organ donation outcome lies in the future, and like the identity of the future recipient, that recipient's reaction to receiving the organ and the length of time that the transplanted organ would "*survive*" cannot be known when consent is given. Similarly, most relatives who decide to donate organs do not have a fully formed sense of the significance of each of the organs that can be donated and their entanglement with the body. Importantly, even when a donor had registered a decision before their death and/or spoken to their family about their desire to donate their organs should they die, it is difficult for surviving relatives to say with absolute certainty that this is still what the donor would have said, had they known the specific circumstances under which the chance to donate arose. Only in rare cases does a person know that there is a real risk that they might die and the opportunity to reiterate that should they die, they would want to donate some of their organs just before it happens. However, I do know of one such case, where a wife whose husband knew he would undergo surgery that he might not survive expressed this desire very shortly before she consented to donation on his behalf.

Because of the uncertainty and potential for future disagreement or conflict about the decision taken, some donor relatives I met emphasised that they felt it was important to leave space on the forms used in the donation process. For example, an issue arose when one group of relatives who had decided to donate the organs of a young man together wanted to all register their decision by placing their signature on the consent form – in part to remind themselves in the future that it was a decision they had taken unanimously. Keith, the father of the donor and now an active part of the DFN, expressed his disappointment that there was not enough space on the form to allow for this. When the time to sign the form came, all three of them, the parents and the older sister, had hoped to place their signatures on it. However, the form only had space for two signatures.

> *We insisted that all three of us would sign the form; there was only space for two. It wasn't just important to us three; quite a lot of organ donor families agree that when there is a family involvement, they should all have the opportunity to sign the form to show that they all agreed to do it.*

Keith expressed his belief that more than two people in a family are often involved in the decision, and he anticipates that in some cases, discussions about whether the decision to donate was the right one can occur in the future. In these cases, he felt forms should have room to allow for the individual needs of different donor families should they think the involvement of more than two people is essential. This form-design dilemma is similar to that of designing the part of the form that asks relatives to decide which of the organs to donate – legal forms need to confirm very personal and, in some cases, complicated decisions. A form that is universally used needs to be appropriate for the needs of deceased-donor relatives whose priorities and expectations may differ significantly. Additionally, many of the relatives I spoke to recall having been in a sense of shock when they made the donation decision throughout the time they spent in the hospital and for some time afterwards. While relatives grapple with the news of the inevitability of the death of the donor, they must at the same time have the capacity to provide informed consent to organ donation. Based on my conversations, relatives often do not retain essential parts of that information that become relevant later, such as guidelines on what to expect in terms of recipient contact and why some organs could not be donated. This indicates that it may be good to have a second chance to provide information to relatives once they have had time to recover from the shock. Presently, the Donor Family Care Service can be contacted to obtain such additional information if relatives do reach out. However, many of the people I spoke to were unaware of this as an option. Of course, by the time additional clarification may be requested, days, weeks or months later, consent previously obtained can no longer be reversed.

Overall, the need to choose what organs to donate and to take on the responsibility for what happens to the body of the person when relatives learn of the inevitability of the death can entail several significant mental steps. In many cases, the relatives I spoke to recalled that they still perceived body and person as one. However, they were being asked to dissociate a person and organs to decide which organs to donate. Faced with this question, relatives often began to contemplate what the organs that were donated might mean for the deceased. The reasoning given here never corresponded to specific religious reasons to donate an organ or not to donate another. Still, notions about the significance of the heart, for example, gave rise to the idea that some important part of the donor would be preserved. In those cases, the prospect of donation created hope among some donor relatives at the thought that some organs might continue to live and that they would be used to help others. To the extent that such hopes are placed in the survival of an organ, there is a risk of donor relatives later experiencing a second sense of loss if the donation of that organ is ultimately unsuccessful and the organ "dies" (Lock, 2002). Here, a synecdoche is in play. An organ represents a facet of the potential donor's continued presence on earth. Simultaneously, relatives often continue to perceive the donor's body as co-existent with the person, leading some donor relatives to express their desire for the person to still be treated as themselves after the death is made evident during considerations influencing the consent process. The donation decision is influenced by a collective sense of what the person would have wanted and is often generated by drawing on memories of who the person was. Essentially, relatives are demonstrating some recognition of a continuing social presence of the body, which can become translated into a chance for some organs to develop a form of social life as parts representing the whole as meaning and significance come to be attributed to them following donation. At the same time, the legal system and biomedical terminology begin to look at the body as deceased, which needs to be used and evaluated to be able to help as many recipients as possible. This includes the hypothetical fragmentation of the body into parts that can be offered or rejected for donation individually as part of the consent process discussed in this section and the assessment and preparation processes that are completed before organ removal are discussed in the next section.

4.4 Post-consent behaviours towards the donor's body

As discussed in the chapter introduction, donor relatives do not always feel that the hospital environment is a comfortable space for them. The literature indicates that medical professionals who continue to treat the body of the donor as the person the relatives often continue to perceive can have a positive impact on the donation experience. On the contrary, the impression that the same care and consideration for the relatives and the donor body is no longer taken post-consent can have a negative impact (Stouder *et al.*, 2009; Jensen, 2016; Bea, 2020). The deceased-donor relatives I spoke to recalled similar experiences. Kathy, the mother of an organ donor I introduced earlier, found the time between providing consent and organ removal very challenging.

> *I think part of my coping strategy was to channel some of my anger about the whole process. Really, it is not a nice thing for donor families to go through. In the process, you feel there comes a point where things become a commodity – things become very recipient-leaning. It means that once you agree to donate, the process becomes about the recipient.*

Kathy was angry about the way she felt donor relatives were being treated and about the way the body of her son was being treated. After consent was obtained, she felt a shift in focus, and everything felt as though it became about saving the recipient. She no longer felt there was enough space for her as a relative to wait and sit with her son in a comfortable environment, nor for the harrowing experience of loss she was going through. While not all donor relatives felt that there was a point at which "*things became a commodity",* others shared that they, too, had felt uncomfortable in the hospital environment. Others had felt that the desire among some health professionals to prepare everything for organ removal had infringed on their time with the deceased. Tina, the mother whose teenage son died, explained how the conduct of one member of staff made her feel that the final chance to spend time with her son had been unnecessarily interrupted.

> *The heart surgeon came onto the ward, into ICU and wanted to sort of start looking at my son and find out the figures and he asked us to leave the room, and that was the only time in those 36 hours that I was asked to leave the room, and we wandered around aimlessly in the corridor in the end and after that he went. And I think it bugged us a little bit, and afterwards, with the organ donation nurse, I said to her that I did not feel that was right*, *because that was our last few hours with our son, that was my time. He might have been officially braindead, but at that time, he was still mine. When he got onto that theatre table, he is his, but up to then he is mine.*

Tina's statement pinpoints a critical tension that exists in hospitals during this time, between the relational experiences of donor relatives who often continue to perceive the body of the donor as synonymous with the living person and the medical staff, who must work with a legally deceased body (in the case of brain death) to save another. For her, the moment organ removal needs to take place marks the moment where it is appropriate for the status of the body to notably shift – here, she says, her son's body is no longer hers in the sense that the focus can then go and become about the recipient. She felt very possessive over her time with her son until then and expressed a sense of ownership over her son in the way she remembered him in life; she was not ready to let him go until it was time for the organs to be removed.

> *And I said he took away ten minutes of my time with my son to come in and do whatever it is he did. Basically, come and check, to consider whether the heart is gonna be suitable etc. If my son had got into theatre, and his heart was not suitable for transplantation, that doctor goes home*. *But he took time out of my time with my son*. *Obviously, there is constant monitoring, but at least it is the ward staff and not the transplant surgeon. He should not have been there because it was not time yet.*

Tina's concerns point to a disconnect between the time frame governing legal and hospital processes and the way donor relatives experience that time. To her, the final hours with her son were very precious and her very last chance to spend time with him in this way, with her son's body still present as if belonging to a warm, living person. At the same time, she felt that the surgeon she named focused on finishing the procedure because, for him, it was part of a working routine. The sense of dissonance that can occur because of the contradiction between the legal definition of brain death and a body that can present as though it still belongs to a living person has been previously well-documented as a source of tension Sque and Payne, 1996). This is why the transplant process guidelines require different teams to take care of different parts of the transplant process, as described in Chapter 3. Tina’s account illustrates how significant seemingly minor disruptions to time spent with the donor can have on the recollection of the whole process.

> *The nurses are, of course, always there, and you can’t have any privacy during the whole procedure, but the surgeon came onto the ward specially. I was told he was the only one who ever did that, so it was clearly not absolutely necessary, and that was it for me.*

Tina’s assessment of what marked out the surgeon's conduct as problematic is intriguing – she recognises a need for the presence of medical personnel and tests to be done. She draws the line at the point where she is being asked to leave her son’s bedside so a member of the procurement team who is concerned about the success of the transplantation can be there instead. She felt this meant that her rights as a family member in the whole process were disregarded too soon. Some of the relatives I had spoken to did not feel similarly possessive over the body after giving consent to the medical team because of the information they had received to confirm the death; the body was no longer synonymous with the person. They wanted the transplant process to go ahead as they began the process of adjusting to the loss and beginning to grieve. While an argument can and has been made that donation is becoming increasingly routinised and embedded into normal hospital processes, a disconnect between medical perspectives of the body and the sentiments of some donor relatives towards it remains visible in the discourses about the donor when professionals communicate. For example, I attended several talks and discussions about transplant technologies remotely at the annual British Transplant Congress of 2022. I was struck by the terminology used to refer to the donor. Professionals discussed the need to assess “*donor quality”* and the benefits of “*cadaveric tissue”* that could be donated. It seemed these usages marked the donor body as a dead body, the quality of which was being determined based on its usefulness for donation, and the difficulties that arose when working on a “*low-quality donor”* were being outlined. Similarly, there was a moment when there was difficulty in getting enough relatives to consent to donating the pancreas of different people. Professionals laughed because they had noticed that, looking at pictures of a pancreas, some relatives seemed to think it looked like a male reproductive organ. They concluded that relatives did not know the different functions of some organs, so they believed consent was more challenging to obtain for these particular organs. Contrasted against the complex considerations about donating body parts discussed in the previous section, this created a sense of unease when I heard the exchange. The professional discourses were very different from the language recommended and used in the guidelines for donor family care in hospitals, which would sometimes refer to the donor as the "*loved one"* of *"donor families*". Differences in the terminology used of this kind reiterate the relevance of the different ontologies of the body that exist during the transplantation process and the tensions that can arise because of it. Based on my conversations with my interlocutors, tensions seemed more likely to arise when the wrong kinds of professional discourses spilt over into the hospital environments donor relatives experienced. The examples outlined above indicate that donor relatives can pick up on indications that the donor becomes an afterthought in the transplant process. The risk of the donor not being actively recognised as a part of the transplant process was evident when the deemed consent law was first introduced. Original plans intended to call the new organ donation law Max's law, after the young boy whose life was saved by a heart transplant. However, I quickly learned that this was changed once multiple parties voiced their concern about the exclusion of the donor in the name, including Max himself, as Keith pointed out.

> *Apparently, with the new law, it was actually Max himself who said he wanted it to be Max and Keiras Law. I actually met him before, he is a fantastic young chap.*

Max, the recipient who was a young boy when the law was prepared, reportedly felt it would not be right for Keira's name to be excluded from the bill. Members of the network had also learned of the original plans for the law's name and reached out to voice their concerns to politicians independently – the founder shared that he had put his concerns in writing.

> *When the new law was first discussed, the name they included just had the name of the recipient but not the donor. I don't often do this, but when I feel I need to, I do. I wrote a letter to them, just explaining clearly why I thought it was important that the donor would also be included in the name of the law – so that there are both sides represented, the donor and the recipient.*

When the donor is not appropriately recognised or treated, and relatives come to feel as though once the decision to donate has been made, the donor's role becomes less important or is omitted entirely, it can be upsetting and make an already challenging situation more difficult. Organ removal in hospitals is a complex medical process, and the steps to monitor and prepare the donor body are necessary. They cannot be entirely concealed from the relatives present. Furthermore, the act of obtaining informed consent legally requires that the relatives understand what the process entails. However, donor relatives like the Lakefield family had positive recollections of how the hospital staff had continuously acknowledged the donor body as belonging to their sister and thereby made them feel as though it was easier for them to feel content with the choice they had made.

> *My friend often tells me, "You are so amazing for what you have done," but even the cutting in the hospital, the question, it was all done so well. We walked her down to the theatre, and they never stopped treating our sister as our sister. After the procedure was done, the next time we saw her was at the chapel of rest; they then had her brought to the funeral directors.*

The family were involved in the process, and they took part in an "*honour walk*", a phenomenon that is an increasingly common part of the transplant process and is often performed in the United States as part of the Donation Process. Here, medical personnel stand on both sides of the corridor leading to the theatre, often clapping, thanking the relatives or the donor and showing their appreciation of the donation decision in front of the family before organ removal. The relatives say goodbye to the donor after having brought them to the theatre and are surrounded by medical staff expressing their respect as they do so. For the Lakefield family, an experience like this encouraged trust in the professionals who handled the procedure and reassurance that they had made the right decision. They received further comfort and recognition. The process was not as difficult to bear because of the way the hospital staff treated the body of their sister/daughter. By enacting care for the needs of the donor family as part of the overall procedure, the family were given the impression that they did not compromise their sister/daughter's personhood in terms of the treatment of her physical remains. Overall, there was less of a perceived gap between the priorities and interests of the hospital staff and those of the donor family than in the previous accounts. The act of honouring the donor and the relatives present had the potential to create a sense of closure for the Lakefields. It helped them have a sense of closure about the decision they made and reduced their worries associated with the decision.

Isabel also found that the knowledge that healthcare professionals had taken extra care during organ removal, as she requested, gave her reassurance and comfort.

> *The second SNOD (Specialist Nurse Organ Donation) was the one that had taken my daughter into surgery, and I had asked the surgeon to try tying a little knot in the stitches so she would have lots of little bows in her stitches. So, I got to meet her (the nurse) again at the St. Johns meeting and she said oh yeah, the doctor was a female surgeon, and she was really happy because nobody had ever asked her to do something like this before. So, she tied a beautiful little bow in all the stitches. It's the stitch strength of thread that let her do that. So, so that was a bit of closure so that was good.*

Isabel, whose daughter became a donor, made a special request from the team at the hospital where her daughter had become a donor. To her, it was important that some of her tenderness and care for her daughter as a mother would be carried into the invasive environment the transplant surgery created. The idea that her daughter's body had been closed with careful little bows shows a juxtaposition between the awareness that the body had undergone surgery and organ removal, meaning that the body was no longer alive, and a simultaneously lingering sense of protectiveness over her daughter. Although her daughter was now dead, she wanted care to be taken to acknowledge who she had been when she was alive, even after her daughter's involvement in the donation process was over. Had Isabel not had her chance to meet with one of the nurses in the future, she would not have known that her motherly love had been carried forward in this way. The doctor who tied the stitches and the nurse who told Isabel about it both had opportunities to demonstrate that they, as professionals, had been as respectful of the donor and the mother's wish as they could have been.

The significance of these smaller acts of care concurs with those of a project in Denmark (Jensen, 2011), which explains how such ritual practices honouring the deceased donors can support not only families but also health professionals themselves: "*The Danish hospital staff (…) stages such performances of peaceful death to support families and themselves*" (Jensen, 2011, p.133). Jensen stresses that everyone involved in the process can find comfort in the ritualisation of organ donation as part of the standard hospital care provision. I argue that what arises here is an example of how new funerary rites are forming alongside the novel medical technologies that give rise to new kinds of choices that can be made at the end of life. The forming of a guard of honour by hospital staff and the closing of the body after organ removal in a way that is solely an expression of care akin to the preparation of a body for an open casket funeral are examples of how familiar expressions of honour and care for the dead body are being brought into the hospital environment. The need to do this and the opportunity to create similar rituals will vary depending on the different donor relatives and situations that arise in hospitals. Similar moments are less likely to occur when hospitals are limited in staff availability, time, and space for relatives and personnel available to provide care to them throughout the process. This creates an uncomfortable trade-off in which strained resources in the service can add further strain to an already complex experience.

As previously outlined and indicated by Sara Bea's work in Spain, the donor is a "*relational person*" whose relatives are tasked with "*transferring or inferring*" the donation preference (Bea, 2020, p.1935). If that decision led to the treatment of the donor no longer as a patient but instead as a deceased body, even in a small number of cases, this could cause lasting frustration and concern associated with the donation process among relatives. The idea of the organ donor as a patient embedded in the hospital processes becomes challenged in the context of the recipient simultaneously being a patient, rendering the donor's presence particularly relevant in light of organ procurement (Bea, 2020). In the English setting, similar experiences of a continuing sense of personhood for the deceased played out in the ambiguous setting of the IC Unit, as exemplified by my conversations with my interlocutors.

I, therefore, propose the adaptation of the notion of dividual personhood as an analytical tool to draw out the complexities that can exist when the different ontologies of the body, the legal requirements for informed consent and the experience of grief by deceased-donor relatives are experienced in interactions with healthcare professionals. Douglas Davies proposed dividual identity as an alternative to notions of the bounded individual in bereavement care (Davies, 2020). Briefly, Davies introduces the notion of dividual personhood in the context of death studies as a way of thinking about the relationship between the deceased and their family that cannot be captured in its full complexity when drawing on notions of individual personhood (D. Davies, 2020). In most cases, the person's death does not at once cause the cessation of the existing emotions felt towards the body that were synonymous with the person in life (Lambert and McDonald, 2009). Building on the notions of personhood affected by the exchange of substance codes (such as food and drink) that flow through the body and reveal the relational aspects that connect people with one another, as discussed by Marriott, Davies develops the idea of a person whose identity and essence can be shaped and influenced by interactions with other people. Consequently, Davies emphasises that "d*ividual personhood describes someone whose boundaries with others and the wider environment must be considered as selectively open for a variety of 'flows' of materials, relations and the emotions that constitute personhood"* (Davies, 2020, p. 4). Moments where memories, events, relationships and experiences are shared can be understood as affecting the very sense of self a person has – through dividual personhood, people become part of one another (D. J. Davies, 2020). I postulate that this, as Davies suggested, can lead us to think of the body of the donor as being more interactively interrelated in dynamic ways with the surviving relatives that thinking of the donor as a distinct bounded individual (D. Davies, 2020). Because of the sense of shared embodiment (D. Davies, 2020) that often exists between donor relatives and their relatives that has been created for example between a mother and a child, a little of the identity of one person becomes intertwined, dependent upon their connection to the other – for example, because they are their mother's child. When the donor dies, because they have become part of their relative's dividual identity, the disruption of the relative's own identity is often very significant and can also become entangled with the donation decision. The complex sociality contained within the donor comes to impact upon the donation decision beyond their or their relatives' moral, cultural, or religious persuasions or individual trains, and this deep relationality is still vividly at play at the moment the relatives are involved in the consent process.

Dividuality understood in this context is closely aligned with Melanesian ideas of the person as defined by Marilyn Strathern. Strathern introduced the concept of dividual personhood as a theoretical framework for understanding social relations and identity formation in Melanesian societies. Strathern's concept of dividual personhood challenges Western notions of individualism by highlighting the relational and interconnected nature of personhood (Strathern, 1988). According to Strathern, individuals in Melanesia are not discrete, bounded entities but are instead conceived as fluid and divisible entities constituted through social relationships and obligations distributed across kinship networks and other social ties (Strathern, 1988). Mcintosh, reflecting on Strathern, explains that this understanding cannot grasp a person without recognition of the social entanglements that connect the person with other people (Mcintosh, 2018). Building on this, Davies argues that the connection between people built in this way becomes relevant when people lose somebody, they have a strong attachment to. At this point, they go through a process of "*dynamic changes within the embodied identity (as) a bereaved person*" (D. J. Davies, 2020, p. 8). Upon death, the embodied social identity of the body does not suddenly detach from the deceased body – which is why the biomedical task of partial deconstruction of the body for organ donation cannot ignore the social identity of the body as it goes through the donation process (Lambert and McDonald, 2009). In the context of organ donation, the social presence of the body of a person who has been declared brain dead does not necessarily immediately cease to be synonymous with the interlinked social being it was a part of (Lambert and McDonald, 2009). The difficulty arises because, in many cases, the person's body does not yet present as fully, that is, clinically, dead at the moment the decision is made (Jensen, 2011). The relatives are being asked to accept the responsibility for the body's fate, while they may, when looking at the body of someone with whom they still have close social ties, still see the person. The degree to which the essence of the person, however, conceived, is thought to be intertwined with their mortal remains varies across cultures and circumstances, but there is sometimes great value for donor relatives in spending a few final moments with the person before organ removal takes place because it provides an opportunity to say goodbye. During this time, the deceased person's relationship as attached to their mortal remains in the eyes of their relatives has not yet changed – the social ties connecting both are still intact in the view of many donor families. Consequently, there is a continuing protectiveness over the body, at the same time as the memory of the person is invoked to guide the decision about organ donation that needs to be made.

The ethnographic examples I have drawn on showed that this need to manage separation from the donor body and to acknowledge it as something that continues to be a social body as it goes through the donation process can be responded to by behaviour akin to new funerary rites within the hospital environment. As the experience requires relatives to acknowledge and process the news of the inevitability of the death, they must engage in the acts of thinking of the body as synonymous with the person and transform their understanding to begin to see the person as a collection of organs. During this process, interactions with health professionals, recollections of exchanges and memories shared with the person in life, and beliefs about the significance of particular organs can all come into play to facilitate this transformation. What results is a fundamental tension between the very variable act of sense-making that allows relatives to get to a point where they feel ready to make their decision and the need to standardise and routinise these spaces using health system guidelines. How separation from the corpse is handled and whether relatives feel a shift of attention away from themselves and the donor and towards the recipient can impact the overall experience. To better respond to the variety of factors that can affect this time and to show appropriate respect and recognition for the donor, finding a way to embed ways to honour the deceased into the care process can be beneficial.

In previous work, Chapple acknowledges that hospitals can often be thought of as places that are situated between life and death but are generally better equipped to treat and heal people than to accompany the death of a patient (Chapple, 2016). Being in a hospital and learning of the death can be traumatising for relatives, and my research shows that the use of medical terminology and a lack of space for the donor relative presence in the donation preparation process can amplify posttraumatic stress (Bjelland and Jones, 2022). However, acts of recognition intended to honour the deceased and that recognise the bereavement experience of relatives can help treat the donor as a social body and reduce this effect (Bjelland and Jones, 2022). In contemporary hospital settings in England, there is little availability of processes that acknowledge the passing of the body from living to death, and the forms associated with the process organise donation as a legal matter but are less able to guide the emotional complexity that follows the death that has occurred. The moment of death in the minds of many relatives I spoke to was associated with the timing of organ removal, which indicates that the passing on is often imagined as happening in the hospital. Based on my fieldwork, I suggest that what the donor body goes through in the hospital is a "*liminal phase*" (van Gennep, 1960).

In organ donation, a liminal phase, an in-between stage is almost built into the process but not yet managed and acknowledged with any sophistication because there is a period during which the donor seems to belong neither to the world of the living nor that of the dead. Where spontaneous acts of recognition for the "*liminal stage*" the donor was in occurred, they brought reassurance, closure and a sense of being understood by the healthcare professionals in attendance to my interlocutors. As discussed by Mary Douglas, death can cause a threat to social order, an unsettling understanding of the world and a disruption to the reality and identity of the bereaved. She emphasises the potential of rituals to manage the threat to a sense of social order that death and similar disruptive experiences can cause (Douglas, 2002). When familiar signs of respect and recognition from one's social environment are adapted to express support and empathy in the hospital setting, for example, the act of forming a guard of honour, this can enable relatives to overcome some of the sense of dissonance that arises from unacknowledged liminal states between life and death as outlined in this chapter. However, Margarete Lock's work on the complexities surrounding brain death in the context of organ transplantation, comparing Japan and North America, highlights how traditional notions of death and practices of mourning can differ – death, including the complex liminal phase in organ donation I have touched on can be culturally constructed in a variety of different ways (Lock, 2002). Therefore, I want to avoid suggesting that standardised new funerary rites should be externally designed, standardised and formally inserted into the care process, as what is meaningful to some relatives may not be meaningful to others. Instead, I want to go so far as to say that instances where health professionals have demonstrated a sensibility to the liminal phase between life and death that organ donation creates in the minds of many of my interlocutors have proved reassuring and beneficial. Acts honouring the dead or acknowledging the continued care and protectiveness over the body some relatives feel through lovingly hand-tying stitches after organ removal into bows had reduced the dissonance between the gravity of the loss and the routinisation of organ removal felt by some. Consequently, there is an opportunity for further research into these emerging funerary rites and acts of recognition of the death for the benefit of both healthcare professionals and deceased-donor relatives that would benefit from further research. There may be a breadth of unexpected desire for acts of care to be incorporated into the medical interactions with donor bodies, such as the small bows that were tied into the stitches when closing the donor body as an expression of the continuing motherly care for her daughter's body that Isabel felt. More research can be done here to explore how the care process and health system capacities could be adjusted to respond to this opportunity to acknowledge the ambiguous status of the donor body. Simultaneously, there is an opportunity to avoid over-trivialisation of the time that relatives experience in the hospital and processes that frame the deceased-donor relatives as service users without appropriately acknowledging the impact the bereavement is likely to have had.

4.5 Service usage surveys for deceased-donor relatives

As indicated in the previous sections, deceased-donor relatives are often deeply affected by the death of the donor. In many ways, their relationship with the donor may have contributed to their sense of self and identity as well. Where relatives may have thought of themselves as the parent, sibling or child of the deceased, the death frequently caused a painful disruption to their sense of normality. For Isabel, the mother whose adult daughter had died, the simple act of performing daily tasks and sticking to a routine became an achievement.

> *And every day I got up, I got dressed, I made the bed, and I had breakfast every single day. I didn't have any lie-ins. I didn't have any Pyjama days. I ate properly at the right times. I would just watch junk on the telly. In the afternoons, I would get myself comfortable on the sofa, and go to sleep, for a couple of hours, like a baby because the crying when you cry you are absolutely exhausted and only want to be asleep again.*

Isabel did her best to go through the motions of daily life. However, she found that she struggled to perform simple tasks and felt overwhelmed for a long time, unable to reflect on the donation or to engage with many of the condolences she was receiving. During this time, she had a minimal capacity to think about anything other than her daughter's death. Later on, her experience became a source of insight for the NHS, because she became an organ donation advocate and had the opportunity to explain to the local transplant service why they were getting low response rates for questionnaires they were sending out to deceased-donor relatives following donation. She had to explain how the experience of acute loss had affected her within the first three weeks of her daughter's death to highlight that she had not been in a state where she would have filled in and returned a questionnaire about her satisfaction with the transplant service.

> There *was a questionnaire that the NHS staff wanted to know why families of organ donors were not returning this questionnaire about the experience they had in hospital. And they sent it out within something like three weeks.* ***The*** *last bloody thing you want to do is fill in a stupid questionnaire that somebody sent you. It is like, sorry. They had not thought of it. They were just wondering why replies to this questionnaire had been historically low. And I was saying it's just another piece of junk that you can't cope with.*

Isabel explained that the questionnaire had been sent way too soon. She explained that her capacity to cope with various aspects of daily life had been limited and that the questionnaire was not a priority in that situation.

> *They want to know about your experience in the hospital; you know, can you rate the performance of the nurses 1-5, what was your experience of the waiting room 1-5, what was your experience of how the doctors talked to you 1-5… you know, it's like a bloody Amazon feedback survey.*
>
> *Yeah, and I was just like, you know, sod off! Then we went through the questionnaire, so you know I feel cross about it. That's why I want to help. So we went through the questionnaire, and the question that was at the very end was: do you need further help, or would you like*

> *somebody to talk to? And I said, that should be the first question! Would you like somebody to talk to?*

Isabel points out a discernible prioritisation of the efficiency of service delivery in hospitals and how it affected the willingness to donate, with little interest in providing further support if needed. She does not blame staff for this because she appreciates that they "*are under a lot of pressure"* and emphasises that they seemed very ready to receive criticism but that the problems had not occurred to them. She felt that being asked to rate the experience using several simple numerical scales was an attempt to turn the experience into something that it was not. In the context of the ethnographic insights discussed throughout this chapter, the notion that the experience of staff interactions could be adequately rated on a numerical scale comes across as an apparent oversimplification. Her insights once again indicate the dissonance between the routinisation of a process within the health service that wants to generate user satisfaction and efficiency and the deeply complex and often transformative experience that both the death and the donation experience can create for the relatives. Whilst she expressed her discontent at the confusion, Isabel noted that it was positive that the NHS had asked for feedback and made changes to how the questionnaires would be sent in the future.

> *So, they are now sending the questionnaires six months on. It is now shorter and the last two questions are the first two, and you see that is how we as parents or as experts, if you will, are helping them, because we try to just make them understand that how they can make the service a bit more user friendly. I hate these expressions like "you are a service user"… It's like, no, I am a bereaved parent*. *You know, treat me with a bit of like, I don't know, I'm not doing an Asda shopping survey. I'm not going to win a 50-pound voucher spend. So now they know, they know now, why… people were not sending these questionnaires back. It is because it is not important*.

Isabel, in this instance, helped NHS staff understand how they could adjust the questionnaire to be more considerate of donor relatives' needs and not interfere with the initial period when people were grieving. During her work as an advisor, she noticed that organ donation is being looked at as one of the many functions of health services that are performed regularly and are sought to be streamlined and improved. She is happy to advise them on this but remains opposed to the fact that the health system is emphasising "*optimising*" aspects of the service that, in the face of the original loss, are "*not important".* Even in its adjusted form, the survey approach seems to her like an attempt to understand the quality of the service provision in terms that are not as relevant to the experience of bereaved relatives as was assumed elsewhere. None of the multifaceted and complicated effects of the donation experience on deceased-donor relatives that were highlighted throughout this chapter can be adequately managed using similar surveys. Additionally, Isabel got the impression that the surveys were a symptom of the pressure that NHS staff were under to deliver a high-quality service. Part of the issue was that the survey was sent out as part of a conclusion of contact between relatives and the health service, which meant that the answers that were given would also be unlikely to impact the experiences of bereaved relatives going forward positively.

The limitations and problems of the use of patient satisfaction surveys as a part of health service delivery have been criticised elsewhere in the literature. In research comparing quantitative survey responses to colorectal cancer care in Teesside in England, with insights obtained from qualitative investigations of patient satisfaction, a disconnect between the satisfaction indication based on numerical feedback and the more nuanced emerging qualitative accounts became apparent (Dougall *et al.*, 2000). Quantitative surveys like that described by Isabel were consequently identified as inadequate for obtaining a complete representation of how patients felt about their experiences. Instead, qualitative research has been identified as an alternative that was much more likely to accurately capture the nuances involved (Dougall *et al.*, 2000). Indeed, it is difficult to imagine how a quantitative survey might capture the complexities in the realm of personhood, the social significance of individual organs and the time in the hospital as a liminal phase characterised by multiple medical and private ontologies that frame the donor body in different ways and can manifest themselves in conflicting desires to take ownership of the time with the body before organ removal. The loss itself can be an experience that disrupts the reality, expectations for the future and even their sense of self.

Kathy summarised that feeling of disruption in one short sentence when I spoke to her about the way she and her family felt when her son died.

> *Our world fell apart.*

A second middle-aged female donor relative whose partner had died and subsequently became an organ donor felt similarly when they explained:

> *Our hopes and dreams were shattered.*

Both women emphasised the gravity of the loss and the impact it had on their lives. However, as Isabel's account shows, deceased-donor relatives can, in their own time, begin to reflect on the loss. Bereavement support services, friends, and family may help them do this, as well as private artistic projects and personal acts of looking for meaning, some of which will be outlined in the next people. Few deceased-donor relatives knew what to expect from the biomedical processes necessary to facilitate organ donation and were confronted with the need to understand the consent process and the associated forms whilst simultaneously grappling with the reality of the donor's death and the consequences it would entail for the future. An experience as complex as this could not be captured in pre-written quantitative survey questionnaires to its full extent, even after adjusting the time frame during which the survey was sent and the order of the questions it included.

4.6 Conclusion

The discussion in this chapter sheds light on the tensions between the different ontologies of the people involved in the donation process in hospitals, starting with the factors that influence the donation decisions embedded in the hospital process. The recollected accounts described by the deceased-donor relatives indicate concerns that go beyond the religious, procedural and trust in the healthcare system-related factors that are often primarily targeted by donation campaigns. The conversations described supporting the idea that relatives asked to decide about organ donation benefit from knowing the donation preference of the deceased and that, in cases where the preference is not known, a sense of who the person was invoked to determine what they would have wanted. This suggests that campaigns like those recently emerging under the "*Leave them certain*" slogan are intended to motivate conversations about donation preferences in which people inform the relatives of their choices so that should a situation arise when they are asked to donate, the relatives have certainty about what the deceased would have wanted. Simultaneously, the further need to encourage conversations about organ donation among the living after the deemed consent law in England came into effect indicates that the law has not replaced the need for personal conversations in life to establish certainty about the donation decision in the minds of many. Furthermore, the results highlight that because the highly affective setting of the hospital environment is coupled with the news of the death of the donor, unexpected priorities and ideas about the afterlife and the significance of organs can arise. The reactive responses of some relatives that were also rationalised and reflected on later highlight that there are limits to the degree of preparedness one can achieve for a situation that is unique and unexpected for most. Ethnicity and religion are unlikely to be the sole drivers of the donation decision. They may or may not come to influence the decision that is ultimately taken, but they should not be treated as predictors of the decision.

The body has been previously revealed as being deeply relational in the organ donation setting. However, the ambiguities that arise out of this relationality in terms of the donor's personhood have been explored in greater detail in this chapter (Jensen, 2016). I proposed the adaptation of the notion of dividual personhood into investigations of the complexities that are involved in the donation process. Dividual personhood as an analytical tool has the potential to capture the contradictions between a person who is simultaneously legally framed as dead by consent forms and similar documents, but that is continues to be treated as a patient until organ removal and is often still perceived as the person in life by the relatives in attendance until organ removal takes place. How relatives refer to the body but also to their role in the donation process, it is evident that the decision that is taken frequently draws on shared memories and past experiences with one another. These close connections have often led people to feel that they became part of one another, and for that reason, some donor relatives described the decision as a shared choice that the donor had silently partaken in. In the donation context, individuals rarely appear as strictly bounded and instead arise as deeply connected through kinship ties that often persist throughout the donation process and beyond.

Furthermore, the research highlights the significance of particular organs, which can be seen as entangled with who the deceased donor was in life. Here, the notion of part for whole relations in terms of the social lives of material objects was drawn on to establish what significance the "*living on*" of some organs would have in another. In England, deceased-donor relatives are not just asked about whether they consent to organ donation but are also given a form on which they can offer some organs up for donation but refrain from offering others. Organs that are thought to be exceptionally entangled with close kinship ties to the surviving relatives, such as the heart, were frequently thought of as being potentially more significant to donate than others. To capture the relational connections that can arise in the imaginations of deceased-donor relatives between the donated organs, the donor, the recipient and the relatives who consented to donation, I introduced the idea of the social life of organs and the notion that this can come to influence the decision. While some relatives view the body after death and all of its organs as completely detached from the deceased and their soul, others desire to donate or not donate specific organs as a result of their potential significance for either the afterlife or their continued "*living*" existence on earth following the death of the organ donor.

This chapter lays the groundwork for an understanding of hospitals as environments in which deceased-donor relatives begin to experience a liminal phase during which the donor body is thought of neither as completely alive nor as fully dead. Depending on the care the deceased-donor and the relatives receive, these settings can evoke a sense of dissonance between the frequently traumatising emotional responses to the new reality brought on by the death of the donor and the need to comprehend organ donation in legal and procedural terms to give informed consent. Frequently, hospitals are not places in which rituals to honour the dead or to help relatives navigate the liminal phase that is experienced during the wait for organ removal are common. Instead, standardised processes and best practice recommendations are in place to work the interactions with grieving relatives into the routinised processes of the daily work of healthcare providers. Interactions with healthcare professionals and the hospital environment that revealed the prioritisation of healing or saving the recipient as the next priority exacerbated this effect. In some cases, professionals showed a lack of appreciation for the significance of the last moments relatives were able to spend with the donor before organ removal or appeared to have shifted their priorities away from the donor and towards the recipient once consent had been obtained. However, in other cases, healthcare professionals had taken steps to incorporate familiar rituals or expressions of love and care towards the donor’s body to acknowledge the loss that the relatives were experiencing. For example, when a guard of honour was formed and spontaneously adopted into the hospital space, an opportunity to incorporate imagery familiar from honouring the dead who made a sacrifice for their country and to express respect was successfully adopted. Here, staff demonstrated the comforting potential of rituals to acknowledge the death of the deceased without compromising the necessary medical processes needed to facilitate organ donation.

Consequently, this chapter lays the groundwork for future research into the novel forms of last rites that emerge in the organ donation context and the symbols and practices used to honour the dead in other contexts that are being drawn in to create meaningful acknowledgements intended to comfort the relatives present. In contrast, the chapter also highlighted the negative perceptions of overly reductive and routinised communication processes, such as the questionnaire that was sent out to obtain feedback from donor relatives about their satisfaction with the transplant service. This can lead relatives to feel that the impact the loss had on their lives is not being adequately appreciated. Instead, the ontological plurality and relational complexity of the whole donation process discussed in this chapter underscores the difficulty in creating a standardised approach that could completely transform the donation process into something that can guide the relatives’ experience of loss. While the complexities would be difficult to illuminate, a renewed sensitivity to the contrast between how the law and biomedical processes involved categorise and standardise the conceptualisation of the donor body in deceased organ donation could benefit the development of care guidelines that move away from categorisations of donor relatives based on ethnicity and religion. Instead, the effects of the donation decision on relatives and their needs and reasons for the decision ultimately taken can be difficult to predict in advance. However, the incorporation of ways to acknowledge the loss and to allow donor relatives to make reasonable requests for their comfort during the process may make the experience a more positive one. For example, the availability of additional space for further signatures to provide closure to relatives who wanted to document that the decision had been taken collectively or the willingness of the surgeon performing organ removal to take extra care when tying stitches into little bows can give relatives a degree of control and reassurance. Capacity in terms of space and time in the transplant service to facilitate similar requests can counteract the notion among some relatives that the priorities in the hospital setting had shifted once consent was obtained. Furthermore, it could grant donor relatives a degree of individuality that can foster a sense of trust. Room for individual requests could empower donor relatives to make their concerns or additional needs known. Even for donor relatives who had previously discussed organ donation when the donor was alive, there may be unexpected needs and concerns that arise with the immediate prospect of organ removal in unexpected and non-standardisable ways.

5. Emerging Challenges associated with Charity Bereavement Support

5.1 Introduction

The previous chapter explored the inherent relational tensions that need to be managed during the organ donation request, the wait in the hospital before organ removal, and ultimately, during communication with relatives immediately before organ removal and in its aftermath. Once organ removal has been completed, the relatives of the deceased face the consequences of the bereavement and go through the motions of organising a funeral. Initially, as indicated by Isabel's account of the immediate effects of the death of her daughter and the organisational tasks that arose from it, many donor relatives do not find themselves contemplating the effects of organ donation. Instead, there is a need to organise a funeral and to fulfil any relevant legal requirements of dealing with the death, coupled with the continued challenge of grappling with the reality of the loss and its complex effects on the bereaved person's sense of self and their expectations for the future. However, after some time passes, deceased-donor relatives often think back to the decision and, in some cases, struggle with the recollection of a stressful and traumatising time in the hospital. To deal with these thoughts and questions, many donor relatives feel they need additional bereavement support. As indicated in Chapter 3, charities like the Donor Family Network or smaller local support initiatives frequently offer counselling and care during this time. This chapter, therefore, turns to the question of how relatives begin to reflect on the donation decision and what barriers and limitations exist regarding their ability to receive support. Moreover, one must ask to what extent charities can provide this kind of service and what barriers to access volunteer-run organisations face when trying to reach out to deceased-donor relatives to make them aware of the availability of support. The below vignette is a reflexive expression of the kinds of questions that my interlocutors recounted arose for them, the challenges they faced, and what later helped inform their charitable work. The data that I draw on to inspire the vignette and the subsequent discussion in the chapter refers to my work with people who are involved with running the activities of the Donor Family Network, people who have attended the activities looking for support, and my participant observation during the network's memorial event.

You are sitting in your living room, holding a letter with a small gold heart pin in your hands that has the word "yes" written on it. The pin was sent to you because when your loved one died in hospital a few weeks ago, you and your family decided to consent to organ donation on their behalf. You take a deep breath, you try to remember where you put the pieces of paper you were given by the specialist nurse that she said held all the information about what to expect from the donation process. For the *first time since the day of the donation, you are thinking about the implications of your decision. You wonder how the recipients of the heart and the two kidneys you agreed to donate were doing. Had they felt grateful when they received the organs? How old were they, and where did they live? Did they want to know more about the person the organs came from, are they ever thinking about your loved one? You blink tears away that have formed in the corners of your eyes – you try not to think about the organ removal process or about your relative in hospital. You have tried to wait for the questions and images in your mind to leave you for a while now, but they refuse to disappear. You want to remember your relative the way they were before they fell ill, and you think you made the right decision, that your relative would have wanted to help someone else. Despite this, endless questions move around in your head.*

Suddenly, you feel as though you can no longer sit with your thoughts, you want to find out more – you walk over to your computer, and you start to look for ways to get in touch with someone who experienced a similar loss to yours – someone who might understand. You come across a page for a charity entitled "the Donor Family Network", you hesitate, you ask yourself whether the specialist nurse mentioned an organisation with this name, but you cannot remember. You click on the page, tentatively at first, but quickly, you feel encouraged by the testimonies of other people who have written something by which to remember their loved one, and you think about the way they speak about what donation means to them. Then, you spot a support phone line that donor family members are invited to reach out to. Nervously, you contemplate the idea of calling them. Taking another big breath, you decide that your desire to talk about your questions is greater than your nervousness – after all, you tell yourself, you can always hang up.

When your call gets picked up, there is a reassuring and friendly voice on the other side – someone who, early on in the conversation, shares how they became a donor family member. This makes you feel more comfortable talking about some of your thoughts and questions about the process to date – the person you are talking to does not seem surprised by how you are feeling, they stress that you are experiencing feelings similar to those of many others. When you both get ready to hang up, they invite you to reach out to the network and to consider attending a memorial service that is run annually in autumn to meet other donor family members. After the call, you feel reassured that some of your questions have been answered and that you have someone to call in the future. At the same time, you find yourself wondering how many similar calls the person you spoke to gets on a regular basis, how they came to know the information they shared with you about the donation process. You think about whether you should speak to your family members and tell them to also reach out if they are going through similar feelings. You realise that your elderly parents who have been feeling very emotional over the loss might not yet be ready to, and that you would need to write the network's number down *for them as they were not very tech-savvy. You sigh – you are beginning to realise that you will have to think carefully about what further support you and your family need and that it will likely be your own initiative and ability to seek out this help and the scope for support the charity providers have that determine your processing of the donation experience.*

As the vignette indicates, this chapter presents three main interconnected arguments. Firstly, the chapter draws on the degree to which the donor relatives I spoke to felt they needed support that related specifically to their organ donation experience and indicates their confusion amid their difficulty recollecting what they had been told to expect when they were given the information about organ donation. Secondly, I underline that for many, there was an initial passive reception of the honorary materials provided but also a sense that not the right kind of support, not at the right time, or not in-line with how much they individually needed it had been provided. I describe how for many deceased-donor relatives who became actively involved with the Donor Family Network, this need for help, support, the sharing of one's experience, looking for additional meaning or information led to the desire to help improve and shape the experiences of others. Lastly, I discuss that there is a trend in the way that further care and information is currently offered by the health service that relies on the donor relatives to actively reach out and seek further support, which is at odds with the more passive, expectant awaiting of support offers and information that many deceased-donor relatives I spoke to assumed would characterise the post-donation communication. This coincided with the difficulty that many deceased-donor relatives said they had organising informational materials they had been handed during or shortly after the donation process. Many outlined the way in which the effects of the loss had let them to struggle recollecting what they had been told or reflecting further on the meaning of their donation decision or the questions they would have liked to ask. I explain that in contrast, the Donor Family Network has ambitions to offer the kind of support that would have helped them, to make contact with new deceased-donor relatives, to offer information materials, resources, and let them know what support the network could provide. However, while the neoliberal trends in the health service outlined in Chapter 3 emphasise the value and responsibilisation of community organisations and volunteer groups, they overlook the limitations such groups face when it comes to accessing and retaining the contact information of donor relatives. The members of the Donor Family Network seek to provide the support that they would have liked to receive and draw on these to create symbols and support resources, but they must construct their activity around the health system and official structures.

The barriers that donor relatives and volunteer-run organisations face are situated in the overarching context of the bereavement care and support landscape in England. Bereavement support in England is highly localised and dependent on the circumstances of the loss, and the capacity and availability of services can vary as a result. Various government-funded and supported services contribute to the overall framework of bereavement care and support available to individuals and families (Hewison, Zafar and Efstathiou, 2020a; Wakefield *et al.*, 2020). These services are often provided through the National Health Service (NHS) and local authorities and include GP consultations followed by possible referrals where counselling is needed. While these "*official*" avenues exist for bereavement care and support, their extent and availability can vary according to location, funding, and individual circumstances. Some individuals may find that additional support from private or voluntary sector services is beneficial in supplementing the support provided by state-funded services, and indeed, many official government websites offering information on bereavement support encourage citizens hoping to speak to someone to contact charities like Marie Curie or Sue Ryder (GOV.UK, 2024). The fragmentation and inconsistency of care provision have been previously identified as an issue with negative consequences for those facing bereavement. Research by the UK Commission on Bereavement, a group of research institutions and charitable organisations offering bereavement support in the UK, has emphasised that there are challenges when bereaved people try to access support and highlighted that the time when support was made available was frequently not when it was most needed (The UK Commission on Bereavement, 2022). The availability and reach of bereavement support in the UK have been identified as under-researched. While special care can be needed by those who were affected by a bereavement following a remarkably complex, sudden, or violent death such as suicide or a traumatic accident, the manner of death is not a reliable indicator of the degree of need for support (Hewison, Zafar and Efstathiou, 2020). Consequently, there is little evidence that can determine whether the people who were bereaved following a particularly traumatising death are, in fact, the ones who report that they felt the greatest need for external support. Coupled with a great degree of variation in for whom, when, for how long and under what circumstances services are available, the literature paints a picture of a support landscape that appears inequitable and difficult to navigate (Nagraj and Barclay, 2011; Hewison, Zafar and Efstathiou, 2020b; Wakefield *et al.*, 2020; The UK Commission on Bereavement, 2022). Based on my conversations with deceased-donor relatives, these trends are already well-known and reflected in the experiences of seeking out bereavement care and support. Some of the lack of transparency and issues around equal access arise because of the large amount of responsibility bereavement care charities and other not-for-profit organisations shoulder. For example, research conducted in the North East of England highlighted that charities were grappling with limited financial means and capacities to offer help where the needs of the local population exceeded the help, they could provide (Wakefield *et al.*, 2020).

The increasing emphasis on community care and on volunteer service provision exists in line with similar neoliberal health and wellbeing service provision trends that have been on the rise in England in recent years. The term “neoliberalism” is defined as ““the policy of supporting a large amount of freedom for markets, with little government control or spending, and low taxes” (Cambridge Dictionary, 2024a). In practice, this is indicative of the normative notion that the communities that use a health or wellbeing support service and other healthcare provisions have diverse needs and can best design and prioritise the provisions they need themselves, which is in turn intended to provide greater freedom and relying on community engagement (Pemberton, Peel and Lloyd, 2015). When one relates this freedom to the inequalities in service availability for bereavement care run by non-governmental organisations, the consideration evidences the pressure towards citizen self-responsibilisation that neoliberal policies which rely on volunteer and community provisions of care can exert (Small, 2023). Therein, bereaved people are increasingly responsible for seeking out sources of bereavement care and support based on their self-determined need (Koksvik, 2020). In doing so, individuals are thought of as people who can make empowered decisions about the care that they need and as being able to rely on community resources for support, allowing them to take a form of ownership of how the death affects them (Koksvik, 2020). The healthcare system is then left to the task of dealing with the medical needs of the bereaved populations, which is intended to respond more efficiently to needs that can be responded to in professional medical ways and simultaneously placing emotional labour and support outside of the state-run service provision in healthcare (Whiley and Grandy, 2022).

However, the neoliberal strategy for support provision can have negative unintended consequences for healthcare workers, who often find themselves continuously confronted with the emotional needs of patients and in need of responding to those needs outside the demands placed on them by their professional duties (Whiley and Grandy, 2022). Additionally, it has been argued that citizens should have a right to certain universal services which should not be delivered by external organisations. This was suggested to prevent people in need from being faced with a situation where their ability to receive support depends on circumstances they cannot control or their capacity to locate and access a suitable source of support (Wood, 1997). Furthermore, concerns have been raised about the difficulty of monitoring the quality of care and support provided by charities and non-governmental organisations, as well as their governance structures and internal hierarchies that determine service delivery and decision-making processes (Wood, 1997; Small, 2023). These trends in bereavement care provision in England provide the backdrop for a discussion of the challenges and options faced by deceased-donor relatives who need additional support following organ removal.

As the accounts from my interlocutors in this chapter will show, it is often in this context, in addition to the need for support when grappling with the trauma that relatives may experience, that deceased-donor relatives experience a desire to have someone to speak to. As outlined in Chapter 3, the transplant service offers some points of contact for additional information to donor relatives. It honours the donor and the relatives who have supported organ donation through symbols of appreciation and recognition. The pin badges sent to donor relatives also have a secondary purpose – a purpose which Chapter 3 established indicates a trend towards a neoliberal desire to promote personal acts of charity by lending one's decision to consent to organ donation as a declaration of support for the national transplant service. In this way, the support for the transplant service and the desire to promote organ donation is practically expressed, reaffirming the decision to give publicly while simultaneously showing recognition of the "*gift of life*" received. Charities like the Donor Family Network are often invited to join the ceremonies for deceased-donor relatives organised by the Order of St. John. They can indirectly introduce themselves by meeting new relatives at ceremonies honouring the donor but generally rely on transplant specialist teams who agree to hand out information materials in the hospital as part of the information that is provided to deceased-donor relatives. However, charities like the Network have no general entitlement to ensure the materials are shared as intended and must reach out to NHSBT units to request support promoting the charity's details. However, the Donor Family Network website is linked on the NHSBT "*Donor Family Care Services*" page under additional support options. Despite this, awareness of the network among both specialist nurses and hospital teams and newly bereaved deceased-donor relatives is limited.

Organ donation is governed legally and enacted privately in a system organised by medical professionals. How it is later honoured and advocated for in some cases is subject to generalising assumptions about the needs of deceased-donor relatives. Consequently, the donation process and subsequent support, care, recognition and privacy initiatives make assumptions about private persons' needs, values and beliefs. Suppose contact details for charity support are not handed out by the specialist team or shared at an event. In that case, deceased-donor relatives must take personal initiative and look for support to learn about the charity. The challenges that arise from these circumstances are explored in the subsequent sections.

5.2 Transplant support and timescales

Section 3.4 detailed the schedule based on which donor relatives are sent information about the outcome of the donation and the gold heart and donation certificate that honour the decision. Like the materials and forms distributed in the hospital, this communication is standardised (although it can be personalised) and shared very shortly after organ removal takes place. An offer of counselling or additional professional support from the health service is not usually made to every donor relative. However, it can, in some cases, be provided if the death meets specific criteria (for example, when a person has taken their own life). The counselling offer is not usually tied to the decision to donate; it consists of more general bereavement counselling (GOV.UK, 2024). The transplant service provides anonymised information about the donation outcome if the donor's relatives wish to receive it and processes communication expressing gratitude to the relatives and honouring the donor for their part in making organ donation possible. During this time, bereaved relatives can feel initially overwhelmed with the need to return to their lives and to deal with the organisational repercussions of the death, as well as the changes to their lives that the death has caused. The Donor Family Care Website has links to different advisory materials that can help relatives navigate the legal steps that need to be taken following a death, and local communities, family members, friends and religious leaders can also step in to help.

When the Ibbingtons left the hospital after the death of their son, they did not feel ready to explain what had happened to him and were afraid that questions would arise. They were grateful that their local vicar had stepped in and communicated their situation to the community on their behalf.

> *When our son was still on the life support, we spoke to the vicar about what had happened and he afterwards told the congregation and the school, when we went to inform the school, they already knew what had happened, because he had gone and spoken to them. That really helped because it took some of the burden off us; we were worried about us having to tell so many people.*

The parents were primarily worried about their other son and the way he would cope with what happened. They recalled being handed material on support opportunities in hospital but not feeling ready to look at it when they first received it. Later, they struggled to remember many of the details about what they had been told.

> *We did read the leaflets we were given in hospital, but it took me some time. I think things just got put back a little bit. We were given a leaflet when we were still in the hospital, but I just put all the paperwork to one side; I could not look at it, and I am unsure if I remember this. We found that it was difficult to encourage our son to partake in activities. We did try to have him get involved. We felt that especially our son needed to be supported by counselling, but we struggled to access help for the first year – we did buy some games that are meant to help. We did contact a support group to get help, but they told us their waiting list was too long.*

There was support available from a local charity that worked with families who had lost children who died in the local hospital. The charity usually provided support during a one-off event, and no formal counselling specific to the nature of the bereavement, including the organ donation aspect, was available. To get counselling support for their son, they reached out to a different charity, only to be told that they could not help as the charity had exhausted its capacity. Their recollection of having been given materials that they struggled to use effectively and information that was difficult to recall because it happened simultaneously with the loss is not unique. Their account reflects both the issues with the availability of bereavement care in England that the literature discussed in the chapter introduction and the experiences of the other interlocutors I spoke to, such as the members of the Hewett family.

> *I don't think we were given the materials from the donor family network in the hospital, or if we were, we don't remember; we were in shock, really. When people are on life support, it all happens very quickly. It just happened very fast. When you are grieving it is hard to get your head around it. We understood what was said to a point, but we can't remember why we could not give her heart. We did get upset we could not give her heart, but it has turned into curiosity now, I might try to google it, I would like to know the reason for why it could not be donated.*

The Hewett family expanded on a point I touched on earlier – the idea that donating some organs can have a more profound significance. They recalled that while they received an explanation of why their daughter's heart could not be donated during the process, they could not recall much of the detailed information provided to them about the donation process at the time. They recollected the overriding feeling of being upset at the time, which stuck with them because they had placed some hope into the donation of their daughter's heart. Having access to a chance to ask additional questions about details that had been forgotten or not adequately understood during their time in the hospital could have alleviated that confusion to some extent. They still wondered about it in hindsight and would have benefitted from another chance to ask any questions that arose once they had had time to reflect. When Mrs Hewett was offered counselling, it was provided independently of the decision to donate.

> *I had some counselling, but I always used to get upset; it would often make me cry to think about it really. We did not need that much support; we are probably quite strong, and we had other support offers because of how our daughter died. For me, the bereavement counselling was difficult. It is good to try, but I sometimes think it was offered too soon, and you always get days that are hard.*

While the mother of the donor recalled having received an offer of counselling, she felt that she was given a chance to talk about her daughter's death too soon when she did not feel ready. She recalled that at the time counselling was offered, she would get too upset to talk about her loss. Mrs Hewett also reflected on how she and her husband's needs might compare to those of others and concluded that they might have been stronger than expected. When bereavement counselling is offered based on the same timeframe for different people based on the manner of death and other standardised criteria and not based on self-reported needs, there can be a mismatch between the timing of the support offered and the degree of need and availability for counselling. For most donor relatives I met, it was difficult to recall some of the medical details and information on what to expect after transplantation as of the broader transplant process that had been shared at the time informed consent was obtained. Relatives felt a sense of being overwhelmed with information immediately after the death.

Isabel's experience was previously briefly touched on and explained the reasons for her preoccupation very well.

> *When I got home, a few things came through the post, but you are in the middle of organising a funeral, and you get lots of little bits of paper, and I just did not pick up; it did not register… Something might have been given to my other daughter, but I don't remember. So, I did not have any contact at all, they did not contact me at all, unless they had given me some paper that I just dismissed or threw away, or somebody else received. Three weeks after your child is dead, you are busy organising the funeral and ignoring all the millions of phone calls you get. I mean, I had twenty-seven voicemails on my phone and I never listened to one of them because I just did not get round to them. And you try to get over the shock, and you, yeah. You have to organise what colour lining you want in a coffin.*

Because Isabel could not recall having received any notably helpful or clear information and because she felt too overwhelmed to answer the phone, having been busy with funeral organisation, she was not in a position to express support needs or begin to reflect on how the donation affected her until the initial organisational consequences of the death had been dealt with. Her account highlights the risk of offers of counselling or information about other helpful resources being usually sent out close to the time of death. At this point, it is possible that relatives won't yet feel ready to engage with the material. Many other donor relatives, like the Davies family, who felt they were personally better able to detach the donation experience from the loss, the communication from charities and the NHS and the objective to promote donation were not as problematic. They did not have an expectation nor a need to receive more support.

> *If anybody asked, I would stress that we believe organ donation is important – we have spoken about it quite a bit. We shared our opinions, but there were not many follow-up questions. We do not have a close relationship with the recipients, all we wish them is long life and health really. We do wear the Donor Family Network badge, just to generate awareness. Because we have been through the process, and we are very proud of it really. When the Donor Nurse came to see us, we made the decision, we never regretted it. We have since learned more about the*

> *process, but once the final decision was made, the process took place without our further involvement, somebody else handled all that. Some people will need support from Counsellors/Charities, we did not need any support, we were quite strong.*

The Davies family reflected on their personal strengths and their ability to deal with loss on their own. They did not feel a need for formal counselling and sounded as though they took pride in their ability to manage the consequences of the death without additional external support. Likewise, the Lakefields', two adult daughters and their mother expressed a similar sentiment. Having experienced the loss together, their ability to support one another within the family was their most important source of comfort. They stressed that time had helped them learn to live with the loss more than anything else. One of the adult sisters explained how the loss felt for her.

> *I still think about the loss the most – I still think that is what you feel, how you carry on living…. We do have our own plot in our cemetery. We go there on her anniversary and the day of her death – mum gets a lot more quieter moments where she may think more about everything. The loss is the worst trauma we have gone through. There was this thing called "After Life" by Ricky Gervais; someone told him grief was like a heavy rucksack you carry; it never gets lighter, but you get used to carrying it – I heard him talk about that on television. Sometimes, it overwhelms you out of nowhere, and it feels like someone is squeezing your heart really firmly. We are incredibly lucky to have the relationship we have got, because we all know what it feels like.*

The burden of the grief on the lives of many donor relatives and its tendency to remain impactful for many years after the loss was first experienced was central to the accounts of many donor relatives. The idea that someone can best help another person if they have something in common, which means they are more likely to know what a loss feels like, is common among the donor relatives I have spoken to. Here, the source of common experience is the loss of the same person that the different family members experienced. In other cases, the sense of a shared experience comes simply from being the same age as somebody else or because the other person has also experienced a loss. Kinship through shared experience does not need to be bound by specific criteria that cause the different parties to understand one another but usually establishes itself simultaneously through a spontaneous sense of connection in these instances.

However, for some donor relatives, it can feel crucial to get a chance to speak to another deceased-donor relatives who can relate to the specific elements of the donation-related experience. For others, like Kathy, it is more important that professional counselling that does not rely based on a shared experience of loss can be made available to every donor relative who needs it.

> *When I went through the experience in hospital, I was just dealing with the donor coordinator, but I think having more people, like voluntary helpers involved could help. You feel very abandoned during the process, and all of your family are grieving already. I think there should be psychologists and counsellors available to provide support; I think you almost go through posttraumatic stress. We took him to the hospital, we were there all night, and we were traumatised – it is traumatising when you get into the graphics of it. I would have felt better if I had had someone to talk to. You have dreams about it; I had nightmares.*

Kathy believed there was something about the donation experience itself that, on top of the loss, further amplified the negative impact of the overall experience, describing the hospital setting as a traumatising environment that donor relatives have to be in. She understood donation at its core as something made possible by a graphic process, and images of that graphic process were what she dreamed about long after the donation.

> *When you are offered support, it depends a little bit about who you have lost and it tends to be just the classical bereavement counselling. There is absolutely nothing that can prepare you for it. I ended up googling around to try and find a support group and I happened upon the Donor Family Network by chance. I feel quite strongly that the transplant service should have a support arm. At the end of the day, your son or daughter were not heroes; they did not die to become a donor. Romanticising it is not the same as providing real support. It is always the families who have to decide. There should be more professional support available. With the hospital, I got the sense that there was short staffing, so there was no further contact. Overall, I get the sense that there is patchy coverage of support staff across the country. I would have appreciated support from three months afterwards.*

For Kathy, based on her own experience, transplantation is a distinct enough traumatising experience to warrant further specialised transplant support that trained professionals provide. She had to take the initiative to look for additional support herself and to find different charities that offer donation-specific support, like the Donor Family Network. She was in favour of the service they provide but thinks the donation experience is too severe and affects too many people across the country to be managed by a charity. Like others before her, she felt that support in terms of bereavement counselling was offered too soon, and she has a precise idea of the sort of timeframe from which she would have liked to have received formal support offers from the transplant service. Her account reflects the self-responsibilisation tendency in neoliberal healthcare systems discussed in the chapter introduction, which highlights that had she not felt able to look for information herself or had support from family and friends, she would not have been aware of any support at all (Small, 2023). Instead, she received materials honouring the donor and the donation decision. To her, these materials were an attempt to romanticise the process she was having graphic dreams about, as well as an attempt to avoid the need for more tangible support from specialised providers.

Previous work on bereavement counselling has challenged the underlying assumptions about the uniformity and predictability of grief health services. Specifically, the way it is embedded in care procedures as something that tries to standardise the timescales during which support is needed and the kind of support that may be required based on who died/how they died has been determined to be an issue (Cleiren and Zoelen, 2002; Corr and Coolican, 2010; Hogan, Schmidt and Coolican, 2014). Poignantly, Kenny et al. establish that in many cases, there is friction between the expected ability to comprehend the loss and to begin to grieve and be ready to overcome the grief and the reality that the people going through the bereavement experience face (Kenny *et al.*, 2019). As is also evident from my research, grief does not follow the same timescales and patterns for every person and the need for support cannot be determined solely based on the manner of death of the relative or the age when it happened.

These insights highlight the risk of misallocating resources for support based on external factors that the deceased-donor relatives have no control over, whose importance for the real-world needs of the bereaved is overestimated. The reported variations underline the need to view more organised models that predict grief that follows a particular order or manifests itself in very similar ways with some caution. For example, familiar models of grief, such as the five stages of loss described by Kubler-Ross and Kessler (2005) imply that grief manifests itself in more linear and organised ways than is reflected when we look at evidence from real-world contexts. The literature on the experiences of deceased-donor relatives has previously touched on the potential for the donation experience to have a traumatising effect, albeit not consistently more traumatising than other forms of bereavement (Cleiren and Zoelen, 2002; Hogan, Schmidt and Coolican, 2014). What I want to highlight with the examples outlined in this section are the complex effects the neoliberal grief care and support approach that exists in England has on deceased-donor relatives who are coming to terms with the loss. Frequently, relatives are not aware that they are the ones who need to take responsibility to seek out the help and support they need. They also do not always have the capacity to do so, so they take an initially passive stance instead or take some processing time before beginning to reflect on the meaning of organ donation for themselves and the donor more deeply. This is particularly notable in the way many donor relatives struggle to recall details of information provided in the hospital when informed consent was obtained and shortly afterwards, when they may have been given additional information leaflets.

Many of the donor relatives I spoke to were offered support when they did not need it; some were offered support too soon, some felt they were too strong to need it or that having to talk about the loss when the support was offered was upsetting. For those who needed support to deal with the transplant decision and the fears and doubts that came alongside it, the personal initiative was needed to try to locate an appropriate source of support. Some of the people who had reached out to request support had felt abandoned when they were told there was no capacity to help them, and others felt abandoned by the transplant service after organ removal. This sense of abandonment in terms of professional bereavement support or counselling caused them to view the communication honouring the donation decision that was sent by the health service as an attempt to romanticise something in an abstract way, which remained a graphic and not fully processed memory.

5.3 Personal initiative in accessing donation-specific support

Isabel, like Kathy, found that she needed further support to help her cope with her concerns about the organ removal process. She was having dreams about the transplant surgery that were causing her distress. For her, the problems started about eight months after the transplant.

> *I've had to do all this myself. Nobody has come to me. So about eight months after the transplant, I started having really bad dreams about my daughter's body being cut open and how the operation would have happened.*

At the time, Isabel was already having bereavement counselling with a counsellor who was only a little bit older than her, a mother who had also lost a daughter. In many ways, this was helpful because Isabel felt she could relate to this person because they had had similar experiences of loss. She did not think younger counsellors who had not had children themselves would have been able to understand her.

> *We actually had quite a few things in common, but the counsellor can only tell you so much, what she did tell me worked, but you struggle finding help in terms of specific counselling about the donation. This was something that they couldn't cover; my counsellor said it was outside of her knowledge, you know, how to help me.*

Because the professional counsellor Isabel spoke to had not had donation-specific training, she did not feel she knew how to comment on donation-related anxieties. This prompted Isabel to look for donation-specific support for donor relatives, and the Donor Family Network phone line, as Kathy also discovered, was the only thing she could find.

> *So, I phoned the Donor Family Network and Keith, you know Keith, and he picked the phone up and just started talking to me like he'd known me for years, you know? And we spent about an hour on the phone. I felt a bit better afterwards, so then I actually joined the network. And then one day I phoned, it was another day and I ended up speaking to Tina and she decided to talk to me about when her son died. She used to go around the house slamming doors. Because she was so angry, so that's mad. But Keith told me that my mind would play tricks on me. And that the death of my daughter was never going to go away, but I would learn how to live like a new normal. You can only have your bereavement counselling for so long because you run out of things to say after 16 months. I think they exhaust their scientific resources, and at the end of the day, you need to be alive, and you need to carry on. I think not having to explain anything to anyone is so important, and you get that continuity and that support.*

Isabel felt that the support phone line allowed her to speak to others who could understand her and had time to learn to live with similar experiences they had struggled with. The volunteers from the Donor Family Network who answered calls to the phone line had all also consented to organ donation on behalf of a deceased relative, and all of them had experienced different personal struggles that were linked to that decision as well. By recounting their own experiences and explaining how they eventually found "*a new normal*", the network provided a meaningful source of support and understanding that Isabel felt was only made possible because similar experiences had shaped them. Additionally, she pointed out that bereavement counselling runs based on a schedule and tries to bring people through the process of grieving, but that it runs out eventually. However, the effects of the loss on Isabel and the people answering the phone never ran out, because the network were willing to provide an ongoing support community and foster lasting support relationships with those deceased-donor relatives who needed them. Isabel believed the DFN's support was significant because it offered its members an ongoing sense of community. It remains there as donor relatives "*carry on*" trying their best to live their lives. The support phone line the Donor Family Network provides was generally viewed as very positive by the donor relatives I spoke to, although some raised concerns that the volunteers were not professionally qualified to provide the support needed and that their experiences did not necessarily reflect the breadth of possible influences that the network could.

Isabel's account of the limitations of professional bereavement counselling highlights the potential benefits of receiving support from a charity consisting of people who have gone through a similar experience and who do not cut off the support that is provided after a specific period of time has passed. The sense of a supportive community in which bereaved deceased-donor relatives can form lasting connections and close personal ties is something charities can provide, whereas official service providers cannot. Additionally, while the people running the phone lines may not have professional training in counselling, they do have a sense of how the person on the other side of the phone might have felt. This is because they went through the donation process and as they support more and more people and hear their stories, that understanding grows, furthering their "*expertise*" on the topic. Moreover, the members of the network also have a good understanding of the other sources of information and opportunities for involvement in the transplant community that exist and frequently act as a connection point that can help deceased-donor relatives who are looking to understand more about where they fit in and how they can receive more information and support in the transplant community. However, their ability to do so relies on deceased-donor relatives making contact, reaching out and sharing their needs, and the availability of volunteers willing to answer the phone and offer help and support. Because their experiences of dealing with the loss are not universal, the people calling may not feel connected when they speak to the network over the phone, and the service is not accessible in a multitude of different languages, nor does it have the capacity to answer calls from all donor relatives. Many of my interlocutors were unaware that they needed to seek out help or that the system was designed in a way that relied on them taking responsibility for their support needs. Instead, some gratefully received their communication but waited for further contact regarding support that did not materialise. Charities are very limited in their ability to actively reach out as the healthcare service does not pass on contact details of bereaved deceased-donor relatives who may need support. The following section unpacks the challenges charities like the Donor Family Network face in their attempts to provide help and advice. It also indicates the risk of symbolic communication being considered trivial when the state provides no tangible support.

5.4 The role of charities in official service provision

The Donor Family Network, the Order of St. John and NHSBT frequently work alongside one another and send representatives to their respective events to create a web of available recognition and support for deceased-donor relatives. Keith, one of my primary contacts at the Donor Family Network, stressed that the Order of St. John *"recognised the gift"* in a way that included the presence of attendees who indicated the high recognition of the award, explaining that Lord Mayors and Lords Lieutenants or their deputies are regularly in attendance. He explained that ceremonies were often held in *"prestigious venues such as Town and City halls and other high-profile places".* The recognition by the Order is available to deceased-donor relatives, and the ceremony is not faith-based. The source and imagery of recognition from the order align closely with the notion of the gift of life and emphasise the honouring of donor relatives and deceased donors on behalf of people and in venues that are often believed to be of a high status by the deceased-donor relatives I spoke to. However, there are indications that the images previously criticised as attempting to "*romanticise*" donations are not received in the intended way by some of the relatives who were invited. The way honour and appreciation were expressed and presented was not universally well-received by all the donor relatives I spoke to; although most were very proud and felt honoured that they and the donor had been thought of. Similarly, individuals who had a difficult time in the hospital during organ removal or who felt they were not treated well during the transplant process sometimes felts reluctant to wear a badge that expressed support for the transplant service. Not every deceased-donor relative wants to step into the role of an advocate for the wider transplant service. This is not necessarily because they do not support donation itself or because they regret their own donation decision. Instead, the symbolism and abstract references to donation used in communication honouring the donor can sometimes feel at odds with the difficult memories of the process that deceased-donor relatives have or a lack of support after the donation they experienced.

Charities and volunteer-run activities increasingly exist around, alongside, and sometimes inside the health service, giving some the impression that all services originated from the same source. This blurs the lines between whom the information came from and who provides support. Where relatives assume centralised communication, they presume a connection and complex cross-communication between distinct governmental and non-governmental service providers that do not exist in this way. For example, the Hewett Family was under the impression that the Donor Family Network had initially contacted them and shared information about donation outcomes.

> *Later, the network got in touch and told us how the recipients had progressed and how they could use the heart valves. We became part of the donor family group and went to the National Memorial Arboretum, which is fantastic. We were awarded the order of St John and a certificate of appreciation from the Donor Family Network. (They proudly showed the arboretum version of the Donor Family Network badge, the framed certificate and the Order of St John.). It is also really nice to receive the newsletters from the network.*

Where relatives take a passive stance, expecting organised offers of support and information that is somehow based on what they are entitled to, they can be deterred from reaching out and asking for additional information and support themselves. Additionally, they frequently cannot recall the details of information provided to them in the hospital on whom to reach out to. Despite this, many Donor Family Network members feel the network is doing a *“fantastic job”*. It can relate to the way of making sense of the donation experience that the network provides to its members. The Ibbington family explained that the practice of recognising each donor and their families with a personalised letter on the day of the donation was particularly meaningful. They felt this showed that the network's people *“really care”*. Where there previously was no bigger charity that could support donor relatives, the

Donor Family Network now provides a wide range of services for deceased-donor relatives on behalf of deceased-donor relatives and the broader transplant community. Notably, the way this support is provided is born from the imagination, values, knowledge, and experiences of the people who organise the ceremonies and run the events. For some relatives, the rhetoric and imagery that are drawn on to tell a comforting and heroic story of donation can feel at odds with the real pain, loss and trauma surviving relatives can experience. Pin badges, like those handed out by the Donor Family Network and by NHS blood and transplant, can sometimes be received very negatively for this reason. This was the case for Kathy, who felt badges were a waste of money that could be better spent to provide counselling and other professional support to relatives instead.

> *I heard from Blood and Transplant in my city, and it happened within two weeks; they sent me a badge with a gold heart, and it says "Yes" on it.*
>
> *My son is dead, and you are sending me a badge. You want me to walk around with a badge on my clothes to promote organ donation. It feels like it is basically there to prop up the service. I don't feel I should have to. I would have a problem talking to healthcare professionals; I don't think my job is to stand there and promote it. I don't see the point in any kind of pin badge. I think it is a waste of money. It (organ donation) is basically asking somebody to face a very unpleasant thing. It is a Cinderella service. You have to look at the costs for everything; I don't think the money should be spent on badges."*

Kathy was personally in favour of donation, despite the challenging experience she had, and she felt happy that she agreed to donate her son's organs. Despite this, she felt it was inappropriate that the acts of recognition seem tied to the promotion of organ donation by the donor relatives who already consented. Her personal experience of transplantation was not wholly positive, and messages that over-emphasise donation as an abstract, morally virtuous act did not reflect her personal experience.

> *People generally respond differently to different things, but professionals should do something as big as this. The Donor Family Network are great, but it should not be up to them, and I think if there is only one thing that can be made available, it should be the support, not the trivial things and the ceremonies, but really, you should have both.*

For Kathy, the value of ceremonies would have been greater if they had not been accompanied by the sense that other, in her view, more tangible support services were unavailable to donor relatives. However, in an increasingly de-centralised health system where volunteers and charities take on an intermediary position between members of the public and professional health services, charity-designed and delivered support and recognition is becoming more common.

One of my conversations with Tina, one of the people running the Donor Family Network services, explained the dynamic between the activities of the charity and the broader transplant community.

> *When there is something that is charity-based, that when we provide some support, it is always on our shoulders, rather than when it is something the NHS can provide. Because we know there isn't somebody else doing it. Charities like ours are there to plug the gaps because the NHS are not doing it themselves. Because they have not got the capacity to do it, so you are actually relying on people who are absolutely committed to the idea, which is usually because they have been through it. They are so committed; they are doing it for the health service, really, aren't they? We are doing it for the NHS, really because the government can't or won't, so we are doing it instead.*

Tina clarified that the NHS cannot currently provide all the support that the network has offered to help donor relatives and that, as a charity, the network is partially there to plug the gaps in NHS Donor Family Care provision. She explained that because the charity members have experienced the whole process themselves, they are very passionate and willing to step up to support the service because the government has not done so.

> *And all I can hope is that that will continue because as people fall off one end, because they haven't got the capacity anymore, they are getting older, and I just hope they can keep rolling because the network and everything that comes out of it, because otherwise you have to fight for everything. Obviously, the specialist nurses are absolutely amazing, but we all have to acknowledge that once you have left the hospital, the family is gone; their job is to deal with the next donor family; they cannot support every family that comes through their books, can they? So, you need organisations to fill that gap really.*

For the current members of the charity, there is a concern about their ability to find enough committed volunteers who can keep the charity going in the future, as older volunteers are no longer able to continue supporting it in the way they used to. The charity relies on the availability of donor relatives to act as sources of support. Tina had previously seen that the specialist nurses involved in the donation process could not usually continue to be retrospectively available to all relatives they supported once they left the hospital. At this point, Tina felt the responsibility for continued support for "*donor families*" fell to the Donor Family Network. The primary goal of the members of the network is to step in as a support resource where there are deceased-donor relatives who need them, and the network's other activities are secondary to this primary aim.

> *The Donor Family Network isn't so much on the promotion and advocacy side. I mean, we do speak to organisations, but we are more on the support side; after it has happened, we are not so much getting the information out there beforehand. We are dealing with the aftermath, aren't we? So, it is two different facets of organ donation, but both are very important, and in a way, they do join together. The ongoing support, that is what we are trying to provide. The hospital will, of course, provide a limited amount, and friends will provide a limited amount.* **.** *But at the end of the day, you are the ones who have lost somebody, you are the ones that made the decision, and you are the ones that have to move forward with it and it is extremely hard.*

Tina shared the sentiment that organ donation is the only thing donor relatives have in common in the beginning but explained that this is an important link between the different donor relatives she had met because it had created a willingness to support one another after the donation experience. In a sense, the network has made it its task to "*deal with the aftermath"* that the hospital experience has created and the questions that have arisen as a result of it.

> *And if you know somebody who is at the end of a phone, or at an event where we can go together…. And that is what we try and offer, nothing more than that. But over the years, we know that it has been appreciated enormously. And I know I appreciated it way back, in 2003, when I first spoke to (the founder of the network); I know how useful that was for me, not only that we had lost our child but that we had that decision we made after that, the moving forward a bit*. *It was good to speak to another bereaved parent and somebody who had made the decision because I found that when I was with my friends or I went back to work…. I remember people saying to me, "The decision you made is amazing, but I don't think I could have made it". And I thought, "I actually need to speak to people who have had this double whammy because you have the loss, and you have the donation decision – so it is almost like a two-fold thing for donor families, and people don't always get that – and of course, I knew nobody.*

Some donor relatives felt as though the donation added an element of complexity to their loss; it impacted the whole experience surrounding the death and gave rise to a need for further reflection later on. I hinted at this element of ethical complexity when I described the process of privately reflecting on the significance of the donation decision that frequently comes after the initial decision in the wake of the loss and under time pressure has been taken. While the pin badges and materials honouring the decision express a deemed moral virtue in the eyes of the state and the health service and one that is inserted into this sense-making process, the private ethical significance of the decision is frequently subject to further reflection. As Tina explained, at this point, it can be crucial to speak to someone who knows what that particular experience feels like, implying that the donation process feels similar enough for different people that having had the same experience creates a sense of shared insight or understanding.

> *Moreover, everybody does not want to get involved, and of course we get that some people say, right, I have made the decision. But, of course, most people want to know a bit more about what is going on, and they need support. And I don't usually ring people; I let them ring me unless somebody will ring me first because I don't want to make a nuisance of myself.* ***I*** *just want people to know that we are there. People ring us for things that they forgot to ask at the hospital, and they don't want to go back to the donation nurse because they are at the hospital dealing with the next family. But people will have niggles and I will always say "don't have a niggle, because we can sort out those niggles". We can always find an answer for you, so use us as a go-between. I always say to families who want to get in touch, 'I am also a bereaved mum, and I am very happy to talk to anyone'. The mum I spoke to this morning I was totally there for her, but she inevitably asked me who I lost. But I tell her as little as I can because I am there to support her. However, inevitably, she is going to ask me, who did you lose, how old was he, and how long ago? It is only by knowing that the person you are talking to has gone through a similar experience that you can get anything out of it. If we can help them, we are happy to help, but we do not push anything on anybody. Everyone is welcome to talk to us and get involved in our events.*

The Donor Family Network's main aim is to be there when people reach out but to not create any pressure for people to access the charity's services for information, support, or other emotional needs. Of course, relatives need to be aware of the option to receive support from the network before they can reach out. If the NHS staff do not pass on the necessary information materials or relatives don't look for resources online or speak to others, they may not be aware of the option to call the Donor Family Network for support. In these cases, they may be left with more unanswered questions. Tina stressed that the networks are not there to create any pressure; they are there in the background if needed.

> *We are not saying you can't come unless you are a member, and a lot goes on the Facebook page. And it really depends on what people ask, on what they want to know. Obviously, a lot of our work is with donor families who have already been through the loss, so our work is then trying to share in their experience. We empathise because of our own experience in the past and we can anticipate how people will feel.*

Tina also shared that the volunteer service often creates a situation where her own connection to an organ donor, her son, was brought up. In this sense, being a volunteer created an opportunity for her to revisit and recount her own decision to donate and her reasons for saying yes to donation because of what she believed her son would have wanted. Additionally, the work on the support phone lines created opportunities for her and the other trustees to gain insights into some of the things that went wrong in the donation process, which they could share when representatives of the Donor Family Network were invited to different stakeholder events or policy discussions.

5.5 The Donor Family Network and policymaking

The work with deceased-donor relatives on the Donor Family Network support phone line and during their other events created opportunities for Tina and the other trustees to gain insights into some of the things that went wrong or were challenging during the donation process. This is one reason why the members of the Network are considered experts on the needs and perspectives of deceased-donor relatives and why they are often invited to different stakeholder events or policy discussions. Tina explains how members of the network help inform government and health service bodies on how their plans and decisions may come to affect deceased-donor relatives moving forward.

> *As a charity, we are involved in a lot of stakeholder groups, and we are on a lot of committees for the simple reason that they like to have somebody who is lay, you know, we are not health professionals, but we have been there. And whenever we have been there, we have been very well recognised for the fact that we were there as the voice of the families, whereas doctors are focused on worrying about what they can do. And we are there going "no". We get involved in a lot of ethical decisions; we get asked to read a lot of policies, which we readily do because we are looking out for donor families. But I have to say, there is nothing much that comes back the other way, other than gratitude.*

Tina explained that the network is often consulted to review proposals or participate in discussions, speaking on behalf of donor relatives based on the trustees' experiences. She stressed that the network does not always receive transparent information that tells them whether their insights helped inform the decisions ultimately taken or the plans that had been drawn up.

> *We are often asked if there is some sort of new intervention being researched on how to make an organ last longer. Well, we would be involved in that, and we would often get onto those sorts of committees. We can say you can't tell families that, or you must tell families that, etc.*

Tina explained that the advice the network share to policy planners often ensures that crucial details are shared with donor relatives and that the representatives of the network are usually there to advocate for the preferences and needs of deceased-donor relatives.

> *We usually don't receive specific feedback to let us know whether or not a suggestion has been included in these research programmes, but yeah, unless we find out for ourselves. I feel we are probably asked to take part in small, specific parts of a project where they feel our input is relevant. We have been asked various times, even just to read the document and we can feedback, but we the never see that document again, so we do not know if our input was taken into account in the wording of that document. We give feedback, but we don't have the right to know what becomes of it. We give our input because we hope that it affects something.*

Keith, on the other hand, explained that when he participated in different committees, he always felt that the network took his thoughts, opinions, and insights seriously.

> *We sat on committees discussing different things all the way through, and our trustees have addressed MPs in London. Everything we have done has gone on to do lots of good. There are lots of organisations that speak for specific recipient groups to particular organs, but there aren't many regional groups who speak for a specific organ, except for some of the hospital ones. The Freeman Hospital has one up here, and they set up their organ donation group, possibly predating the DFN. Most of them tend to stay within their group, but we are the only national organisation, so they always come to us. We try to cover everyone, we cover the whole of the UK mainland and Islands. I think there are often one or two very minor things that pertain to family perspectives. So we provide as much insight as we can. They certainly all give the impression that they do listen. I do think they communicate that they take certain things into account.*

The Donor Family Network is often consulted as a representative national voice for donor relatives and invited onto different committees. However, its members only make up a small portion of all deceased-donor relatives in England, and the trustees running the charity are even fewer. The diversity of opinions at the centre of charitable bodies is frequently reduced by efforts to ensure the leadership continues the founding values of the charity, creating a siloing of opinions at the centre of non-governmental organisations (Wood, 1997). Consequently, it is unlikely that the trustees of the Donor Family Network can accurately represent the diversity of perspectives about proposed procedures that different deceased-donor relatives, particularly those not in touch with the network, might have. Despite this, they have over two decades of experience speaking to other relatives and have also experienced the process themselves. Still, they would likely be better able to give a more complete account if they were in contact with a larger portion of donor relatives. Unfortunately, the Donor Family Network's ability to reach out to donor relatives without the help of the health service is minimal. The network intends to be available whenever needed, to all deceased-donor relatives, but there are limitations to the coverage they can provide. As Keith explains, changes to data protection regulations (GDPR) and a lack of access to the contact details of bereaved deceased-donor relatives limit the network's ability to provide people who may benefit from accessing the charity services. The lack of awareness about the availability of charity support has been shown to create obstacles to their successful coverage for support in the past (Wakefield *et al.*, 2020).

> *Much more needs to be signed, even regarding GDPR and data protection. We went through an exercise with the donor family network about four or five years ago, where it turned out that a lot of people had not been receiving the newsletter, even though we ourselves didn't, because we had never formally signed up. Even when my son died in 2001, we never signed up for the newsletter. We had received two pin badges in the hospital, but there were 7 of us in the hospital when he died, so we wanted 7 of us to be wearing the badges at the funeral, so we ordered a whole lot of them. And then we received the newsletters about two or three times a year, but we had not realised that there were anniversary cards as well. Then, one year, my sister said that she really liked the anniversary cards and we had not had them. My sister had registered to become a member in the correct system, and we had not, that was why we did not get them. Bearing in mind, it was before it was even made a charity in 2003. So, the data protection regulations caused all sorts of disruptions.*

Legislation setting out the permitted communication channels and the need to sign up for different kinds of information through the appropriate channels created unexpected practical hurdles to the charity's ability to legally reach out to people. When regulations change, a charity may need to re-obtain consent from all of its previously registered members and lose access to several people whom they were once able to contact.

> *When the regulations changed, we even sent out a request for people to formally sign up on a form and send it back to us; we even sent them stamps along with the form because otherwise, we would not be able to keep contacting them. But we still lost the ability to contact about 200 people (donor family members); some of them had moved, and some of them had not signed up to the database so that it can be really difficult… There were three people to join over the weekend, and then there were three families who got in touch via Facebook to say they had not been receiving the newsletter anymore. The problem is that they had not filled the forms out to stay on the register. We suspect that we may hear from a lot more people via*

> *Facebook who aren't getting our newsletters anymore since the law changed and we had to change the register. There are some people who remarry or marry or change their name, and they may no longer get a newsletter when they might be expecting one or looking forward to receiving one. And then there are the pin badges and things like that, there is the NHSBT who at some point printed lots of our newsletters, and they also get our pin badges to hand out to families….*

Charities are in a position where they need to respond to changes in legislation, changes in the transplant processes, changes in the availability and capacity of volunteers who can help run them, changes in the needs of people who request support and changes to the technologies that are used to communicate with deceased-donor relatives. This is why the Donor Family Network relies so heavily on autonomous outreach by the people who want to access support and must work around what official bodies provide.

> *We are a small organisation; we are a national organisation, but we are far too small to be able to affect the way things are done. What we will have to continue to do is basically try to support as many people as possible. We can't do anything else, we can't find out about people, people have to come towards us. If we continue to grow, we might need to look into becoming regional because, as you say, you don't know everybody; we know an awful lot, but like you say about putting people together.*

Tina stresses that the Donor Family Network, despite its great ambitions and good connection with other transplant organisations, has limited capacities. If every donor relative did contact the network for support or tried to attend events, the network, with its current structure, would not be able to accommodate that need. Despite this, the network's organisers are open to future adjustments to the charity's size and running.

> *But we are too few; there are only ten trustees, and we can't support hundreds and hundreds and hundreds of people to the level of the kinds of personal conversations like the one I had this morning. I can only support a small handful of people to the extent they need at the moment. So, all we can do, we have to try to offload that a little bit***.** *We could maybe have people in different areas who can take on that role. That also means for us we have actually got to allow ourselves to let go; if we grow, we maybe need to step back a little bit and let others in, and maybe we could invite the NHS in, although I would guess that the majority of staff don't know that we exist. You can bet nobody else even knows we exist because we are not like the cancer research or the heart foundation, where everybody knows or has heard of them. If only you knew the amount of times that I mentioned the Donor Family Network*

> *because people will say what is that, because we are a small, niche, charity, and we are not going to get around that, are we?*

Because the network is not well-known not even among NHSBT staff, it is unlikely that all donor relatives are informed about its existence. This limits the charity's ability to fulfil its ambition so that no donor is forgotten. In some cases, the charity would benefit from greater external support and more formal incorporation of information about its work into donor relative communication processes. Sometimes, their activities are supported, and sometimes, they are hindered, creating a situation where the distribution of information about the charity's existence can depend on the specialist staff members working in a particular transplant unit. For people who feel unable to reach out by themselves or do not know that they need to do so, instead of waiting for support services to contact them or are unable to devote time to look for support, informal charitable services are unlikely to be capable of providing tangible help.

5.6 Donor Family Network: From ethical pioneers to moral navigators

Having established the various challenges deceased-donor relatives face as part of the immediate aftermath of the loss, as well as the challenges and limitations that the Donor Family Network face in their capacity to contact new relatives and to offer help, I now turn to an example of a new initiative that tries to respond to these difficulties. Because of the challenges associated with being in the hospital environment during the donation process and the subsequent challenges associated with the loss, information in the form of flyers and pin badges is often overlooked or discarded. The members of the Donor Family Network must rely on donor relatives reaching out themselves and cannot enter the hospital setting. Consequently, they identified a period during the transplant process where they knew a universal need for warmth and comfort existed and during which specialist staff would feel happy to offer deceased-donor relatives something that constitutes an embodied expression of care. Because of this, the network has created a "*Hugga*" blanket initiative. Hugga blankets are small purple fleece blankets that the network has funded and offered to specialist care units in hospitals, to be gifted to new deceased-donor relatives as they wait in hospital for organ removal. The blankets are intended to resonate across different backgrounds because they speak to a common visceral human need for comfort. The initiative is born out of a widespread response to loss, a human need for warmth and comfort when receiving bad news. The network has started to fund and produce fleece blankets which have the Donor Family Network logo embroidered on them to be offered by the SNODs in hospitals as a way of comforting donor relatives and providing a more tangible item that has the Donor Family Network logo on it which they are more likely to hold on to than a leaflet. The intention behind the blankets was to make the often unfamiliar and uncomfortable environment of an ICU ward more comforting for the people waiting for organ removal to take place.

The blankets create an opportunity for the Donor Family Network to introduce something positive in the form of the blankets, which transplant coordinating staff might feel constitutes a small token of appreciation and support they can give to relatives who have chosen to support organ donation. A more oversized, more tangible and potentially helpful item from the nurses' perspective, like the embroidered blankets, is something the health staff can feel more comfortable providing deceased-donor relatives with. When Keith first told me about the blankets, he gave me one as a gift to keep. It was a medium-sized purple fleece blanket with the Donor Family Network logo embroidered in one corner and a postcard with some information on the Donor Family Network and contact links. The blanket was soft and cosy. Keith explained that this sensory experience, during the at times lonely and often unfamiliar environment of an ICU ward during the transplant process, can mitigate an otherwise uncomfortable and even traumatising experience. The blankets, he said, were primarily intended to offer some small token of comfort and support during this time.

> *The name HUGGA was chosen as it is an Old Norse word meaning 'comfort', and we hope it will comfort families at a very dark time.*
>
> *With our Hugga blankets, we are also hoping that more people will reach out to us and get in touch. The idea with the Huggas is that they have something much more tangible; if they put it on their loved one before they go to the theatre, it is also much more meaningful. And the postcard has our address on. It is still early days, but we are hoping that it might be able to get us many more new members and it is also looking like it may be able to bring ex-members back in. We don't currently actually have a huge amount of members. It can be tedious because, quite often, politically, donor families can be a bit of an afterthought.*

Keith underlines a further element of care for "donor families" that the members of the network know they have introduced into some ICUs. The Donor Family Network hopes that more people will reach out if they have something tangible from the charity to hold on to. The charity wants to continue to support more families and grow. The early and meaningful comfort offered through the distribution of the blankets is meant to show donor families that someone is concerned for their wellbeing. Because of the charity's commitment to providing support for every donor family, blankets were also sent to members they had previously been in touch with, who would, of course, not be able to use them in the ICU setting. They were intended to re-iterate former acts of outreach and encourage people who had not engaged with the community in a while to engage with the charity and the community more frequently. However, the decision to spend money to send blankets to existing families was viewed critically by some of the network's members, like Kathy.

> *I don't know; the whole experience is cold and dark. I just think maybe it should not be the Donor Family Network that spends that money. When we were waiting in the hospital, we were all lying around in corners in the ICU; we had nowhere to stay.*
>
> *I think it (donation) is the right thing to do, but I don't like it when they trivialise things. I get given mugs and bottles and all sorts to promote it, and I don't need all this stuff. With things like the Huggas, I think if I had been given it at the time, it would have still been just a blanket; it would have helped me feel warmer, but nothing more. Since I was not given one at the time, I don't understand why they sent one to me; I think they should have sent one to the hospital.*

Kathy explained that she would have felt warmer and more comfortable while waiting had she received a blanket in the hospital. Receiving the blanket outside the hospital setting was unnecessary in her view. Despite her concerns about giving blankets to families after the donation has already taken place, the reported effects on families and staff in the hospital environment itself have been very positive. Tina had heard from several members of the charity who felt that the blankets had made a big difference.

> *The details we give and the blankets we offer give them something they can come back to if they want support; it is something so that at least they know we exist because a lot of people want to join or just thank us for the Huggas. We are looking for something that we felt when we were in that situation could have helped us. This is something in most families I have spoken to throughout the years because the donation process is incredibly slow; by the time you have done all the tests and gone through that process, you have already made the decision to donate, and you have lost half a day. They can't start the donation process until all the teams are ready, so half the time it happens in the middle of the night. It is just nice to have something that is comforting.*

The slow speed of the organ donation process is something that many deceased-donor relatives struggle with. While the last hours with the donor before organ removal can be a precious chance to say goodbye, the environment can feel cold and unfamiliar. In Tina's account, the desire to offer the body of another person comfort and care during this process was passed on to the donor's bodies themselves by some relatives while they were waiting.

> *People use the Hugga in ICU to comfort themselves or to wrap their loved one in it, and you know they might want to take it home with them. It might have a smell, you know, after you*

> *have wrapped your child in a blanket for a few hours, whether it is psychological or not, you still feel there is an element of them. But it just came out of a spark of an idea for one of the trustees. You know, we all went through our experience, and there are so many similarities between people sitting in the middle of the night in a hospital and hospitals are not cold, but you might still need something comfortable there.*

Tina's description of relatives wrapping the donor in the blanket while they wait shows that the blankets can enable relatives to perform an embodied expression of why they are there – placing the blanket on a body that likely no longer feels its effects is a liminal act of expressing the continued protectiveness and love for the person that existed in life. In this way, the blankets can help shield the intimate setting of a death bed with grieving relatives in attendance from the medicalised processes preparing the donor's body for organ removal that goes on around it. Although the blankets were not initially created for this purpose, they are now being utilized by relatives of deceased donor unexpectedly. This occurrence draws attention to the potential benefits of introducing items that can help make the period before organ removal more meaningful for both the donor and their family. Using items can also help create a more seamless experience within the hospital environment. Therefore, the blankets play a crucial role in addressing the issues of the unrecognised transitional phase and the donor bodies in relational terms as discussed in Chapter 4. The Donor Family Network has incorporated something that can become a significant part of the final hours with the donor and an essential keepsake, a last memory. Furthermore, the blankets are a physical offer of warmth and comfort from the Donor Family Network to deceased-donor relatives, passed on through specialist nurses, offering comfort as relatives wait and connecting some of the fragmented parts involved in care and support provision. Keith outlined how the blankets were first introduced into hospitals.

> *We started it off when we started it as a project. One of our trustees is one of the nurses and she almost works as a liaison between us and the hospital because we are not allowed to know who has donated and we are not allowed in ICU. So, she can give it to the unit and give it to the specialist nurses and it is then their responsibility to give it to the families. But we now have it in other hospital trusts as well, and the idea is to get it in all of the trusts, so that every donor family is offered one**.** The feedback has all been very positive at the moment and we are looking to roll it out a lot further.*

To begin the initiative and reach the desired recipients of the blanket, the Donor Family Network has navigated access into hospital units to reach out to deceased-donor relatives as they wait, relying on individual connections with people who are part of the charity and the NHS. Once they establish a point of access, they work to spread the initiative further.

> *We have to leave it up to the nurses to give to them, but again, they have been really receptive. I guess it has given them something else to do. I think maybe it is pretty nice for them to have something tangible, to say to the families "would you like one of these, this is an organisation that has purchased these for us to give to you" It is a sort off handover. It is such a difficult time because all they are doing is they are talking to families at such a tragic time.*

The idea of a "*handover*" is poignant because the Hugga blanket handover that includes the Donor Family Network logo sees NHS professional care staff providing relatives with the details of a charity that feels responsible for their support after they leave the hospital setting. Tina emphasises that the initiative's success also relies on luck and is difficult to control for the Donor Family Network.

> *And of course, we rely on them, because we do not have the details of the people, they are giving them to. We can just say these are for the families, please give them to them, but please offer them to every donor family. If somebody says no, fine, if someone has a big family with siblings there and they ask can we have two – not a problem, you know we are very open with it. We all need something warm on a cold night, and yes, it does come with our logo on and yes, it does come with a card explaining the meaning behind it. That is the only thing they know about us, and that does not mean that they don't get one, everybody gets one and then it is up to them whether they want to get in touch. We just say, this is a gift from the donor family network, and it is up to them if they do contact us.*

While the network did hope that more families would reach out because of the blankets they received, and while the initiative appeared to be working, there was no expectation of receiving something in return after offering the Huggas. If the blankets were given to the relatives and maybe helped them somehow, they were thought to have fulfilled their purpose. The Donor Family Network invested further time and money to deliver the blankets, but they complemented the nurses' professional care. Furthermore, with families agreeing to organ donation, nurses were now able to provide a reciprocal act of thanksgiving as representatives of the health system responsible for donor family care during the wait for organ removal. The message behind the blankets is clear: The Huggas transcend any sociocultural and religious differences. The Donor Family Network logo is only embroidered in a corner, no interpretation of the experience is imposed on families beyond the desire of the network to indicate that there are others who have gone through the same experience and who are available to offer comfort and support. The initiative points to the network's ability to adapt, respond to problems and criticisms, and face the challenges that arise from the charity's status as health system adjacent support providers without formal access to personal information.

The status of the members of the network as non-professionals who are not part of the health service means that their ability to modify the transplant process and extend support to families is both limited and conditional on the willingness of professionals within the NHS to pass on materials and information. The network is constantly re-positioning itself in a changing system, which can continue to impact deceased-donor relatives in new ways. While the way they tell the story of organ donation and perform advocacy may not be met with universal agreement, and while they cannot represent every perspective, they try to respond to problems and criticism with new initiatives like the distribution of the Hugga blankets. Tina explained that the Donor Family Network had to get creative and do its best to get in touch with deceased-donor relatives, but that only donor relatives who feel ready and able to reach out in search of support were ever likely to receive it.

> *When it is charity run, you cannot expect that you have the data of everyone; you can't get the contact details, and it almost comes down to the chance of whether or not you get put in touch with charities like the network. At the end of the day, you are leaving it up to chance whether or not people can get the help that they need, and the people who are already more proactive are the ones able to seek out support autonomously. The likes of us who have gone out and found the network, you know, we go out of our way to get the information out there because we feel that we can then help, where we know there is no other help, we are plugging that gap. We have our Huggas that go out, and we send our letters, and we have worked long and hard for our leaflet that goes out with them. But that still puts the onus on the person reading the pamphlet when they might not want to, with data protection etc. We can go no further.*

In this statement, Tina precisely pinpointed a central issue about the support that is largely made available by non-governmental intermediaries – the reliance on people in need to take action and to reach out. While the network can go out of its way to reach out and try to raise awareness of the support it can provide, in the current system, relatives have to get in touch on their own initiative. This is even true if information about the charity is passed on by an NHS representative and held onto by relatives because it is accompanied by something as tangible as a branded fleece blanket rather than a leaflet.

> *We are encouraged when there is any new decision-making to be done, we are encouraged to become part of the stakeholder groups; at the end of the day, that is only if they remember to ask us. We have no way of knowing what is going on in the NHS; we are very lucky that people like head honchos support us and push for our involvement. Without the likes of them, we would just be a charity that helped people because that is what we are without access beyond that. The fact that we push ourselves, if you like, to go out there and plug ourselves is the only*

> *reason we are doing as much as we are within the NHS. Otherwise, they make all the decisions, and we pick up the pieces with the support side. But initially, it was set up as a support network and I still see that as our biggest role, is as a support network.*

In Tina's view, it was vital that the Donor Family Network could also be included and was able to represent the perspectives and interests of deceased-donor relatives during any meetings that may come to impact the experiences of new donor relatives. Beyond the provision of help, the network wanted to speak up in more formal settings and advocate for deceased-donor relatives, to ensure that relatives as a group are thought about and taken into consideration as an important part of the transplant process. To increasingly achieve this, the network has carved out a space for itself by pushing for their involvement in decision-making and making sure a voice that is intended to speak on behalf of deceased-donor relatives is heard wherever possible. The involvement of intermediary organisations on the service provision and support side supplementing the standardised care that is made available does not automatically lead to the involvement of the interests and priorities of those organisations in decisions made about the official transplantation process. Therefore, charities must push for their involvement as a secondary goal, like the Donor Family Network has.

As previously stated, their ability to represent the full breadth of deceased-donor perspectives is limited, and their own position on some proposals is likely subject to siloing. However, increasingly, the network has acted as a point of contact for a wider range of recruitment providers outside of the network, sharing calls for deceased-donor relatives feedback by the NHS and in research projects on their social media pages and inviting its followers to get in touch and share their experiences directly. While the network has its own positions on the organ donation process and emphasises the positive aspect of the decision to consent and contribute to the promotion of organ donation, they do not attempt to act as the sole representatives of deceased-donor relative perspectives. Additionally, they aim to be transparent in sharing their involvement in decision-making or their take on particular issues in the newsletters they regularly send out because of their overarching aim to facilitate deceased-donor relative engagement in the transplant community.

Crucially, the members of the Donor Family Network stressed that charities that provide private sector, volunteer-run healthcare support provision must be reactive, with new challenges appearing and conditions constantly changing. In transplantation, novel technologies continue to be proposed and developed and regulations governing how charities must operate and volunteer capacities are subject to change. To encapsulate the process by which the trustees of the network continue to draw on their own take on the way transplantation affected them in the wake of their loss, I go on to propose terminology that aims to capture how their involvement in service provision takes shape. To do this, I will first distinguish between their private decision-making about organ donation in relation to the donor, and the wider beliefs about appropriate donation support and the significance of organ donation that grew out of this through their involvement with a volunteer-run support organisation. To more clearly differentiate the two contexts, I draw on an analytical distinction between the ethical and moral realms developed by Zigon (2010). Zigon identifies morality "*as the embodied dispositions that allow for non-consciously acceptable ways of living in the world*" (Zigon, 2010, p. 5), operating at the institutional level, as part of the public discourse, and in embodied dispositions (Zigon, 2010, p. 6). Therefore, to study morality in anthropology, we must consider what "*counts as morality in the various social worlds we and our interlocutors inhabit*" (Zigon, 2010, p. 13). Conversely, the idea of ethical consideration is defined as referring to the "*moment a person becomes reflective and reflexive about her moral way of being in the world and what she must do, say or think in order to appropriately return to her nonconscious moral mode of being*" (Zigon, 2010, p. 8). During instances of ethical consideration, a person is making a decision born out of an assembly of various moral influences and assembles them creatively to arrive at a decision that is determined to be the right action for them in terms of the "*kind of person one wants to be in her social world*" (Zigon, 2010, p. 9).

The general question of whether or not one is in favour of or against organ donation in an abstract sense poses a new kind of choice that exists at the end of life where it previously did not. Therefore, I draw on the term moral pioneer used by Rapp in the context of novel pre-natal scanning technologies and the choices they created for pregnant women who could choose whether to receive a scan knowing that the consequence might be a decision to terminate the pregnancy (Rapp, 1999). Rapp introduced the term to describe pregnant women suddenly faced with the need to examine their moral values in response to evolving pre-natal screening (Rapp, 1999). Rapp referred to pregnant women as "*moral philosophers of the private*" (Rapp, 1999, p. 306), encapsulating the idea that women drew on their moral values and beliefs to determine what they should or would do if they decided to have a scan that informed them of a medical issue with their unborn baby and one that could cause them to no longer want to proceed with the pregnancy. In doing so, women were making choices based on concerns for their bodies and those of their children, and with future implications for their whole family. The routinely available scanning procedure created a situation in which women had the option to find out medical information about the bodies of their unborn children that could lead to interventions with severe consequences. This decision they needed to make is similar to the decisions made by relatives of deceased organ donors in that they do not know the future impacts of their choice before they know the outcome of the organ donation, or in the case of pregnant women, the scan. I will begin to refer to deceased-donor relatives making their individual decision about organ donation as **ethical pioneers** in line with Zigon's distinctions, because they are making a new kind of choice about donation with real-world implications for the body of their relative for the first time.

This organ donation decision happens in a healthcare setting, where individuals are not entirely alone. Here, the relationship of members of the public with their healthcare providers and the interactions that surround the decision impact the impression of the donation process relatives get in a way that is similar to the impact that contexts can have on the decisions of pregnant women on prenatal screening (Williams *et al.*, 2005). Indeed, the potential donor relatives approached by hospital staff are going through routinised and, to an extent, pre-choreographed processes, and their decisions might feel simultaneously private yet public as a result. An awareness of the medical need for donor organs among one's fellow citizens, considerations of what the deceased would have wanted, and personal thoughts on a desire to support others may play a role in the decision-making process. Because of this, an element of the conclusions of research on prenatal screening presented by Williams et al. can be used to characterise aspects of organ donation as well – the description of the screening decisions as part of a "*private dimension of public life*" (Williams *et al.*, 2005).

However, as the first section of this chapter shows, the process of reflection and reckoning about the kind of person one wanted to be in one's world, not least in terms of one's responsibility to the deceased donor, can often only unfold when organ removal has already taken place. This is because of the affective context of the death and the relational complexities explored in Chapter 4, which can delay the time when deceased relatives begin to reflect on the moral and ethical significance of the decision and their related expectations of the healthcare system and the recipients until after the loss. If deceased-donor relatives become involved with volunteer work with a third sector organisation as is the case for the people running the Donor Family Network, they open up the personal decision they have taken to a broader reflection of the institutional processes that impact all donor relatives and the support that they believe other should receive or would benefit from. Therefore, in the context of third-sector organisation work and in keeping with Zigon's distinction, they undergo a shift from ethical to moral, because the navigation includes judgements by volunteers and trustees about processes that could be put in place to circumvent structural hindrances and improve the experiences of donor relatives. They come to act as their own kind of institutional authority, drawing on a pioneering ethical decision that made them "*experts*" in combination with their experience of running the charity and interacting with other organisations in the transplant community, governmental organisations and the health service.

Because the trustees of the network have operated for some time and have since had some experience in responding to challenges, the term "*pioneers*" is less apt to describe their activities as intermediaries. Consequently, the people responding to such processes cannot be described as "*pioneers*" anymore – since, as Williams and colleagues point out, the term *pioneer* refers to the exploration of the beginning of something (Williams *et al.*, 2005). Instead, I propose a different description to encompass what donor relatives from the Donor Family Network are now doing: Volunteers like the trustees of the Donor Family Network have increasingly taken on the role of *navigators*. The term *navigator* describes the people running the Donor Family Network and other charities that work to provide support around these kinds of changing technologies more appropriately. The trustees steer around challenges and changes made by more formalised institutions with greater access to information and power to establish processes in the health system. In using this term, I apply the idea of social navigation as it is understood by Vigh in his work on Cameroonian migrants in Paris (2009). Social navigation encapsulates simultaneously moving parts, a moving environment that exerts pressure, and navigators who can take steps to react to those changes and steer in a new direction to reduce the restrictive effect of the structural pressure (Vigh, 2009). The notion of navigation in this context is drawn on not because the charity is not already well established and trying to come to terms with a new setting, but because it is subject to a changing medical and legal landscape. The navigation thus does not refer to pioneering activity or working with alien contexts, but with shifts in the legal and biomedical context that the charity's work is situated in.

Consequently, the notion of social navigation is applied to a new context, where the element that is changing is not just the group of people navigating, but the context that they are situated within itself. The trustees attempt to instil the kind of attention and care for the needs of deceased-donor relatives they want to be taken by others but also offer moral guidance that expresses the network views on transplantation and organ donation and pursues their interests. The Hugga blanket initiative is a combination of these various considerations and marks the trustees of the Donor Family Network and others involved in the running of its affairs out as **moral navigators**. The direction-giving principles that guide them are moral because they concern themselves with how people ought to treat deceased-donor relatives and how the significance of donation might be perceived. Navigation occurs because volunteers are not in control of the formal legislation that governs all the processes involved, nor do they have access to the information of deceased-donor relatives that they wish to offer help to in the way official bodies do. Instead, they must construct their own support work that provides the kind of additional information, care and community on the basis of their lived experience they feel should be available both during and after donation around the healthcare system. The responsibilisation for this additional support therefore lies with the volunteer providers who understand what it can feel like to undergo the process of organ donation, but without formal universal access to the information of new donor relatives or a straightforward route for integrated communication that could propose and implement something like the Hugga blanket. This creates greater variability and inconsistencies in who can initially receive a blanket depending on the team of specialist nurses, and for contact after the donation through which the charity might be able to offer further support, there is a reliance on new deceased-donor relatives understanding and being able to take responsibility for seeking out the resources that meet their needs.

5.7 Conclusion

Neoliberal systems place pressure on the people affected by organ donation and the charities and family members, and friends looking to help and support them. In the face of this, people are left to grapple with complex decisions themselves. Charities must take the initiative and go to great lengths to let people know they can help. In some cases, deceased-donor relatives may find themselves in a position where they need additional support in the form of professional transplant-related counselling to reflect on their difficult experiences. The kind of support necessary to help donor relatives in this position in this way is not formally set up as part of the NHSBT care provision system. As a result of the parts of the process involved in facilitating organ donation, some deceased-donor relatives who found the processes required to make their relative an organ donor and the time in the hospital traumatising have said that they stood behind their decision to consent but would not want to promote organ donation. Therefore, it is a fallacy to think that all donor relatives who consented to donation also wish to facilitate the process or would encourage others to do the same. While some deceased-donor relatives later find comfort or fulfilment in advocacy work or organ donation promotion, others feel that the process is too complex and challenging for promotion requests to be appropriate and have nuanced reflections about the decision that arose after they have had some time to reflect on the significance of their decision. In these cases, sending materials such as a gold heart that says the word “yes” on it or other badges that imply that the deceased-donor relative might wear the badge to promote organ donation are not always positively received. The primary availability of materials to honour the donation decision that tends to be related to a degree of abstraction and emphasises the positives associated with offering up an organ donation can feel to some like an incomplete representation of the complex effects the decision can have.

However, transplant-specific charity support can offer opportunities for a sense of personal connection through a shared experience if deceased-donor relatives contact the Donor Family Network Support Phone Line. That phone line is charity-run and relies on deceased-donor relatives who reach out to the Donor Family Network to access the support because they cannot obtain the contact details of new donor relatives themselves. It takes personal initiative in line with the self-responsibilisation implicit in neoliberal healthcare systems for deceased-donor relatives to access support services. Donor Family Network leaflets and pin badges are sometimes given to relatives in some transplant units, and the NHSBT website lists the network as a source of support that relatives can contact. Still, even if information materials are handed to deceased-donor relatives as part of the information about transplantation, they may be lost or forgotten during the time after the loss, characterised by acute grief. My conversations with deceased-donor relatives show that many are too distracted and affected by the news of the loss to hold onto leaflets and retain details of some of the more nuanced information about transplantation, such as what they can and cannot expect in terms of communication with recipients. The hospital's primary care and information provision schedules frequently do not align with the times when individual relatives come to reflect on their decisions or may experience issues that warrant counselling. The system intended to offer greater opportunities for deceased-donor relatives to choose the care they receive is not set up to recognise that often, people who reach out to charities, NHS services or their local authority are told that there is no capacity to provide additional support or need to join long waiting lists.

The availability of care and support situates the experiences of grief, loss and confusion about the donation experience that deceased-donor relatives often feel along timescales of efficient service delivery that frequently fail to align with the self-reported needs of deceased-donor relatives. Charities can and are willing to facilitate more long-term support but are not a formal part of in-hospital process communication. Increasingly, the availability of support depends on the ability of people affected to look for possible sources of support and to contact them on their own to receive additional help. Additionally, people need to be aware that the system requires them to take independent action and that different points of contact are charities with no access to their personal information to seek out the support they need. Instead, some assume that they will be sent the communication and resources they are entitled to or that the fragmented official and non-official providers they hear from are in contact with one another. Because support and knowledge of alternative services like that of the Donor Family Network are critical and can be difficult to find, and because information gets lost, the Donor Family Network has started a new initiative. The network draws on a near-universal physical human response to bad news and loss to reach out to deceased-donor relatives in hospitals in a more tangible way by offering the branded Hugga fleece blankets to specialist teams, to be offered to all relatives who need them. For charities, the task of navigating the system in this way also involves a set of choices about how the donor family experience should best be represented, how the story of organ donation should best be told and consists of the staging of a symbolic identity that is advocated and represented throughout different parts of the transplant community.

I have introduced the term *moral navigators* to describe the actions that charities like the Donor Family Network take to position themselves as agile intermediaries and advocates between governmental organisations and the healthcare service on the one hand and deceased-donor relatives on the other. In the case of the activities of Donor Family Network, the messaging generally aligns well with how organ donation is presented by other large organisations such as NHSBT and its social media channels. This includes the frequent characterisation of organ donation as the act of giving the "gift of life", the dominant narrative about the significance of organ donation in public discourses about donation throughout promotion campaigns in England. This metaphor seeks to manage several implications that can cause conflicting emotions and unmet expectations among donor families and recipients, who had hoped to hear from the recipients of the organs they donated or who grapple with the possibility that organs were removed for transplantation and could not be donated or were rejected and failed after transplantation. Indeed, questions, confusion and disappointment about not having heard from organ recipients some of the issues that deceased-donor relatives grapple with most frequently and request support from the network.

Given that the donor relatives and the deceased-donors themselves are frequently recognised for their support for organ donation and thanked for their decision, one can make the case that they deserve more structured and consistently available support regarding experiences related to the transplant process that is facilitated by government means. While the Donor Family Network aims to provide a growing number of services and speak to more relatives, the responsibility they took on as a charity to appropriately represent a national voice for donor families and anticipate family needs in a changing healthcare environment is a huge task. Due to their status as a charity, they invest large amounts of time and financial resources into spreading the word about the help they can provide, as they have no formal means of contacting deceased-donor relatives without them reaching out first. There are limitations to the universality of perspectives the Donor Family Network can represent and the amount of dedicated one-to-one support they can offer. In other words, they are currently too small a provider to offer representation for or support to the larger collective of deceased-donor relatives, although they continuously work to expand and to change this. The next chapter will highlight the imagined connection to the recipients of donated organs in the context of the legal anonymity that protects both parties in the donation process as a frequent source of frustration and confusion for deceased-donor relatives.

6. The “Gift of Life”: Balancing Legal Anonymity and the Desire for Meaningful Connection

6.1 Introduction

As previously highlighted, NHSBT, the Order of St. John and the Donor Family Network frequently describe organ donation using the rhetoric of “*giving the gift of life*” to offer deceased-donor relatives a degree of comfort and abstraction. In this way, they intend to emphasise the significance of the donation decision itself, highlight that the organ was donated generously and freely, and work to promote organ donation among members of the public. The language of the gift of life and much of the associated symbolism used to invoke a sense of intimate connection between the two parties involved in the process. Frequently, they commemorate the deceased through the imagined relationship they have with the recipient and extend this imagined connection to the surviving deceased-donor relatives as well. The immense gratitude recipients are said to feel for the organs they receive and the hugely positive impact they are said to have on their lives often oversimplify the medical and psychological difficulties that can arise during the process. The English organ donation system was set up to avoid the possibility of commodification of organs and the anonymity involved in the process is intended to help ensure that donation happens without additional expectations or debts that are associated. However, anonymity can also hinder and limit the relationships that can be established and be at odds with the meaningful and intimately connected image of the deceased donor and the recipient the gift of life metaphor paints. To analyse the tensions that arise from this, it is necessary to first understand where the idea of organ donation as the gift of life came from and how it has been discussed in the literature to date.

In 1925, Marcel Mauss published his work on the impact gift exchange has on social relationships, postulating that the exchange of a gift is often an expression of the relationship between two groups. The receipt of a gift carries with it an obligation to reciprocate on the side of the receiver- that obligation then serves as a continuation/affirmation of the bond between the two groups and strengthens the relationship (Mauss, 1954). The term "*the spirit of the gift*" encapsulates the notion that the intention with which the gift was offered, a part of the giver's spirit, becomes attached to the object of exchange. Therefore, the gift item carries the intention with which it was extended, and the recipient's choice to accept the gift can be interpreted as the recipient’s willingness to accept the obligations that come with the gift exchange (Mauss, 1954). The understanding of the social significance of the gift, as described by Mauss, was first applied to the act of organ donation in the US context by Fox and Swazey (1992). The language of the gift began to be used to discuss the significance of the donation of an organ for transplantation in the US context – casting organ donation in terms of a gift exchange where the donation of the organ carries with it a set of hopes and expectations of the recipient on the donor side and where the receipt of the organ evokes a sense of responsibility to reciprocate, or a form of guilt at the inability to "*repay*" the donor and their family on the recipient side (Fox & Swazey, 1992). This obligation to compensate or repay the donor in some way has been used in discussions around issues of organ commodification, where the promise of financial compensation or other repayments can lead to morally repugnant exchanges. Thus, pressures can be created that incentivise those in the greatest need of money to agree to organ donation when they otherwise would not (Scheper-Hughes, 2000; Strathern, 2009; Hoeyer, 2013). However, there is an alternative notion of gifting/donating, most notably defended by Titmuss, which, as mentioned in Chapter 3, does not carry the expectation of reciprocity: instead, the donation is made altruistically and without an expectation of reciprocal action. However, the challenges families who agree to donation experience and the invasive nature of the process concerning organs can act as obstacles that hinder the abstraction of the transplant process using symbolic language like that of the gift of life (Sharp, 2006; Walker, Broderick and Sque, 2013b). This is because organs can potentially have complex and ambiguous imagined importance for the identity of the deceased in the minds of their relatives, alongside the possibility of perceived ongoing social ties to the surviving family members. Families can struggle with the idea of having been the ones to allow the organ removal procedure to take place and terms that incorporate the identity of the deceased donor into the agency of the surviving family (e.g. donor-family) have been highlighted as opportunities to imply that the choice to give was at least partially made by the donor (Long, Sque and Payne, 2006; Sque et al., 2008). In this sense, the family are viewed as merely having confirmed the choice the donor would have otherwise made, and the act of voluntary giving was initially made by the deceased (assuming the deceased did not register a preference against organ donation that was overruled by the family) (Galasiński and Sque, 2016). There is some confusion in the transaction about who is the giver and who would benefit from reciprocation if there were to be any. The gift of life given by a donor family also allows one to acknowledge and recognise the family's role in enabling transplantation when they consent, making it possible to honour the donors for a selfless choice and their families (Sharp, 2006). Notably, the desire to honour the family and the donor for their decision correlates with who has ascribed the responsibility for giving – donor families have been reported to locate the "*giver*" in organ donation as the deceased donor. Recipients have been reported to be likely to view the family members as responsible for the decision and to want to express gratitude to them for that reason (Galasiński and Sque, 2016). In practice, there is no way to predict whether either party will choose to reach out to acknowledge the receipt of the organ or to reaffirm support for the recipient in the form of letters written by either the donor relative or the organ recipient.

In many cases, the reflection on the meaning of donation and the realisation that one may have had an expectation or desire to receive some response from the health service or the recipients themselves often happens after organ removal has already occurred – when the ethically "*pioneering*" choice is reflected on as outlined in Chapter 5. A desire that the donation is acknowledged and met with a formal, heartfelt "*thank you*" from the people who received the organs is widespread. A lack of a response from the recipients is often viewed as disappointing or rude – there was a hope to receive something in return, even if it is "*just*" a thank you, among most people I spoke to. Such an expression of gratitude can help establish and affirm the value of the donated organ and perhaps acknowledge the kind, generous spirit with which it was given.

While not all donor families feel that the "*gift of life*" is the correct description for how they view organ donation, many will be confronted with the terminology, for example, in the ceremonies and campaigns described in the previous chapter. The description can contribute to the idea that a thank you should be received – it is common to thank the giver of a gift for their kindness in other situations in life. Extending a thank you affirms the fact that the receiver values the gift and reassures the giver that their intention when giving the gift was understood. Suppose a successful donation is not confirmed or a positive impact on the recipient or their family has not been reported. In that case, donor relatives might feel the donated organ was not as valued as it should be (Berntzen and Bjørk, 2014). Furthermore, deceased-donor relatives might be unsure about their role in the exchange as a result, given that they agreed to donate a part of the body of the deceased they might have felt responsible for or protective over. Suppose their offer of support was not acknowledged or did not have the impact they had hoped for. In that case, they may no longer feel comfortable or positive about having consented to donation, or at least invest more time reflecting on the complex and perhaps disturbing details of the process/ organ donation might no longer offer them the positive reassurance that came with the otherwise negative experience of going through the death of a relative.

At the same time, the language of the gift of life casts the recipient as a receiver who should be grateful and perhaps feel responsible for saying thank you and looking after the "*gift*" they were given. That role omits many of the difficulties that recipients face. They did not choose to need an organ; they are not necessarily cured because of organ donation and can remain life-long patients who are not in complete control of their health after donation and cannot prevent their bodies from rejecting the organ. They may face confusion or trauma associated with the transplant, as well as the need to reflect on the significance of the transplant for their identity (Kierans, 2017).

Lastly, the deemed consent legislation, intended to help organ procurement by raising consent rates among families who are approached about organ donation, impacts the perception of donation as a selfless and voluntary act on both the donor and the recipient. In the context of the desire to give the "*gift of life*", families who are approached want to consent freely, with no preexisting pressure to decide to donate. Some deceased-donor relatives feel that their ability to do so was diminished when they were asked whether they wanted to "*honour*" a deceased relative's preference to donate following the introduction of the deemed consent law – the right choice, some felt, had been implied before they could make the same choice independently. On the other hand, many recipients feel guilty about the fact that they were able to live when a deceased donor had died and thought they needed to be sure that the organ they had received had been given freely to allow them to quell some of that guilt and to reassure them of the fact that the family wanted to provide them with the organ. The knowledge of the new legislation has increased the concern that the consent could have been given under an increased degree of pressure and, therefore, less freely in the eyes of some recipients and donor relatives. The Donor Family Network has recently shared a story in their newsletters in which they described how a recipient approached them to say that the positive impact donation has on the lives of recipients and the permanent improvement to their health was not what they had experienced. The over-emphasis on the positives in some of the network's messaging had been at odds with the recipient's history of organs being rejected and of having further medical complications following donation, intensifying their "*survivor's guilt*". Consequently, the network announced it would reflect further on how to respond to these concerns in communicating recipient stories.

The discussion in this chapter will shed light on the unintended implications of organ donation that affect the experience of donor families and recipients alike. The predominant emphasis on the potential of organ donation to allow the donor and their relatives to give a gift of life can be at odds with the real-world perception of the deemed consent law and the set of expectations and perceived obligations both donor relatives and organ recipients have, and the medical complexities with the outcome of the transplant itself. The academic literature has focused on the symbolic meaning of the gift and argued from a prescriptive approach – the discussions have included discourses on how organ donation should be governed and made safe for donors and recipients, what compensation or reciprocal symbolic and monetary actions should be offered, and how abstract symbolic terminology could be used to comfort families and recipients to ease their thinking about donation. This has also included research intended to inform the public communication of the potential of organ donation to help suffering members of society and to encourage families or individuals to consent to donation to make a positive, proactive choice in the context of the death of a relative, or to leave a meaningful legacy that showcased/expressed the positive moral attributes of the deceased. Little work has been done to examine the relationship between the requirements for legal distance and anonymity and the ways in which they contrast the sense of indebtedness and connection the gift of life rhetoric creates.

Using the gift of life rhetoric in conjunction with the new deemed consent law creates a situation where the existing ambiguities are at risk of being further amplified. While the abstract and simplified rhetoric of the gift of life might indeed help provide a means of talking about donation in positive and meaningful terms for some and simultaneously eases the thought of the donation process, making it less graphic, it is ill-suited to answer the many lingering questions, doubts and emotions that continue to be felt on both the donor and the recipient sides. In some cases, the rhetoric can create confusion about what can be expected in return for the donation from recipients and why the expected thank you is not received. In other cases, confusion about how to appropriately accept and look after the gift (assuming the recipient is comfortable with the idea of having received an organ from a post-mortem donation at all); in others, confusion about the meaning of the gift if it did not lead to the giving of life/or a life outside the hospital. This happens either because the organ was never transplanted or because the donation failed. In research, the language of the gift has specific connotations, and its use in rhetoric seeks to illicit a comforting and positive idea about the significance of organs, which cannot always fully accommodate real-world complexities. In a more practical context, the donation process creates multiple instances of ambiguity and confusion. Many donor relatives, recipients and other people affected by transplantation continue to feel the gift of life is an apt description of organ donation. However, the muddle created because of the different implications of the word ‘gift’ and the emphasis on emotional connection in an anonymous system of exchange indicates that greater care needs to be taken when using it for research purposes and as the dominant rhetoric in donation promotion. Monica Konrad explains that any free gift must also be impersonal so that no social strings remain attached to it, which means that a “*gift is deemed free, without interest and calculation, the form of the gift as quintessentially social and implicated in relations, appears to have vanished*” (Konrad, 2005, p. 66). This, as Konrad notes in her work on anonymous egg donation in reproductive health, makes determining the social significance for the individuals who exchange the anonymous gift more difficult. The giver of the gift always has some notion of a return. In organ donation, there is a simultaneous emphasis on meaningful connection with the recipient that underlines the value of the donation and a legal and procedural requirement to maintain anonymity. The potential prospective recipient is a stranger, imagined in a particular way, likely as a person for whom the donor relative feels empathy or wants to help in some way. Usually, they are imagined as someone who became afflicted by ill-health through no fault of their own. The idea of having tried to help somebody in this situation can make the giver feel empowered and result in an improved view of themselves. That feeling can be affirmed and amplified externally, for example, through effectively used rhetoric.

In the case of the gift of life narrative, the rhetoric cannot entirely do away with the legal and medical complexities that govern the process. Mary Douglas (2006) expresses that a gift that is both an expression of a relationship between giver and recipient but that is anonymous at the same time seems impossible. To address this, thinking in theoretical terms, one could draw on the notion of an inalienable gift. Therein, the organ that is being given could be conceptualised as a deeper symbolic expression of life as valued and inalienable within the health system that the donor, the recipient and the donor relative is connected to. Consequently, the recipient is conceptualised as equally valuing the organ as symbolic of an inalienable expression of life. [5] Davies introduces the notion of an inalienable gift at the beginning of his analysis by pointing out the issues that arise when a "*threefold process of obligation*" that Mauss outlines in his work on reciprocal gift exchange as "*giving, receiving and giving in return*" to acknowledge a relationship between the giver and the receiver reaches its limits when applied to the notion of grace (D. J. Davies, 2020a, p. 54). Drawing on the work of Godelier (1999), Davies distinguishes between alienable, explicitly given gifts, and those that are inalienable because they are mere symbolic expressions of a deeper connection that a person has to their cultural roots, something that is essential to the identity of the person and that the person cannot part from (D. J. Davies, 2020a, p. 195). Davies uses this approach to redefine grace "*as a quality of relationship and as some kind of commodity that has been passed from one to another [..] or that needs repayment through 'faith' or 'good works*'" (D. J. Davies, 2020a, p. 196). What matters, then, is the imagined intention with which the organ is given and whether it is seen as a mere expression of an inherently held goodwill that is indicative of a deeply rooted and inalienable link to the health system and its ability to support and maintain life which is being demonstrated through the donation using the organ as a symbol.

This re-framing assigns a deeper meaning to the donation beyond the biological material that is being transferred from one body to another and emphasises the altruistic nature of the organ that is being given freely and without payment. The donor and their surviving relatives could in this way be conceptualised as giving the gift together, if they are understood to have a shared belief and connection to the health system that holds life as inherently valuable, recasting the gift as a joint acknowledgement of this. Consequently, in-line with Davies, the inalienable gift "*comes from the donor, but is never separated from the donor*" and the organ becomes the "*vehicle of and for*" life as something that all parties involved value, seek to foster, share in, and hold onto and pass on within the health system (D. J. Davies, 2020a, p. 200). A similar analytical move away from the approaches of reciprocal gift-giving and the debates of altruistic gift-giving in organ donation has been proposed by

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[5] This analytical move was helpfully suggested by Professor Douglas Davies, one of the examiners for this thesis.

Lukow, because he identified a similarity between the attributes of altruistic giving (social separation, replaceability of the parties in the exchange, non-obligatoriness) and those of market relations (Łuków, 2020). Instead, he proposes the adaptation of the idea of "*sharing in another's misfortune*" to move closer to supportive actions and solidarity between humans and away from similarities with exchanges in commercial settings. In so doing, the emphasis is shifted away from transferable and finite biological material and towards the intention with which the donation is being consented to (Łuków, 2019, 2020).

However, in the context of real-world examples of organ donation situations continue to arise for some deceased-donor relatives, when some relationship or acknowledgement of the connection to the donor was expected but never received by the donor's relatives who agreed to the donation. Similarly, many of the recipients I have spoken to, and recipients whose experiences were outlined elsewhere in the literature, describe the guilt and pressure they can feel upon receiving the organ and feeling unable to give something in return or to guarantee that their bodies will receive the organ well. In the case of some deceased-donor relatives the effects of the ambiguity and lack of clarity caused by the anonymous donation are amplified by descriptions of the donation as the gift of life and can cause individuals to question whether they made the right decision. Consequently, despite the theoretical ability to render the gift of life rhetoric less relationally problematic that the inalienable gift holds, there are limitations to the power this analytical move has to transform the expectations that some deceased-donor relatives have. Moreover, as the organ donation rhetoric about the gift of life and the symbolism in the introduction and Chapter 3 indicate, the idea of a thank you or of a recognition of the gift is often drawn into the use of the gift of life metaphor. Therefore, the gift of life is not consistently framed as an inalienable gift in organ donation promotion and recognition efforts and the ambiguities that have been highlighted as problematic in the literature are continuously being constructed and maintained. Lastly, the notion of the inalienable gift that is not akin to a resource that is alienable is incompatible with the organ shortage that the rhetoric is seeking to address and that the recipients are painfully aware of, further limiting the relevance of this theoretical move in light of the real-world context.

In addition to the doubts that can be cast on the possibility of thinking of the gift relationship as both socially meaningful, completely free and completely anonymous at the same time, there is uncertainty about how realistic an exchange that is kept entirely anonymous is, particularly in the age of modern technology. Where the gift would need to be disinterested to be given completely freely, it carries an undefined sense of entanglement with the identity or memory of the donor whose body the organ once came from. Sometimes, the donation is imagined as something that involves the entanglement of some memory or aspect of the personhood of the donor with the recipient's body. Furthermore, it carries the hope for an improvement in the recipient's life and is, in that sense, bound up with ideas about the person who is to remain anonymous (Jensen, 2016). The rhetoric about organ donation that draws on the idea of the gift of life tries to accommodate more than one definition of the gift. The rhetoric suggests that the gift was given freely and effectively tries to remove social ties by creating anonymity whilst simultaneously seeking to bring the social ties that were legally removed and that are procedurally kept anonymous back into the picture. This is done by evoking them in several symbolic exchange ceremonies and performative expressions using imagery that emphasises a meaningful connection between the anonymised parties. These contradictions can harm the deceased-donor relatives, who, after further reflection, may spend much time contemplating what the decision to donate has meant for them and whether they made the right decision on behalf of the deceased. The act of donation is constructed differently by different actors and experienced in different contexts by different deceased-donor relatives. The constructions make assumptions about donor, donor relative and recipient characteristics and emotions that are not universally true, and symbols representing donation often obscure these tensions. However, because they influence the lived experiences of donor relatives and recipients, they cannot be obscured and disappear, resulting in a public donation discourse rife with opportunities for unmet expectations, conflicting experiences and personal communication needs and preferences. However, when more people share these diverse accounts of organ donation, the complexities of organ donation become better represented.

6.2 The Gift of Life: Who gives, who receives?

The rhetoric framing organ donation as the gift of life is prevalent throughout the support provisions of the NHS, the Order of St. John and the Donor Family Network. It is most explicitly expressed as the central message in the Gift of Life memorial pictured on page 51. Indeed, many donor relatives I have spoken to or who have shared their stories publicly have expressed their pride in a deceased donor who "*gave the gift of life*". However, the real challenges relatives who agree to donation go through and the invasive nature of the process concerning organs of potentially complex and ambiguous importance for the identity of the deceased and with potential ongoing social ties to the surviving family members can act as obstacles that hinder the abstraction of the transplant process through the use of symbolic language like that of the gift of life (Sharp, 2006; Walker, Broderick and Sque, 2013b). Families can struggle with the idea of having been the ones to allow the organ removal procedure to take place, and terms that incorporate the identity of the deceased donor into the agency of the surviving family (i.e. donor-family) have been highlighted as opportunities to imply that the choice to give was partially made by the donor (Long, Sque and Payne, 2006; Sque et al., 2008).

> *Tina: Organ donation happened through us, but the source came from him. We made the decision, but he gave the gift. I said yes, but he gave the gift. But at the end of the day we have to acknowledge that we made the decision not him. So we were the ones who were put in that decision. We made that decision for what we believed were the right reasons, but I am still proud of HIM for what he left, does that make sense? I am very proud of that legacy, we have gained a lot out of it*.
>
> *It is such an active way to remember somebody; no donor will ever be forgotten because they get brought up all the time. And there are times in the year where they just get brought up, and it is their day, such as the precious gift event.*
>
> *For me personally yes, I have always seen it as a gift***.** *My son gave the gift of life and I can't see it any other way.*

Tina's account of how she views the idea of the gift of life places us right in the middle of a debate of who the gift of life (the donor organ) was given by and what it can mean to a family. She is very conscious of the fact that her son was not the person who decided to consent to donation – yet she feels that her son was the one to give "*the gift*", because he was the one to leave something behind. In the way she describes the giver of the gift, the act of giving is itself ambiguous – she seems to attribute the formal and legal responsibility for the decision to herself and her family, whilst associating all the admirable morally virtuous elements to having given up an organ for donation to save or improve the lives of others with her son. Implicit in her view is the idea that her decision to donate was driven by what her son would have wanted – therefore, he has a part in the actual giving of the organ in her mind. She stresses that because he was and is involved in this way, he is always remembered when discussing the decision to donate. Notably, the reasoning behind identifying the person responsible for giving "*the gift*" is very personal. The giving is seen as shared, with the donor remaining ambiguously involved even though the decision to give was taken after their death. The gift, as it is understood in Tina's view, is Titmussian – she views it as altruistically and freely given because of her personal reflection of her family's values and their shared belief about what her son would have wanted. She is careful to stress that this interpretation of donation is her own and that she is giving her personal view on how her son is involved in "*the gift*". Tina also expressed some concerns about the deemed consent law that arose in this context:

> T*hat is why I see the whole new law as being a bit of an issue, because it is felt, you know by donor families not as much of a gift, because it is more expected, you know, and certainly with recipients I have met over the years, they struggle to see it as anything else, because they need to know if that person gave readily, you know, if that family gave readily***.** *Imagine being a*

> *recipient not knowing whether the family, don't want to say coerced, but if somebody said, right, sadly so and so is dying, you do know the law says, unless you have opted out so. And the family go, uh oh, ok then… without making that gift of a decision, they are actually like "OK, that is the law".*

Tina, who often had opportunities to speak to different donor relatives about their views and experiences, was concerned that the new law was having an unintended effect: namely, that it hindered the ability of families to consent as freely to donation as they were previously able to, which is still reflected in the way the decision about donation is presented. In her statement, she implies that an organ should be given entirely freely as it was by her on behalf of her son – it has to be given "*readily*", and a heightened degree of perceived expectation of family consent introduces an undue degree of pressure. While this is not the kind of pressure that would arise if there was an outstanding reward for the donation that was used to pressure families, it can instead be understood as a degree of societal pressure that comes from being in shock and an unfamiliar environment and subject to the moral expectations of strangers.

> *And those recipients, when I have spoken to recipients, they have said they really struggle with the whole idea that somebody has died. How can you ever live with accepting something, unless you know that thing has been given 100% generously. We met many years ago and we met the recipient of my son's liver and his wife had a real guilt, and I had to really say we made that decision, because we want something positive to come out of his death, and we gave that as a gift. And, we were not coerced into that decision, we made that decision because we wanted to.*

Tina is concerned about the idea of donor relatives having been coerced into consenting because she has learned that some recipients already struggle with the idea of having received an organ from another person who died, even before the new law was put in place. It was only through personal contact with the man who received her son's liver that she was able to respond to his concerns. She explained that offering the organ for donation was a desire to do something positive, and she stressed that the liver was given "*100% generously*". The way she uses the term gift underlines the sentiment of a freely offered and wholly altruistic Titmussian gift, a sentiment which is in line with the kind of donation the Nuffield Bioethics Council identified as the most morally desirable one in the UK context (Simpson, 2018; Titmuss, 2018). In her view, deemed consent compromises that emphasis on charitable and free donation unhelpfully and is at risk of making it harder for donor relatives to give with the altruistic voluntary spirit they intended to. The law change has the potential to simultaneously heighten concerns among some recipients that they were receiving something as intimate as an organ that was surrendered reluctantly, making the process more difficult for both parties to accept. If organ donation is framed as a gift, the concerns she voices about the law are that it makes the gift harder to give in a generous spirit and more challenging to accept due to fears of coercion on the recipient side, amplifying aspects of donation that have always been challenging to navigate.

> "*But I remember the recipient saying because we got quite close, he said to me some of the people he knew from the recipient clinics, some of them can't cope with this idea because the liver that they needed, they have gone to Boots and bought it off a shelf, because they can't cope with this whole idea of death and this family that they don't know about. I am sure I would feel the same if I were a recipient. How can you ever accept it at the end of the day, it is the greatest gift of all. Life is the greatest gift of all."*

Through her conversations with the recipient, Tina learned that many others struggle to accept where the organ came from and are uncomfortable with the idea that it was donated. Instead, they think of it as something much more closely characterised by its medical function – an organ they needed to improve their health, which they would have rather bought from a pharmacy than had to receive from a grieving family. Although this means that the recipients in question struggle to accept what she has described as "*the greatest gift*", she does not express disappointment or judgment – she indicated that the sheer magnitude of what is given when an organ is offered up in the spirit of offering life to somebody else after the life of a close relative was lost puts the recipients in a challenging position of having to try to adequately accept that "*powerful gift*". When thinking about the gift more along the lines of a Maussian gift that creates some obligation to reciprocate or at least accept and recognise the spirit of the gift and the connection between the giver and the receiver, it is challenging to come up with something of equal value that the recipients would be able to give to families in return. Tina's thoughts on the matter have introduced us to several central challenges that immediately arise when we think of the organ as a gift under the new law – she has stressed that she feels the term gift of life is an apt description for what she and her family were able to offer on behalf of her son. Still, procedurally, several aspects of the process put pressure on the receiver, and the intentions and expectations of the giver are challenging to control.

While the symbolic description of donation as giving the gift of life is intended to help provide a degree of positive abstraction and comfort to those affected by donation and to offer helpful rhetoric that can cast donation in favourable terms, there are several legal, medical and procedural challenges and rules that must be adhered to govern the whole process (Jensen, 2011). Every aspect, from the donation to an eventual possible meeting between a recipient and donor relative, is subject to a universal structure intended to protect the best interest and rights to information/desire for communication between donor relatives and recipients. What is offered in the way of follow-up information when the parties are contacted and what they can share is controlled.

In this sense, the "*gifting*" process is much less implicit, more so now that it is owned and facilitated by the responsible government and healthcare representatives. The details of how this communication is managed are outlined in Chapter 3. The Family Care Policy Document requires that the deceased-donor relatives are informed of details of the donation outcome. However, there is no formal requirement for communication from the recipient to be sent to deceased-donor relatives or for the health service to push for communication (NHSBT, 2023b). The health service sends a card to recognise the first anniversary of the donation as a token of recognition, but beyond that, there is no further routinely planned communication. Instead of a letter from the recipient, the specialist nurse offers and acknowledgement/expression of thanks for the donation and outlines essential information about the donation outcome. The gold heart pin badges described earlier are sent out with this information unless the family has asked not to be contacted further. The thanks extended for the donation are primarily distributed on behalf of the health service. The information about the recipient that is routinely shared is similarly medical.

Suppose this information remains the only information that is received. In that case, it can make the "*gift of life*" feel relatively short of meaning in the eyes of some families, who had hoped to hear from recipients on a more personal note. After the initial care process has been completed, there is little in the way of further communication from the health service itself – instead, donor relatives are encouraged to draw on charity support resources and reading materials they can learn about on a leaflet or via the donor family care website NHSBT has compiled. Donor relatives can request further information but must explicitly request that information through the right points of contact and their personal initiative. Further information will once again focus on the clinical information if the recipient(s) (do)es not wish to respond to requests for an exchange of letters from the family. My conversations with donor relatives who have experienced the process indicate that there is often confusion and disappointment associated with the communication and support available post-donation. The Hewett family is one such example:

> *We now think it would be nice to know more about the people she has helped; you get an initial letter, but then that is it, and you find yourself waiting and checking, you know, is there going to be another letter? We wonder what are the chances of contacting the recipients."*

The experience of the Hewett family shows that some donor relatives expect active management of further communication post-transplant by NHSBT, where the family is "*waiting and checking*" for additional information, unsure of why they are not receiving it and unaware that they could actively request further updates on the clinical progress of the person. Either that information was not communicated enough, or the family did not understand it correctly when it was shared with them. Still, in any case, there is a lack of clarity that the idea of having been able to give the gift of life cannot alleviate.

The father introduced in Chapter 4, whose son became an organ donor after having a sporting accident, stressed how proud he was of his athletic son, who had been in fantastic physical shape when he became an organ donor. The man proudly described how incredibly valuable the organs his son could donate were. However, he felt that there had been a massive communication breakdown because neither he nor his wife had heard from the recipients. They wondered whether the letters might have gotten lost and did not feel that the communication system, which could have enabled them to contact the recipients, was transparent enough. He felt that there was an obligation and a need for the recipient to get in touch, to say, "*look, I am very sorry for what has happened to you, I am sorry for your loss, but thank you so much for this*". He stressed that he wanted the recipients to know that being contacted in this way would help him and his wife, who were both still struggling a lot with the loss. He did not necessarily express anger at the recipients for a failure to contact him. Instead, he seemed confused and frustrated because he had not been made aware of how the communication worked and whether any letters that did not make it to him and his family had been sent.

This father was an example of somebody who did feel that communication with the recipient should be part of the donation experience and that the recipient should say thank you – he and his wife had been proactive in trying to reach out but had not heard anything back. Their letters may have been deemed inappropriate in terms of content and not forwarded by the responsible mediating organisation, or the recipients requested not to receive them. In any case, the couple had not received any communication that would have specified what had happened to their letters. They were left confused, frustrated and disappointed, unsure of where to allocate the blame for the difficulty they were experiencing. They thought that the support in the form of their consent to organ donation they had offered the recipient deserved a thank you, and the failure to receive that response from the recipient for an unclear reason left them with questions and doubts in their minds. Isabel expressed a similar sentiment, indicating that recipients should get in touch and thank deceased-donor relatives.

> *Some people never hear from their recipients, and I think that is really rude. You know, you should say thank you, but some people don't hear a thing. And I am just like, how dare you not say thank you?*

Isabel stressed that, in her view, it is necessary and appropriate to thank the donor relative who donated the organ a recipient received. She feels recipients are obligated to express their gratitude out of courtesy to the donor relative – donor relatives have something of a right to get a thank you in her eyes. She did not think of donation as the gift of life but still felt the recipients should express their gratitude to relatives because they were given something significant. Many of the donor relatives I spoke to expressed their awareness of the fact that some recipients were themselves struggling with the idea of having received an organ after the death of a stranger and being expected to speak to their bereaved family. However, Kathy agreed with Isabel and felt recipients should still reach out.

> *Afterwards, you get into all the problems of it being anonymous. The receiver of that gift might never say thank you. We know who we are with one of the recipients, and I have had letters with different levels of emotion, and they mean a lot to me. Two recipients had a kidney each, and they said thank you. It can be difficult to talk about, even within my family not everyone wants to talk about it. I think, if someone is willing to receive an organ, they should also be ready to say thank you.*
>
> *I do think about the transplant families. I like the relationship I have with the girl who got the lungs and I get thank you texts from her mum, so I usually hear about major life events. The worst is when you never hear anything, but I understand that it is difficult for recipients.*
>
> *I don't think of it as a gift, I just feel it was the right thing to do in a horrific situation. You can't trivialise it.*

She explained that even though she feels speaking about donation as a gift trivialises a difficult process, hearing something in return, having a relationship with the recipient is meaningful and comforting. She appreciated being routinely kept up to date with the life of one young girl who received her son's lungs. She feels that the recipients have chosen to accept the organ and that they should say thank you and acknowledge that choice. While she rejects the idea of a Titmussian kind of gift, her sentiment and those of others indicate that organ donation is being understood as some kind of exchange between the two parties. In that sense, there is an indication of a Maussian kind of gift relationship that lingers in the background of the justification of the view that recipients need to respond in some way when receiving the organ. Whether or not there is an appropriate response can determine the degree of closure donor relatives feel when reflecting on their decision to "give". Although, as Scarlett explains, they and their deceased relative did not make the sacrifice of the relative's death to save the life of another, many relatives do in part consent to achieve a positive outcome, namely an improvement in the health of the recipient.

> *I don't really think of it as a gift because organ donation was just a consequence of her death. The drugs they use can cause cancer and they need to match up the blood groups, although in*

> *the case of my daughter's recipient they did not match. The more people chat the more it helps. The heart must have been given to a recipient in (the North of England), with the recipient having cardiac arrested prior to the heart arriving, but some other families can't give the actual gift of life, instead it is more comparable to having given the gift of a life outside the hospital. In the sense that the donation is the gift of life it would be the greatest gift.*

In Scarlett's view, thinking about donation as a gift was illogical. She commented on the outcome of the donation offer as an important factor, questioning whether donation could be a gift of life if the recipient's life was not saved but just improved – she proposed that one might say a donor relative had "*given the gift of a life outside hospital*" to be more precise. The question of whether the outcome of the donation and the real impact it had in improving health or quality of life impacted the significance of the donation cannot easily be answered. If the value of the donation, whether or not the gift of life was given successfully, in real-world terms has an impact, the donations from donor relatives who consented to donation but whose offer was never accepted due to medical complications and those organs that are rejected by the recipient's body are in morally ambiguous territory. If we try to determine the value of a gift in this way, we run into questions of temporality – what gives the gift of life its substance? Is it the altruistic offer or the good intention behind it, the moment of successful transformation, the acknowledgement of grateful receipt by the health service or recipient, or the degree of happiness or improved health they enjoy for the longest possible length of time? When should the recipient say thank you? Should they say it once, every year, or every day? Should they say it at all, given that they likely did not have a choice in needing a transplant in the first place? For how long should the health service offer gratitude, if at all?

The use of the phrase "*giving the gift of life*" when describing organ donation raises as many questions as it answers, both from an academic perspective and in terms of the expectations and information needs of donor relatives. Indeed, when the idea of a gift of life is adopted. In that case, the phrase is not interpreted similarly by every donor relative who hears it. Responses among the small group of people I spoke to range from deeming it entirely appropriate to trivialising and factually inaccurate. The guidance on donor-relative care provision and the support available to families cannot currently ensure that these, in some cases, very ambiguous and unsettling questions are definitively answered. Frustrations and questions among many donor relatives are likely to remain – although this should not be interpreted as an expression of unhappiness with the decision to donate itself. A second important set of issues adds to this level of complexity and was briefly indicated by Tina in her account of the significance of the gift of life – receiving an organ can be both involuntary and very challenging for recipients. The next section will shed light on the discrepancies between recipients' role in the "gift of life's" account of donation and the real-world effects of receiving a transplanted organ.

6.3 The Gift of Life rhetoric and the desire for connection

To appreciate the difficulties recipients face and contrast them with the one-sided story about the impact of consenting to organ donation on the recipient side the gift of life rhetoric creates, it is necessary to contemplate the accounts of some of my interlocutors that touch on what recipients go though. Recipients like Khloe, a woman in her thirties who I met when she competed at the British Transplant Games in Leeds, may come to wonder whether the relatives of the donor whose liver she received could be somewhere at the event.

> *I think about the person I got this incredible gift from daily. Thank you! I don't know who they are, I am not in touch with them, and I sometimes wonder about what age they were, what gender, what ethnicity. But then my friend always tells me that they gave me this gift and that is all I need to know. And do you know what? That is all I need to know! I am just filled with such gratitude!" She gestured towards the sky and said thank you once again, her hand wandered to her liver as she continued: "I just feel so connected to them, I have this organ inside of me and it saved my life! What are the odds!"*

When I met Khloe at the Games, she told me that her recovery after receiving a transplant involved intense struggles with her own identity and grappling with the realisation of having received a donor organ. Over time, she has found a way to think about her transplant in a way that feels as though it is part of her, but at the same time, she imagines the new liver as still connected to the donor. Her desire to express gratitude is to all donor relatives, but there remains a lingering sense of physical connectedness with the person whose biological organ is inside her body.

Similarly, Tom, a heart and lung recipient I was volunteering alongside of at the transplant games, told me that he feels immensely grateful for the organs he received and that after the very significant support he received through organ donation, he is willing to "talk to anyone" about organ donation. He described the efforts that he was undertaking to maintain his physical fitness to the best of his ability, as a means to look after the organs that he received. He explained that in his mind, the organs in his body are a part of the donor that lived on, and he feels some responsibility to sustain them, although he did not express that he struggled with this emotionally. To the contrary, he has a matter of fact, proactive attitude towards having received the transplant organ, and feels very passionate about the improvement to his wellbeing and life expectancy organ donation made possible for him and others. In addition to volunteering and taking part in the games, he is always on the look-out for opportunities to participate in research or to talk to others about organ donation, encouraging them to share their donation decision with their relatives.

Amy, the surviving partner of a recipient who had passed away during the Covid-19 pandemic explained how difficult it had been to wait for the transplant organ whilst transplantation was significantly reduced and at times completely halted during the pandemic. The liver that her partner had received was failing and her partner's health had deteriorated, leading them to try to make the most of every day within the best of their ability given her partner's low energy levels and other symptoms of liver failure and the restrictions placed upon them by lockdown. In addition to this, she showed me social media posts her partner had written before he died, in which he highlighted the lack of clear guidance for some transplant patient groups as part of the advice for vulnerable groups during Covid. In one post, her partner had asked for advice on how to navigate the benefits system which despite notes from his doctor and other supporting documentation rendered him ineligible for various different benefits provisions on the basis of requirements he did not meet due to his health problems. Amy said that while her partner had always felt very grateful to the donor and their relatives for giving him the organ that enabled him to meet her and to begin their relationship together, he sometimes tried not to think too much about the person the organ might have come from. He did not quite feel ready to write to the donor relatives, in part because the transplanted organ was failing and he was hoping every day that he would receive news from the hospital that it would be replaced with one that functioned better, before he became too sick for another transplant.

Several other recipients I spoke to shared similar experiences of needing to navigate poor familiarity with the ongoing health and support needs of many transplant recipients from their workplace, benefits providers or acquaintances, who expected them to be back to full health following a short recovery period following their transplant surgery. One pair of parents whose child was a transplant recipient participating in the Games said that the health challenges, the hospital appointments, and their efforts to make their child's childhood as normal as possible became too much at times and that they struggled to stay positive. They expected a degree of consistency in the way the activities for children were laid out at the Games and in the facilities that were being made available to attendees. Since the Games were run in different venues every year and relied on charity and volunteer support, the consistency they were looking for was not perfectly achieved. They expressed their struggle over the fact that even keeping up with a supportive event like the Games. There were organisational and logistical challenges in keeping themselves informed and understanding the layout and what was available each year, making sure they had registered their child for the right activities and they could support their health needs throughout. They had had a very challenging year and felt exhausted and frustrated at times, trying the best to press on and remain positive, but feeling the effects of the health challenges that the whole family was profoundly impacted by.

Despite the challenges they faced, I also met recipients who had met a group of peers that they felt connected with in their fellow transplant athletes that they felt closer to than anyone else they met. For example, Gloria, a middle-aged woman who had been attending the Games for many years, had previously experienced bullying as a teenager that related to her health challenges, felt understood and accepted among their transplant sport peers, finding a sense of belonging. In all her activities at the Games, Gloria says she feels a connection to the person who she had received her transplant organ from, because she is being powered by the organ that they donated. In her view, organ donation has given her her whole life, her partner, and her children. In all of her achievements and significant life events, she sees a connection to the donor and reflects often on how their relatives consent decision made every single one of her experiences after the transplant possible and sees them as a part of all aspects of her life. She extends her gratitude and recognition beyond the biological recipient who she feels the deepest connection to, and applies it to all the deceased-donor relatives she meets.

Over all, the desire to which recipients feel able to think about the donor and their relatives and if so, how they choose to express their gratitude, how much contact they desire and what they imagine the donor to have been like differs. Their hopes, expectations and levels of comfort with the idea of an abstract or actual deceased-donor relative – recipient interaction vary. For some, there is a sense that the biological connection that exists between them and the donor creates a tangible relatedness. When the recipients I spoke to think about how they relate to the donor and how they might be connected to the donor relatives, their thinking is often impacted by assumptions or imagined intentions, feelings and characteristics of the other party. Despite the anonymity and the limited information that is usually available about the other party, there is often a perception of some degree of connectedness.

Sarah Franklin explored the sense that kinship implications result from sharing biological material belonging to different people through modern technologies, who uses the term "biological relatives" in her work on the kinship implications of IVF technologies (Franklin, 2013). She found that the relationship with the people whose donated biological material is connected to a child creates a sense of ambivalent connection. These are connections are the subject of continuous reflection and reinterpretation. Franklin therefore argued for a more nuanced account of relationality, rather than mere biological kinship as a mode of analysis that can accommodate the social and the biomedical dimensions of this sense of connectedness (Franklin, 2013). In organ donation, the biomedical transfer of biological material from the donor body to the recipient frequently invokes a similar sense of connection that relies on the biological link between the two parties. Such a link can give rise to a desire for social connection to follow the biological relation, although the law and some of the people affected establish that the social connection can and should not be made known. In addition to describing themselves as "*donor mums*" or "*donor dads*", deceased-donor relatives can come to describe the anonymous recipient they may be in touch with as "*Mr. Kidney*" or "*Mr. Lung*", depending on which organ was transplanted, because the nature of the transplant organ underscores the biological relation in the minds of some.

Despite this special significance of communication with one's biological counterpart in the donation exchange, the possibility to meet recipients in general, even when they are not necessarily connected to the deceased-donor relatives through shared biological material, can feel like a meaningful experience. In the relationship between deceased-donor relatives and donors on the one hand and post-mortem donation recipients on the other hand, there is a lingering sense of surrogacy and connectedness that is perceived by many. This sense of connectedness exists in the minds of many in part because the language that is used to describe organ donation, that of a donor and a recipient, creates an inevitable sense of two sides that are involved in the act of donation. In recipient care, many medical professionals attempt to remove donor related information as much as possible prior to transplantation, to prevent feelings of guilt or questions about a changed identity from arising in the minds of recipient (Sharp, 2001; Ådahl, 2020). On the donor side, the communication goes in the opposite direction – the gift of life seeks to drive home the virtuous of the decision to consent by highlighting and celebrating the impact donation has on the lives of recipients. Consequently, it is unsurprising that donor relatives take an interest in the way in which recipients are affected by transplantation. In the absence of the possibility of communicating with the anonymised recipients of the deceased donor's organs, meeting and hearing from other recipients who can offer their story instead can still be reassuring and comforting.

For that reason, attending the British Transplant Games and hearing that the recipients are doing well, doing positive things in life and spending valuable time with their families has become a reassuring component of Isabel's daughter's legacy. Being at the Transplant Games allows her to see that legacy "*in action*". Despite this, hearing from one of the biologically connected "*counterparts*", a biological relative of sorts, was even more remarkable for her, because the stories from their lives seemed to be a more direct consequences of her daughter's donation. Both kinds of recipient interaction gave Isabel something positive to focus on and to associate with the giving person she remembers her daughter being. Consequently, in the absence of the opportunity to meet a biologically connected recipients, many deceased-donor relatives derive comfort from seeing the positive impact organ donation has had on the lives of recipients more generally.

Sometimes, the meeting with the biological counterpart of the organ exchange or contact with them does not result in the kind of deep connection envisioned by many who are keen to get in touch with the biological recipients of the organs. For some, there is an unexpected lack of connection and similarity with the people they had hoped to naturally get along with or feel connected to because biomedical compatibility does not equate to social compatibility.

> *I do feel a connection to recipients, and I have made some friends and some of them have become family friends. But it's not necessarily our recipients you get along with the most. Some of them view my son in that manner to where they are grateful to him. I don't feel that same closeness with the "real" recipients, I don't feel that he is there. It is not him; I separate it out like that. "It is not him living in somebody else". The anniversary of the day of donation provokes very different emotions, we remember that day for very different reasons. For that reason, I don't agree with celebrating somebody's transplant. Your celebration can be somebody's end of their world.*

Kathy explained that she has met recipients in the transplant community who she clicked with and felt connected to, who had since become close friends and an important part of her life. The relationships she formed with organ recipients who did not receive one of her son's organs arose because of two factors. Firstly, Kathy was a deceased-donor relative, and the recipients had received an organ from a deceased donor, causing each party to feel like a representative for one of the two sides that are involved in organ donation and connected for that reason. Secondly, they found that they enjoyed one-another's company and got along easily, forming a natural interpersonal connection. The combination of the two factors created friendships that fostered open and empathetic conversations about the benefits and difficulties involved in organ donation and providing a mutual comforting sense of kinship. However, she did not feel the same sense of connection when hearing from some of the biological recipients. Despite the lack of intimate connection with the "*real*" recipients, she felt very grateful that they did reach out and still hoped to hear from the other "*real*" recipients that had not yet gotten in touch.

Kathy's surprising lack of immediate interpersonal connection with the biological recipients of her son's organs echoed the experiences of some of my other interlocutors. While they were all grateful and felt reassured that the recipients of the organs had reached out, they were simultaneously surprised that the communication did not feel more meaningful. Similar accounts of meetings with "*biological relatives*" that do not align with the expectations from the meeting with a biologically linked anonymous "*other*" can be found in the literature on adoption. Here too, legal anonymity is put in place to protect the identities of both parties and later lifted to allow for a meeting between the birth parents and the child that was given up for adoption (Raynor, 1980; Sorosky, Baran and Pannor, 1984; Zunshine, 2005; Melosh, 2006). Many parents who gave their children up for adoption and children who were adopted and have not met their birth parents, form expectations and hopes around the idea of what it would be like to meet their close relatives for the first time in-person. In her work on reunion meetings between adopted children and birth parents in the United States, Melosh (2006) emphasises that many of the people involved experienced disappointment at a lack of a sense of kinship and connection when meeting their biological relatives. Similar unexpected disillusionment with the reunion meetings were expressed in several other cases outlined by Sorosky and colleagues, where the opening of official records and the lifting of anonymity resulted in encounters that did not meet the expectations of both sides (Sorosky, Baran and Pannor, 1984). In Raynor's work, the anticipated meetings between birth parents and adoptees the search for one's biological relatives is outlined as part of a quest for identity and a search for a sense of belonging – the hope was frequently, that the meetings would feel cathartic in some way (Raynor, 1980). Despite this hope, the two parties realised in some cases that they did not feel as similar as originally expected and that they struggled to "*click*", a disappointing experience which shattered the image of the other party they had created in their minds. In the organ donation context, knowing what happened to the organ and realising that the recipients had been helped by the donation in some way or appreciated the decision to consent the family made, can be very important to deceased-donor relatives. However, where some may have expected a close connection or friendship to form or for a kinship bond to form with the other party, the reality of an absence of interpersonal connection can be surprising, disappointing or unexpected.

In Kathy's case, despite not having formed a close personal bond with the recipients she had heard from, hearing from the other recipients was still desirable and important to her. She has shared several appeals in online forums to encourage recipients to reach out to deceased-donor relatives. She and other donor relatives have described care for what happened to their relatives' organs, wanting to know more about what happened. For many relatives, the legislation and anonymity do not remove the desire to know what happened to some of the, in a sense, "*living*" remains their deceased relative left behind. This ambiguous desire for ongoing connection, the desire to know or be in contact with the biological counterpart of the organ exchange among some, also plays in the notion of the social ties that remain attached to the organs, even when they are freely offered up for donation. In the minds of many deceased-donor relatives, a lingering sense of connection and a degree of protectiveness over the organs can exist. Recipients, on the other hand, go through a number of psychologically and psychologically challenging processes themselves that are ongoing before and after organ donation and can have complex impacts on their wellbeing which the gift of life narrative can struggle to accommodate (Kierans, 2011, 2017).

6.4 Aspects of organ donation obscured by the Gift of Life rhetoric

> *For the longest time, I felt very guilty for being alive – I am not a warrior; I did not get a choice; I just had to deal with the consequences of my body failing.*

Emma is a transplant recipient I met at the British Transplant Games. When she spoke to me, she stressed that her identity as an organ recipient had not been a personal choice. Emma became a recipient because she became seriously ill and without her transplant, her life was at risk, she did not feel she had a choice anymore. She told me that she had to "*deal with*" the consequences of her body failing and that she became an active transplant athlete, a person who was doing her best to cope with the consequences of her ill health by competing in the annual event organised by Transplant Sport. She felt guilty for being alive because her health was improved by an organ that was given after another person died, whom the organ could no longer help; a deceased donor whose life could not be saved had saved her life. When organ donation is described as the "*gift of life*", the role of the recipient is framed in terms of the receiver of that gift, and as previously discussed, there is a strong emphasis on the gratitude felt for the gift. The emphasis is placed on how selflessly the donor relatives consented to donation and the immeasurable positive impact the decision is said to have had on the life of the recipient – this is also implied when the term is used in academic research (Kierans, 2017). The rhetoric of the gift of life thus omits many of the things that recipients struggle with before, during and after the organ transplant and can give rise to the kind of guilt and obligation that Emma described she had felt for a long time.

The need to receive an organ for donation is neither a choice nor an easy process for the recipient and their family – the surgery is invasive and not without risks. An organ transplant is usually needed in the wake of serious, often life-threatening health issues the recipient has been confronted with and has, in many cases, battled for a long time. I spoke to Maggie, a woman who worked as a specialist nurse for organ recipients. She outlined many of the challenges recipients must go through and spoke about many of the things what they wanted to know before they received the transplant.

> *The fear of dying, the loss of identity. For people who are used to having control of their life they now have to relinquish it – and that is very difficult for some people. Not because they are scared but because they are not in control. And seeing that in normally very intelligent, articulate people who don't like not having control… How are they going to be – what is their life going to be like, physically, what will they be able to do? Talking of sex, of walking again, being a husband, a parent or meeting someone and getting married – If I am meeting someone, if I may not live very long, should I inflict it on someone else? There are so many issues.*

Maggie described the many questions that concerned recipients and their families had throughout her career before they "*gave up control*" and went into surgery for transplantation – not only did they wonder about the outcome of the surgery itself, but also about the implication on their lives post-transplant. They knew that the transplant would not be a cure and wondered if they would live long enough to have the kind of life they imagined whether they would have the physical abilities they imagined and whether their identity would fundamentally change as a result. In some cases, recipients feel well-prepared and ready to receive a transplant. Even then, a last-minute issue can prevent the planned transplantation from going ahead, causing the potential recipient to undergo an experience of renewed uncertainty about their future. This rollercoaster of cautious hope followed by sudden disappointment is something that some deceased-donor relatives told me they imagined could be very difficult, as Isabel describes.

> *The two kidney transplants and both of her lungs were taken, but there wasn't enough oxygen in the end, so the heart was not transplanted, it went to research instead. They extract enzymes from it. So, indirectly it has helped. It is still helping to research, so it is still of value and use, you know? So, it was not wasted, but, you know, it is a shame for the person who was meant to have it, because they were all prepped up and ready and it's like they turn around and they say sorry, you know, you can't have it… I feel sorry for them.*

When an organ is intended and prepared for transplant but cannot be used as described in the case of the lungs donated by Isabel's daughter, the ambiguities and open questions in the specifics of the gift of life rhetoric are laid bare. The intention behind offering the organ remained the same, the willingness to receive the organ remained the same, but the operation was never completed. Consequently, uncertainty remains on both sides of the exchange, with the potential for guilt and disappointment arising on both ends. Isabel found a way to view the fate of her daughter's lungs in a positive light regardless of their unsuitability for transplant. Still, for the recipient who had been contacted about the potential to receive a transplant and their family, the whole experience would have been complex and confusing. The information and briefing procedures described by Maggie as preceding the transplant may take place to prepare for a surgery that ultimately can't go ahead. Additionally, there are real risks associated with transplant surgery, depending on the procedure in question and the medical circumstances of each individual case. The recipient or their guardian must consent to the procedure, and to be able to do so, they must be made aware of the risks associated with the transplantation. Maggie found that a chance to bring concerned recipients a cup of tea could come in useful here.

> *The social workers said we should not say 1 out of 10 dies, we should say 9 out of 10 survive. You know when you are telling people. And, I actually realised that quite often they are just frightened (patients) and they just don't want to tell you that – they just need to know that you are there and available. Most patients can't sleep at night and lie awake worrying. And that is where the cup of tea comes in actually. It is really English that. But just to come in, have a chat, give them a cup of tea. So, we give them all this information but we don't give them anything about the donor unless they want us to.*
>
> *The first thing anybody asks is where the donor is from. Always. And I have said where the donor dies doesn't mean they are from there. If they think they have got a local heart, think again. But we would give a first name and sex and age normally. But basically, I would say that this is a bit of information I can give you, but I have to maintain confidentiality for you as well as the donor family. So but that was before social media. And now with social media you can find out all sorts as you well know…donor families have found their recipients and vice versa. There is nothing we can do, we don't say where the donor was from. But sometimes they pick it up and it is normally from the surgeons because they overhear that we went to a particular place to obtain the organ. So sometimes they get it inadvertently and they know the date because they know when they got their transplant. And the donor families have a date too. Nowadays I know people who have found their donor or recipient on social media. I normally say what do you want to know. They usually want to know if it is a male or a female. And people realise it [the heart] is a pump and it does not matter what the sex is but they have that inquisitiveness. And more often than not they want to have an age. And I am always a bit wary of the age because sometimes we have a 60-year-old patient who has received an eighteen-year-old heart. So, I often say with the age, you do realise your donor could be much younger or much older. We have put a 49-year-old heart in a six-year-old.*

Maggie explains that recipients may have questions about the donor from whom the organ came and that the information they would like to know is intertwined with the donor's identity and how it might affect them. Information on where the person died is sought to find out where they may have been from.

Maggie's comment on the emerging trend of social media use and its infringements on the possibility of maintaining anonymity points to a trend in recent years that sees the relatives of deceased organ donors, living donors, people in need of an organ or organ recipients and their relatives share their stories publicly. The sharing of one's story can happen on multiple platforms and with various aims in mind. Sometimes, people publicly share how organ donation affected them to raise awareness or promote donation, in other cases, deceased donor recipients who are keen to hear from the biological recipients of the organs tell their stories to elicit contact. One of my interlocutors[6], for example, published pictures of herself and her son alongside an explanation of what hearing from some recipients had meant to her. In other cases, people who are desperate for a suitable donated organ share public pleas or appeals encouraging people to consent to donation. The practice of searching for a donor organ online is currently the best-researched trend. The academic literature has explored how social media can be used to locate potential living donors or to find more altruistic donors who are willing to donate in a public appeal to increase the donor pool and make a life-saving transplant more likely (Henderson *et al.*, 2017; Faherty *et al.*, 2022; Maple and Dor, 2024). However, very little systematic research is available on how the sharing of details of one's stories can cause others to recognise the age of the donor or the organs that were donated (Bolt, Witjes and van den Ende, 2020; Cignarella *et al.*, 2023). Ultimately, this enables members of the public to directly reach out to one another and bypass the officially regulated communication channels designed to bypass anonymity. During conversations with my interlocutors, I heard of several such anecdotes, where recipients and donors either reached out to one another on their own initiative, ran into each other at transplant community events or decided at some point that they wanted to exchange contact details so that they could communicate directly. These insights indicate that the ever-widening possibilities of using social media to find people are making it increasingly difficult for public institutions to monitor and control communication between donors and recipients.

Additionally, Maggie speaks of the effects that knowing certain donor characteristics can have on the way recipients feel about the transplanted organ that they receive. As she explains, organs that once belonged to a woman could be transplanted into a man or vice-versa; transplants from elderly people can be transplanted into much younger recipients. The geographical location of where the donor organ came from is also frequently asked about, implying that some recipients feel that the area the donor might have lived before they died could have impacted their identity. For some recipients, reflection on the implication of the transplant on their own identity based on these characteristics is part of coming to terms with the impact the new organ inside their bodies may have on their sense of self. Suppose the person was the same age as the donor. In that case, this might be interpreted positively because the organ's perceived suitability, both medically and in a more abstract sense of identity, is deemed higher. Maggie was wary of sharing too much out of a fear of accidentally enabling recipients to identify the donor later and because she felt that an excessive reflection on how the donor's

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[6] I am not specifying the person to help preserve their anonymity.

characteristics compared to those of the recipients might raise concerns and questions about the suitability of the organ that were not medically relevant.

> *You know, so in a way we ask what do you really want to know, what is important to you? Because all I can really say is this donor and this family wanted these organs to be donated and, thankfully, they said yes and that is why you have had your transplant. Because some families wanted to send a rosary to their donor. The transplant coordinators, all these letters get sent to SPEAK and then they will marry it up with the donor family. They may have moved, or the address may have changed. We do have records of where the donor came from, and we know the name, the date of birth and date of death. But we don't keep their address and that is kept centrally. Usually, we would just send it with a little note and say this is from this person they had their transplant and wanted to say thank you to their donor family. Some of them (the recipients) don't want to know anything.*

Maggie always tried to emphasise the "*relevant*" information instead, the sentiment with which the organ was given, the fact that consent was given and that this consent was something that had enabled the transplant. When the recipients wanted to contact the donor's relatives, the nurses had to assist with the communication and adhere to the same processes that specialist nurses for the donor side had to follow. The success of the communication was conditional on the whole process working as intended. Maggie also mentioned that when recipients did not want any information to be shared, it was hard for her to obtain informed consent because she struggled to share all the necessary information with the recipients. If the recipients were lucky, the transplant would go ahead, and they would be able to commence the process of recovery. They would need to learn to live with the new transplant and continue to take medication, some of which increased their risk of developing cancer. For recipients, organ donation can mean a vast improvement to their quality of life, but they remain lifelong patients, and the transplant is not a cure. The body of the recipient can reject the transplanted organ, causing the need for the organ to be removed and discarded in favour of another transplant. Some recipients I met had had more than five different transplants and were anxious to reach out to the family of the latest deceased donor to begin a process of thanking them for their donation but also preparing them for the potential future failure of the transplant. The guilt they felt drove them to try to prevent some of the disappointment they felt the donor's surviving relatives might feel. They would try their best to be active and to give their transplant the highest possible chance of working for a long time, not just because they were concerned for their personal health but also out of a sense of responsibility to look after the "*gift*" they had received. Some accepted the organ as something given to them freely and said they felt some deep connection with the deceased or their surviving relatives – others struggled to think about where the organ came from. It is not uncommon for recipients to give the organ they received a name – a human name such as "*Kevin*" or "*Robert*" or "*Lizzy*", to help them take ownership of the organ, to have something to refer to when speaking about it. That name may be the first name of the deceased donor, or it may be entirely different, to anonymise the organ further.

Contrary to what describing donation as the "*gift of life*" indicates, receiving a donor organ, whilst in many cases met with hope and gratitude by recipients, is not an easy experience. Recipient lives after receiving the transplant, while in many cases vastly improved, do not continue without further health and personal challenges. The idea that recipients receive a gift of life is therefore an oversimplification, medically speaking. It does not represent the challenges recipients have to go through, the ongoing health challenges they face and the guilt they may feel at the thought of having received an organ. The task of reconciling the receipt of a donor organ with one's own identity can be a long and challenging one.

Recipients who were told that they had been given the gift of life often felt that they needed to give back or repay that "*gift*" in some way. Still, any desire to reach out to the donor relative that they may (or may not) have had could be hindered by worry over saying or doing the wrong thing. As we saw in Chapter 4, Tina made it clear that, in her view, nothing recipients could say would make the situation worse, and reaching out to say thank you could be an excellent idea. She explained that she was always hopeful that recipients and their families live long enough after transplantation to experience "*the beauty of that gift*", but that she had heard from some people who had only survived for a few weeks after receiving the donor organ. The impact of the length of time the recipient is alive after receiving the donor organ and the memories made during that time are often communicated back to the relatives who donated. Recipients and their families may fear that if a donor relative learns that the life the organ donation had improved was lost or that the organ was rejected, it could feel like a second loss or a failure. To counteract this possibility, they often stress how much of a difference the extra time made to the lives of many. One older altruistic living donor who had donated one of his kidneys summarised this effect when discussing his work as an advocate for the promotion of organ donation.

> *The person that received the organ eventually died and their family informed the donor relative, emphasising that you have still given someone 10 years, 10 Christmases, they got to see their children growing up – organ donation makes a huge difference.*

Organ donation does have a very positive and transformative impact on many lives, and I would be remiss to falsely imply that recipients are not grateful to the deceased-donor relatives and donors who consent to donation. In fact, the opposite is true, with many describing the donor relatives who consented as heroes, feeling an intense desire to thank them or emphasising their intention to do something positive for others to show their gratitude for the help they received. Nevertheless, the "*gift of life*" metaphor minimises the challenges and personal struggles faced by recipients and creates perhaps undue pressures that recipients can struggle to live up to (Ådahl, 2013; Iacono, 2021). Receiving and living with a donor organ is not easy. The challenges recipients face are often the reasons for why they may choose not to reach out to express their gratitude to donor relatives personally. Similarly, if they do reach out and do not receive an answer, they may experience persistent lingering doubts, speculating about the reason for the donor relative's failure to reply. Even if the recipient accepts that the "*gift*" was given freely and selflessly, these concerns and pressures can persist. The idea that the organ was given as a "*gift*" is intended to comfort and reassure but often creates as many difficult questions as it answers.

6.5 Sophisticated forms of emerging kinship transcend expectations

The challenges created by the interplay between the anonymity requirement born out of medical ethics and privacy laws surrounding organ donation and the idea of organ donation as a gift of life have been discussed at length in the academic literature. My interactions with my interlocutors reiterated many of the existing limitations and concerns that can arise both on the side of the deceased-donor relatives and for the recipients and their relatives. For many who support organ donation and who believe that it had a very positive impact on their lives, the process did not unfold without significant challenges. Such disruptions were connected to their sense of self or the issue of determining the ongoing social ties that remain attached to the donated organs. Where organ donation is not followed by a sense of closure that concludes the process as a social exchange, restlessness and uncertainty can follow. The absence of a thank you, an acknowledgement of receipt, a token of appreciation or condolences on the side of the deceased donors and lack of contact from the deceased-donor relatives or feelings of guilt, indebtedness or refusal to confront the origins of the donated organ on the side of the recipient can result in a lack of closure. However, moving beyond metaphors and abstract imagery and leaving the idea of the gift of life that contains an abstract representation of the two sides in organ donation behind, opens up new analytical territory. As deceased-donor relatives begin to get to know recipients and deepen their understanding of the medical processes they must go through, they often begin to appreciate the complexities of the donation experience for both sides.

As new social bonds form and experiences are shared, deceased-donor relatives become increasingly aware of the ongoing challenges recipients face, and recipients come to understand what deceased-donor relatives have gone through. Once a close connection arises, conversations that acknowledge some of the pain and the challenges and the muted desires that are absent in exclusively positive discourses are revealed. Often, when there is mutual affection and a desire not to upset the other party, these conversations are carefully phrased, and many sentiments will be expressed with the feelings of the other party in mind. However, when people connect on a personal level, discourses about donation can become more complex and complete, without becoming overwhelmingly negative. To the contrary, in many examples, an appreciation for the resilience and the challenges included in the process make the perseverance and determination in appreciating the positive impact and the gratitude for the things the donation enabled more powerful. Recipients and deceased-donor relatives have a difficult process that has changed their lives and that they did not choose in common. Speaking about the effect the experience had on them can help them work through some of the remaining questions, frustrations and fears they had together. Where the biomedically matched pairs of recipients and deceased-donor relatives cannot provide this kind of dialogue among themselves or are not in contact with one another, the wider transplant community can facilitate it through the "*surrogate*" connections described earlier.

As outlined in Chapter 3, the British Transplant Games are one of the locations, where different people who are part of the transplant community gather and engage in conversation. At the Games, I observed many instances of deceased-donor relatives and recipients interacting and spending meaningful time together, but never more poignantly than when I met the Lakefield family. During the 2022 Games, I spotted the mother and two adult daughters all wearing T-shirts with a picture of a man in the front, words that cheered him on below it, and a picture of a woman in the back. Intrigued, I approached them and explained that I was working on a research project. I asked them, who the two people were. The Lakefield family told me that their sister had become a lung donor after her death and that the man in the front was the recipient who had received them – he was competing in the swimming competition, and they had come out in force to cheer him (and their sister) on. For them, it was as though both somehow had a part in the competition, almost as if the deceased donor and recipient were competing as a team. Their presence and support meant a lot to "their" recipient, who felt reassured and touched by their presence, knowing that he was participating in the sporting competitions with their support and blessings. However, he had also told them that many other recipients in attendance seemed to wish they had a similar connection with "*their donor family*" and felt somewhat envious.

> *Our recipient told us stories about the other recipients. Some people may feel a little bit envious of the relationship we have with him.*

> *(Recipient) breathes on with (our sister/daughter), we get on very well, we are an extended family now and meeting him has filled a void. We are forever phoning and texting… we only actually met recently, we live in different parts of the country.*
>
> *It can feel like a strange coincidence sometimes; before our sister died, she stayed on holiday very close to where he lives; he only lives 10 minutes away. The time we spent together has been therapeutic; it is good to know that she is still giving every day. Our sister was a reader, and she was at a crossroads when she died. She wanted to be a proofreader for a living. Weirdly, (recipient) has written a book about his experience of being a recipient, so that is another connection. The book is about his time in hospital.*
>
> *He never had a knack for books previously, but our sister never got to be a proofreader and now (recipient) who received her lungs wants to write more books…*

The Lakefield family were mindful of the fact that other deceased-donor relatives do not have the same deep connection with the recipient that they found, but they immediately bonded with the recipient and his family. They felt that in a sense, their sister "*breathes on*" as long as the recipient lives, often finding aspects of his actions and personality that remind them of their sister and noticing strange coincidences that seem as though meeting the recipient was fate. The Lakefield's believed that their sister was still present in some way and still having an impact on their lives in one way or another. They had frequently felt very close to her when interacting with the recipient of her lung's but also in other interactions that had to do with her organ transplant, such as raffle they won at the hospital where she died. At the same time, they were aware that the new-found closeness with the recipient could result in a further experience of loss in the future, when he and their sister's lungs might die one day. Because they were very conscious of the medical challenges he continued to face, they were anxious not to inform him of any such worries, because they did not want to make him feel worried or guilty. Their relationship evolved from the roles of donor relatives and recipients implied in the story of the gift of life to something much closer and more personal; each party involved seemed more aware of and concerned about the well-being of the other party as individuals than their own.

The relationship between deceased-donor relatives and recipients is sometimes attempted to be managed through rhetoric that seeks to offer each of the parties involved in the transplantation process a sense of purpose and an important role. However, metaphors like that of the gift of life do not resonate universally and have both limitations and potentially negative consequences on the expectations of the recipients and deceased-donor relatives. Among other things, it oversimplifies the process and over-emphasises the positive aspects. Where rhetoric meets the boundaries of its effectiveness, meaningful emerging close kinship with biologically, or non-biologically related deceased-donor relatives can result in empathetic, productive and healing conversations. When details of the different things both sides have gone through are shared in a close and mutually supportive relationship, the things both parties continue to struggle with are cautiously laid bare and begin to be spoken about in potentially healing ways. Through the sharing of some of the difficult details that legal and medical requirements for anonymity want to do away with, topics that needed to be spoken about and addressed to be resolved are brought into conversations and addressed. As a result, simplified metaphors and framed stories about organ donation fade into the background and both sides begin to see one another more completely. Therefore, they become increasingly able to appreciate the complexities of the realities they each inhabit. Frequently, such openness does not take away from the support for organ donation both parties feel nor the positive impact they feel it had on their lives. Instead, expectations and perspectives are adjusted and become more flexible to accommodate the different experiences.

6.6 Conclusion

The relationship that the idea of an organ as a gift evokes is problematic. Specifically, it is confounded by anonymity rules and given a multitude of meanings by those involved in what in many ways can be understood as a transactional relationship. This chapter has sought to identify some of these meanings are and how they can be better aligned. The insights shared by my interlocutors support the prevalent criticism of the gift of life narrative as having negative unintended consequences that can obscure many of the complexities that are a part of the organ donation process.

Because the "*gift of life*" framing is heavily prevalent across the different forms of organ donation acknowledgements and advocacy campaigns, including the comfort and support the Donor Family Network offers in its memorial service, I argue for a note of caution when using the gift rhetoric. In many ways, the symbolic abstraction to honour and commemorate the deceased and to comfort organ recipients can have unintended consequences. Frequently, issues arise because the rhetoric seeks to invoke a sense of meaningful intimate connection between deceased-donor relatives/donor and recipients. Meanwhile, the process of organ donation is subject to closely guarded legal anonymity, which is carefully enforced by the requirements for anonymisation that all attempted communication between the two parties connected by biological donation must adhere to. The decision to donate is rarely made in explicitly Titmussian or Maussian terms. Organ donation is seldom consented to with no expectations of "*at least*" a meaningful thank you in return, and at the time consent is given, there is rarely a firm, fully formed expectation of what should be received in return. In the minds of most deceased-donor relatives I spoke to, the role of the giver and that of the receiver make up the two crucial parts that are involved in organ donation.

Some people do not like to think about the specifics of where the organ went after it was removed or where it came from before it was transplanted, because the questions about identity that result particularly on the recipient side are difficult to fathom. Others create expectations about what the other party will be like or what it would be like to meet them. For deceased-donor relatives, there is often a sense that the organ that was offered for donation holds to some degree a continued biosocial connection to the deceased and they can feel protective over the organ as a result. The medical complexities that are part of the transplantation process mean that not every organ that is "*given*" for donation is received by someone, as complications can prevent the transplant from going ahead. In other cases, organs survive for only a short period of time or eventually fail, or recipients experience several complications following the transplantation – even when recipients are much healthier after receiving the transplant, they can feel lingering feelings of guilt. Sometimes, when recipients and deceased-donor relatives meet, there is disappointment over a lack of a sense of connection and kinship to the other party. Biomedical compatibility does not always result in interpersonal compatibility – an insight also often realised during reunions between adoptees and their biological parents.

Despite this, among many of my interlocutors, there was a sense that deceased-donor relatives and organ recipients were surrogates. In a sense, both sides were connected, and a close relationship with a member from the other group could still feel meaningful when there was no biological connection in the form of a transplanted organ. In rare cases, biologically connected deceased-donor relatives and recipients meet and form close kinship bonds which contribute to a shared remembrance of the deceased donor and explicit expressions of support and reassurance to the recipient. Here, abstract metaphors that represent the two sides involved in the exchange in idealised positive terms are replaced by complex and honest conversations about personal struggles and fears and make way for a sophisticated sense of mutual support and understanding. In this way, contact with the transplant community can result in the creation of meaningful, healing kinship bonds. On the other hand, attempts to create such a powerful sense of connection by charitable organisations can also encounter several challenges. Chapter 7 delves into the opportunities and challenges that deceased-donor relatives face upon joining the transplant community in different spaces.

7. Joining Transplant Community Events

7.1 Introduction

The death of the donor often causes a severe and lasting disruption to the lives of the surviving relatives and sometimes raises questions about the relative's identity, the donation decision itself and the significance of the decision for the future. As the previous chapters emphasised, relatives who do not hear from the recipients who received the donated organs or people who were disappointed by the recipient contact they had can experience a sense of confusion and a lack of closure about the decision they made. During the periods when these feelings manifest themselves, many deceased-donor relatives have already passed through all the officially managed stages that are involved in the donation process and have stopped their donation-related contact with official bodies. The donation specific support that is offered by charities like the Donor Family Network was discussed in Chapter 5. This chapter delves into the role charity events, where different members of the transplant community gather, can play in helping deceased-donor relatives navigate this uncertainty. Firstly, I discuss the role of the Precious Gift Memorial Event organised by the Donor Family Network to offer deceased-donor relatives an opportunity for collective remembrance and a space for connection. Subsequently, I go on to analyse the effects the attendance of the British Transplant Games can have on deceased-donor relatives and recipients. The following excerpt from my vignette describing my arrival at the transplant games indicates the special sense of belonging and community that some deceased-donor relatives find when they attend transplant events in search of further contact with other people impacted by transplantation.

When I bumped into Keith upon arriving at the Games, he told me that he and the other members of the Donor Family Network hoped that seeing the "amazing recipients" at the event would help new "donor families" appreciate the difference that their donation made. He hoped that those who were questioning whether consenting to donate had been the right decision would feel reassured by the way they would be welcomed by the transplant community. He was also planning to encourage them to participate in the opening ceremony in the city centre later that evening. The annual opening ceremony, he told me, included a march of the teams through the host city into the area in front of the stage: "like at the Olympics". Once all the recipients and their supporters had gathered, the live donors and the relatives of deceased donors who consented to organ donation were welcomed with cheers and applause by the crowd, which Keith always felt was very special. He hoped this show of gratitude would help the new donor relatives believe "the good that they had done".

To capture the sense of community and belonging that events like memorial ceremonies and transplant sport events create, I draw on the notions of communitas, anti-structure and liminality developed by Victor and Edith Turner. This theoretical material is being incorporated in to the analysis to emphasise the ways in which these social spaces attempt to offer opportunities for healing, understanding and connection to the attendees. The term communitas refers to unstructured and egalitarian solidarity between the people in attendance, which emerges during phases of ritual or social transition. The environments in which communitas can occur are characterised by an absence of hierarchy and social distinction, instead camaraderie and social support among attendees emerge transcending social boundaries. The term was first developed to express the effects of ritual processes that accompanied initiations that saw members of the Ndembu tribe pass from childhood into adulthood (Turner, 1967, 1969). When solidarity and interconnectedness between the people in attendance emerged, the rituals that were being performed also benefitted the affirmation of a collective sense of identity. Throughout his analysis, Turner stressed the social functions of ritual and its potential to resolve conflict, describing modern society as characterised by an individual sense of powerlessness to make a difference in one's community (Turner, 1975). The term *anti-structure* exists in these events and spaces in societies that remove individuals from mundane structures, disrupting established social norms and hierarchies and causing a temporary liberation of individuals from their conventional roles. Edith Turner in her work on spirit possession in Zambia outlines how rituals can result in a sense of spiritual renewal and forms of embodied new identity formation (Turner, 1994). The process of change that is central to Victor Turner’s work is that of *liminality.* Liminality occurs when individuals are suspended between their existing social roles and the renewed and changing identities that emerge as a result of communitas, when a person’s sense of self and belonging is re-negotiated. They undergo a liminal period, which in Turner’s ethnographic work he describes as a phase of *chisungu*, a Ndembu puberty rite that sees girls go through a transformation period during which they are secluded from society and after which they emerge as women, with new social roles and identities (Turner, 1982). Thus, Turner uses the term liminality to describe a phenomenon whereby an event creates a space outside “*everyday norms*”, instead inviting those in attendance into an alternate reality of sorts, where the emotional landscape and environment are different (Turner, 1982). In their work, Victor and Edith Turner detail the non-serious arenas for reflecting and interpreting society that they argue replace the social function of religion in modern communities. Such events create performance opportunities, enabling those who perform to provide insight and social commentary into some of the “*dramas*” of everyday life the community members face (Turner, 1982). To succeed in doing so, imagery and rhetoric used in the performance must have a clear meaning that resonates with the community being addressed. Chapter 3 provided a detailed account of the imagery the Donor Family Network and the charity Transplant Sport draw on during their events. In this chapter, the successes and difficulties in creating such liminal spaces that result in communitas are analysed in terms of their effectiveness in helping deceased-donor relatives determine what effect the decision to donate had on their own identity and what, if anything, it means for the legacy that the donor left behind.

Importantly, the attendance of deceased-donor relatives at transplant sport events in America has been previously explored in Sharp's (2006) ethnography. In her work, Sharp outlines the way organisers of the event in America who were concerned about the wellbeing of recipients were at first unsure about whether donor relatives should be allowed to attend, in case recipients would find their presence difficult. She describes how once donor relatives received permission to go, they wore T-shirts expressing their support for organ donation and proudly embodied the supportive role of donor relatives cheering on the recipients in memory of the deceased-donors. Sharp outlines the significance of the shift towards allowing donor relative attendance and its implications on the dynamics between the donor relatives and the recipients, which added a previously degree of complexity to the encounters with other people impacted by transplantation that the Games enabled. The striking expressions of support for the recipients from the donor-relatives attending was in many cases echoed by the behaviour of donor relatives I met at the Games. In particular, charities like the Donor Family Network and other third-party organisations were in attendance to make their support for transplantation visible, as was briefly touched on in Chapter 3. However, the Donor Family Network also uses the Games as an opportunity to advocate for the presence and recognition of donor relatives as an important part of the transplant community, who should in their view have a high presence at the event, and whose number they are glad to see increase every year. However, the discussion in this chapter adds an additional dimension to the impact attendance at transplant events can have on donor relatives – namely, a space in which they encounter ways of making sense of the meaning of the donation decision and in which they can embody that role. Through that embodiment, they can gain the chance to interact with recipients in their capacity as donor relatives, which can be an unexpected, often emotional and comforting experience. While not all donor relatives who encounter the symbolism and dynamics at transplant events and discussed in Chapter 3 received them in this way, it is the hope of the organisers that they can honour and recognise the decision made, but also bring comfort, acceptance, and a chance to talk about the donor to the surviving relatives. The acts of organisation and social mobilisation among individuals based on a shared biological feature or connection with the aim of helping their newly formed community has previously been explored in Paul Rabinow's work on advances in genetic biotechnology. He coined the term *biosociality* to describe how novel biomedical technologies resulted in changes to individual notions of self, kinship with others and their sense of social belonging (Rabinow, 1997). The rise of genetic testing saw individuals form new support network that relied on collective advocacy and a notion of shared genetic kinship, exchanging resources, sharing information and supporting one-another emotionally, ultimately resulting in a sense of empowerment related to the support of the biosocial group. The idea of biosociality is relevant to this chapter because it captures the way in which a sense of connectedness on the grounds of having directly or indirectly been affected by the biomedical method of organ transplantation. This experience can manifest itself in changes to an aspect of a person's identity or their desire for kinship with others who have been similarly affected. Linked to this search for the implications of organ donation on one's identity are attempts to harness opportunities for representation during ceremonies, where the experiences of individual deceased-donor relatives or recipients is shared to offer an insight into the feelings of the entire corresponding community. In this sense, part for whole relations come into play when ceremonies elicit the support of a representative recipient speaker, whose amicable sentiments and personal accounts are intended to give the deceased-donor relatives in attendance a comforting insight into the positive effect of organ donation on the lifeworld of a person from the anonymous group of surrogates they meet.

7.2 The Donor Family Network and the creation of community

The Donor Family Network strives to provide deceased-donor relatives with access to a community that can provide ongoing support and whose members have organ donation in common and are therefore believed to be better positioned to understand and help one another. The benefits that can arise when bereaved individuals are given access to communities of strangers who are willing to offer social support and who are able to relate to a shared feeling or experience have been emphasised in the literature on bereavement (Klaassens & Bijlsma, 2014). This kind of support is what the organisers of the Donor Family Network's annual memorial event at the National Memorial Arboretum want to offer the deceased-donor relatives in attendance. During my fieldwork in September 2022, I had the opportunity to experience the network's memorial event in-person.

By this time, I had already spoken to several of the deceased-donor relatives who I knew would attend the event, and I had brought hand-painted cards for those I had spoken to, to thank them for their help. Upon entering the building where the ceremony was held, attendees were greeted by representatives of the network, who were handing out candles which would be lit in memory of the deceased donors during the event. The atmosphere before the event officially started was quiet and sombre. I sat with Isabel and her partner and tried not to disturb any deceased-donor relatives in attendance, opting to write my notes quietly on my notepad. The lights in the room where the event was held were dim, and the air felt heavy with emotion. My skin felt a little bit tingly. I was surprised that I immediately began to feel personally affected; I felt a sense of longing and a heavy sadness sitting among the bereaved donor relatives who had come together. At the front of the room, a podium with a microphone had been set up next to a table decorated with a large floral bouquet and plenty of space for the candles that would be placed there later. A large screen behind the podium showed a slideshow featuring photos of the deceased organ donors who were remembered on this occasion. Attendees had been handed a programme which outlined the schedule for the event. It reminded me of small leaflets for wedding and christening church services of family members I had attended. The event began with an explanation for the meaning behind the bouquet in the front – they were the "*recipient flowers*", which were there to represent the recipients who had received organ donations. After the flowers were presented by the trustees of the network and their significance explained to those in attendance, the donor family network candle was lit to represent the collective of donor families in attendance and the presence of the organisation hosting the event. New members of the network were also welcomed. After this, a poem entitled "*We Will Remember Them*" was read. The words "*we remember them*" were always spoken collectively by the audience. The poem spoke about the collective remembrance of the donors by the people who had gathered at different times in the day, during different times in the year, on good and bad days and for the rest of their lives. The poem focused on collective remembrance and did not specifically reference organ donation; the focus was on the memory of the person by their families.

The emphasis on community created by the collective reading of "*We Remember Them*" was striking. Here, it seemed as though the organisers had found a way to illicit a sense of connection at the very beginning of the ceremony, through the simple act of inviting the attendees to speak those words together. Following the recital of that poem, a second poem, which had been written specifically concerning the network, was read to the group. I recognised both the forget-me-not flower and the butterfly used to represent donor families and organ donation in the memorial statue, which stood just a few hundred metres further across the grounds of the National Memorial Arboretum. The poem expressed that the donors would never be forgotten but would be remembered in a memory garden full of flowers, including the forget-me-not. In the poem, a butterfly landed on the forget-me-not to carefully stop before continuing to fly to where angels could be heard singing. The poem explained that the forget-me-not stood for bravery which was attributed to the donors and their relatives who had helped others by giving the "*precious gift of life*". Once again, the poem ended with a call always to remember the "*donor heroes*" who had died and helped others through organ donation after their death.

As we saw in Chapters 3 and 5, the description of donors as heroic is common in donor relatives' and recipients' accounts of donations and other memorial ceremonies, including those held in America to comfort donor relatives (Jensen, 2010). Importantly, the idea that the donors live on in some way is emphasised because of the collective remembrance of the people who passed by the community of families who had gathered together. Following the reading of the poem, one of the donor relatives I had interviewed came to the front to speak about her experience as a donor mum. She explained how she had lost her daughter and what it was like to be asked about organ donation, how she finally said yes and what being a donor mum meant to her. She spoke quickly; the emotions of the donation day seemed to spring into her mind quite vividly, and she did not speak from a prepared script – the story she was telling was raw and came from memory. It was not a happy or "*pro-donation*" story; it was a factual telling of what had affected her. Despite this, she made it clear that she was comforted by the fact that her child's organs were donated throughout the story.

Once she finished, another poem detailing the recipient's perspective, "*I Need You*", was read. This poem communicated the perspective of a grateful recipient expressing their thoughts about the donor to the donor's relatives in attendance. It spoke of a deep connection between the two and said that the donation was a gift that could not be repaid, which had been given after the donor could no longer use it and had led to a link between the two lives. It acknowledged the anonymity of the donor and said that the life force of the deceased had been transferred. The poem expressed the desire to thank the relatives who agreed to the donation and explain what it meant to the recipient. The poem reflected what a recipient might like to say to "*their donor family*"; it includes a sentiment beyond a thank you, a curiosity about the kind of person the organ donor might have been. Because the poem was included in a service about remembrance intended to comfort donor relatives, universal accuracy was not a priority. Instead, its purpose was to present the attendees with the gratitude many recipients might feel.

The candle lighting ceremony, a key part of the event where anyone in attendance wishing to light a candle was able to participate, followed. This part of the ceremony was extremely emotional and almost made me cry again, because I could see the grief of many people going to the front to light their candles. At the same time, I felt reminded of catholic services of remembrance I had attended in the past, including the symbolic lighting of a candle. The lighting of candles as an act of memorialisation is often used to remember deceased loved ones in Christian traditions (Wainwright and Westerfield Tucker, 2006). In Jewish traditions, it is often used to commemorate the anniversary of a death or to honour the deceased. In Islam, the lighting of candles is not commonly used in funerary rites, but they may be lit to demonstrate respect for the deceased (Clarke and Beyer, 2009). In Hinduism and Sikkhism, the act of lighting a lamp is often used to signify the presence of the divine and is frequently offered during memorial ceremonies for deceased ancestors, whereas in Buddhism candles may sometimes be lit during funeral rites to illuminate the path for the deceased for the spirit of the deceased on their way to the next life. Candle lighting ceremonies are also part of mainstream memorial ceremonies throughout Western culture (Graham *et al.*, 2015; Bowman, 2016). For the people attending the event, the lighting of the candles seemed to be received as an appropriate and powerful way to remember the person they were there to honour. The song "*The Gift*", written for a donor charity in Arkansas, was played during the ceremony; the lyrics were emotional. The song's lyrics included language referencing imagery used in Christian services and references to God. In the song, the donor is described as a "*child of God*" who walked the earth, and the idea of the gift having been given to give the singer, an organ recipient, a second chance emerges as the central theme. The song emphasised the difference the donated organ framed as "*the gift of life*" had made to a recipient. Like the rest of the lyrical material at the event, the song's story was closely aligned with how the Gift of Life Memorial framed organ donation.

The song was followed by the story of a recipient's life told by an organ recipient in attendance. She did not just describe her journey post-transplant but also that of her late husband. She had overcome several challenges, had a family, and become a transplant sports athlete. Her husband, another organ recipient, had died, but not before organ donation enabled her and her daughters to make many precious memories with him and to live a happy life together for many years. She stressed it had been the donor organ that had enabled them to meet and be the beautiful family that they were and still are, and it made the audience aware of the fact that many members of the recipient community do have to go through loss and grief as well. The way she told the story seemed to show that the eventual death of her husband did not take away from the value of organ donation and how it had transformed both their lives.

After her story was told, the network's founder took the stage and reflected on the past 25 years of the Donor Family Network. He recalled how, initially, there was no national support organisation for "*donor families*". After recounting the story of the founding of the network, he proudly explained how far the charity had come since. He stressed that its main goal had remained the same: to be there for every donor family and ensure no donor would ever be forgotten. Beyond that, he wanted to ensure donor family interests were represented in the transplant community and were part of policymaking and events throughout the year. Following his speech, a story entitled "*When Goodbye is Forever*" was told, describing the pain and the heartbreak a mother of a donor struggled with when remembering her son; it had undertones of continued love and unbroken remembrance and care. It was about grief more than hope and seemed to acknowledge the pain many of the people in the room felt.

After that story was finished, a regional clinical lead for organ donation spoke on behalf of the medical service and paid his respect to both the donor families and the network – he was there to make sure that healthcare professionals were also represented and able to thank donor families for what they had done. He highlighted some of the practical ways in which organ donation was helpful to the health system.

Once he finished speaking, Certificates of Recognition were presented to those donor families who had requested them for that year's event. Many of them had lost their loved ones (a term used throughout the ceremony) very recently and seemed touched by the recognition but simultaneously struggled to hold back their emotions. Some of them had a family representative go up to collect the certificate as they did not feel able to go up and get it themselves. A few people were comforted by the donor family members who handed out the certificates and empathised with their feelings. Finally, the poem "*There Are No Words*" was read out. It was written by a transplant recipient and akin to an open thank you letter addressed to "*donor families*" grieving their relatives. The good the transplant, which was once again referred to as a gift, did, was described, and the fact that it saved a life was mentioned. Alongside a heartfelt message of gratitude and thanks was an expression of deep condolences for the loss the donor family has had to endure. The gratitude of the recipient family and the author of the poem was reaffirmed, and the fact that there is no way to say thank you that would ever equate to the significance of the "*gift of life*" was emphasised, but the thank you in the poem was extended regardless and reaffirmed in the finishing sentence – life, the author promised, would no longer be taken for granted. At this point, the ceremony concluded.

The event's main themes were grief, loss, and collective remembrance. Beyond that, there were pieces of information about aspects of transplantation the relatives in attendance would likely not know about. For example, information about the network's role in advising committees discussing the use of novel biomedical technologies, as well as contextual information explaining the role of the network in the wider transplant community. The two dominant elements were collective remembrance and the living of the donors as a result, as well as the notion of deep gratitude for the donation from recipients. After the ceremony concluded, tea, coffee, and cake were served at the entrance area of the venue. I spotted a few familiar faces in the crowd and used the opportunity to hand out some of my thank you cards. The comfort and emphasis on community that had remained a firm theme throughout the event continued in the conversations shared among attendees afterwards – trustees of the charity and other attendees whose relatives had died a longer time ago were trying their best to comfort newer families and answered questions about the donation process as best they could. Where appropriate, I was invited to meet attendees who wanted to share something about their donation experience. Slowly, attendees said their goodbyes and returned home in the late afternoon.

The space the trustees of the Donor Family Network tried to create at the event was one of solidarity and shared remembrance, seeking to reassure the deceased-donor relatives that they were not alone in remembering the deceased and affirming to them that their decision to consent had been a positive one. The stories about the impact of organ donation on the lives of recipients and the appreciation and gratitude that were said to be felt by all recipients and that was expressed by the recipient in attendance were shared to reassure the deceased-donor relatives that they had made the right decision. Consenting to organ donation was framed as an extraordinarily heroic and selfless act of immeasurable value to the community of organ donation recipients in need of life-changing transplants. In other words, the symbols that the Donor Family Network had the aim of facilitating a liminal space in the sense that people who usually live their ordinary lives could grief the loss of the donors openly, be understood and supported in their grief, and honoured for having made a very meaningful choice. The promise the network makes to its members is that it will always offer its members a space to be recognised in this capacity.

7.3 Obstacles to a sense of belonging and identity

My conversations with donor relatives who had attended the event suggested that many felt that they were part of a close-knit community at the Donor Family Network and that attending charity events had helped them better understand organ donation. They felt like a part of a group of donor relatives who were one big community where they could talk about the donor and share stories about their experiences. Some even likened time spent with the network members to time spent with family, a family they came to know because of the organ donor, an aspect of their lives connected to the donation. Tina, who helped organise the event I attended, explained that the memorial events felt similar to church services because that is how the memorial events started.

> *Not long after I got in touch with the DFN, they held an event similar to the one we are having in September; the early versions of those were a church service – that allowed us to meet other donor families, and probably that was the first time we met any recipients.*

She recollected that she met other parts of the transplant community who had also experienced transplantation in one way or another at these events. The Ibbington family said that the annual events were an essential part of their lives now but that it took them some time to get used to opening up about very personal experiences to a group of strangers.

> *We got introduced to the Donor Family Network via another family and initially felt a bit apprehensive. We found it a little bit difficult at first, because we had to talk about our own experience as well as listen to others about theirs. We had to engage with strangers, but as the*

> *involvement increased, things got easier, and we got more used to talking about what happened.*

The Ibbington Family felt that talking about what happened made it easier for them to talk about the loss that they had experienced, and over time, they began to open up more and more. However, initially, the symbols and rituals they encountered at the event felt unfamiliar and the prospect of opening up to strangers and letting go of the social norm of not grieving publicly felt challenging for them. For many attendees, the symbols used throughout the event eventually felt like an appropriate way to display the phenomenon of organ donation. The Hewett parents felt that particularly the butterfly and the forget-me-not felt right and that "*whoever thought up the symbol did a fantastic job*". However, they did not feel they needed to attend the memorial service to be able to reflect on the significance of the donation. Nevertheless, they gladly welcomed the opportunity to participate and expressed their joy that donor relatives were being recognised. For others, being at the event felt a little bit strange.

> *People coming together for the memorial service is not really something for me, lighting the candle is not really something I feel I need to do. The problem with charities is, you can either bond with people or you don't – the only thing you really have in common is organ donation.*

Kathy struggled to feel a connection with the people she met at the Donor Family Network, although she thought that the ceremonies, they organised were helpful. She explained that the remembrance offered at the event did not align with what she felt she needed to feel supported. Because a charity ran the event, she thought she would have needed to click better with the organisers to benefit fully from the support offered. The absence of a sense of connection with the people in attendance was an obstacle that meant Kathy never felt as though she had experienced solidarity and belonging akin to a sense of communitas. The Muller family echoed the sentiment that their own way of dealing with grief made them feel alienated from the emotional tone of the memorial event. They would have preferred a greater emphasis on the practical elements that make organ donation possible.

> *It was not difficult to get in touch with the DFN, and (the founder) is a fantastic contact. Visiting the National Arboretum was a very moving experience and the ceremony for the memorial was very beautiful. Once they explained to us about the donations to the charity and everything – well, we don't do that you know. You might think that is strange.*

The Muller family had a positive first impression of the founder of the network and the way the event was organised but felt that there was an overemphasis on charitable donation to support the organisation as this was not something they wanted to do.

> *I do find that as a group of people who meet up purely as a memorial to their lost relatives it can be quite intense – all they want to talk about are the people they lost. We just did not need to remember our son through all this complicated symbolism. We scattered the ashes where he used to walk the dog. Of course, I know the Donor Family Network are doing tremendous work. On the donor side we did have the family over to talk about organ donation and we did speak to them about what they did as a charity. Some of the members of the network are very intense, it can almost turn you off it – you want to move on, you try to move on in a very positive way. Of course, you never forget the person.*

For the Muller family, some parts of the remembrance events were too negative, too focused on discussing the loss and the remembrance in "*complicated*" symbolic ways and an "*intense manner*". They felt they would have benefitted more from the charity if its members had been less intense. Part of their reason for this was that there was never any risk of them not remembering their son – they did so in their own private meaningful ways that had to do with their memories of him. Despite this, they did want to support the charity by speaking to friends and family members about it.

> *When you talk to them, they go on and on and it is more upsetting than anything really. You probably think we are quite cold-hearted, but for us, they are too focused on memories, there is not enough focus on the practicalities. Once you are dead the bits of you are no longer of use.*

Part of the reasoning behind this disagreement is that for the Mullers, the donor organs were not thought of as still meaningfully connected to the donor as a person. Instead, they were more interested in the practical processes involved in transplantation and preferred to discuss what organ donation means in proactive terms.

Beyond concerns around the focus of the gatherings and the themes that are emphasised, there was concern about the accessibility of the network's support, which Kathy expressed.

> *The Donor Family Network, I find it a bit twee, a newsletter coming through… The helpline I think is very useful. In terms of what the Donor Family Network provide, I think both should be there, the symbolic support and the real support like the helpline and counselling. It should not be a case of either or. I know that recipients also have a lot of trauma. I think the support phone lines are in English, it is all very white middle class. There is not the same support available if you cannot pay for private counselling.*

Kathy emphasises something I had also noticed about the attendees at the memorial event – the attendees seemed to be from a majority white background, and the event was held in English – the same is true for the phone support offered by the network, as described in Chapter 5. The fact that attending the single event held in the English Midlands once a year would likely not be an option for many people who lived further away or lacked the resources to come created an important limitation to the universal benefits of the support offered.

Grief was also experienced differently by my interlocutors, and different people preferred to express their grief differently. Additionally, the academic literature suggests that grief is expressed differently across sociocultural groups (Morris *et al.*, 2017). While the donor relatives running the network events were indeed community representatives who could draw on their past experiences to anticipate the needs of others, my findings suggest that the ritual and imagery of remembrance that were created by the network and other charities did not have the universal resonance that was intended. Despite the network's goal of being a community for all "*donor families*", there were limits to the diversity of perspectives the network attracted. With that being said, the trustees of the network have always emphasised their willingness to be flexible in their approach and to change and grow in line with the challenges they face. The network founder often stresses that "*there are no problems, only solutions*". In the case of the memorial event, problems appeared to arise because of the emphasis on shared emotion predominantly and the shared grief that some attendees struggled to connect with in a public way. A lack of interpersonal connection and solidarity with the other people in attendance meant that the event did not always have its intended effect. Conversely, the British Transplant Games offer a more multi-facetted space that consists of structured ceremonies and opportunities for playful interaction between a more diverse group of attendees with different connections to transplantation on both the donor and the recipient side.

7.4 The British Transplant Games and transplant identity

I arrived at the 2022 British Transplant Games in Leeds on a cold, rainy morning in July 2022 after a 1.5-hour drive from Durham. It was still early, but I knew I needed to get into the building and to the registration desk as soon as possible because I was scheduled to work as a volunteer throughout the event. I was excited to experience an event in the transplant community for the first time. I had been asked to report to the information desk next to the swimming hall in the building that led out onto the track and field facility. I took a deep breath, shouldered my backpack, and ran through the rain towards the entrance. Having burst through the main doors, I was greeted by the smiling faces of two women sitting behind a table filled with registration forms, maps, event schedules, and branded water bottles. I introduced myself and asked if they knew where I needed to go. The younger woman, who appeared to be in her late twenties, reached into a box under the table and pulled out a red drawstring bag with "British Transplant Games Leeds 2023" written across the front. She explained that the bag contained *my volunteer pack – a T-shirt, like the one she was wearing, identifying me as an event volunteer, and a nametag with my picture that I could wear across my neck. As I pulled the T-shirt over my head, she told me I would work at the information desk with her for the first two days. Her name was Paula. Our job was to tell the people arriving where they could register to compete in the various events they were partaking in, where they needed to go to watch the competitions, where the medical team were stationed, and anything else they needed help with. We had been given a Walkie-Talkie to help us stay in touch with the volunteer coordinators from Westfield Health, the company helping to organise the event. Paula invited me to take a seat next to her. She started to review the information about where the events were being held – the archery would happen on the athletics track later on the same day. Swimming was scheduled throughout the event in the building next to the one in which we were sitting. Various charities would set up their stalls outside the building as well. Tennis and Squash took place in a building on the other end of the athletic track, and many children's events would be held in the city centre. These mini-Olympics for transplant athletes were too large for all the events to take place on the same campus, and competitors would need to manage the commute between the different venues depending on their personal competition schedules. Before long, the first competitors arrived. They were easy to spot in the T-shirt identifying their transplant unit team. Given the location, Leeds Children's Hospital was, unsurprisingly, very well represented since the Games were hosted in their city. King's London had shown up in force, and competitors from the Freeman Hospital in Newcastle had already started to arrive. Some recipients were Games veterans, walking into the building with an air of confidence and excitement, looking for the familiar faces of their teammates. Others seemed new to the Games – groups of young competitors holding the hands of their parents, who were wearing matching team T-shirts and name tags identifying them as "supporters", headed across to the information tables to find out where they needed to go. Paula and I were wielding maps and reviewing the event schedule to ensure everyone was headed in the right direction. The event gained pace quickly, and the building was suddenly filled with people – the anticipation over the first events of the Games grew. The walkie-talkie was blinking hectically, and we could hear the organiser's distorted voices over the transmission, telling the other volunteers to go to their stations. I was amazed at the size of the operation – the event was bigger than any school sports day I had ever taken part in, but the atmosphere reminded me of a large village hall summer party gathering. Many people already seemed to know each other from previous years, and I could hear chatter between old friends catching up. Health-related struggles came up regularly and catch-ups often included information on transplant-related health and how it was thought to affect the competitor's abilities during the next few days. Alongside discussions about transplant success and health management during the events, extremely ordinary interactions could be overheard. Small children were asking for food, and stressed parents* *were trying to find the toilets. Friends were laughing, siblings were bickering, and team organisers were trying to locate their teammates. The atmosphere was filled with excitement and anticipation of the days ahead.*

Suddenly, I spotted a familiar face in the crowd. Keith, the man from the Donor Family Network representing the relatives of deceased donors, had arrived. He was the one who told me about the Games and suggested I should come along. He wore a pink T-shirt that had the charity's logo on the chest area and the words "Donor Family Network" on the back. He introduced himself to Paula and told me that the Donor Family Network was setting up a stall outside the building, next to the stalls of other charities. NHSBT had sent representatives who would provide support and information on how to write to one's donor relatives. Their stall was on the second floor because of the number of charities that would be present. The network had brought information about the charity's activities and the materials commemorating many of the deceased donors whose families were part of the donor family network. He told me that one or two new families would be coming to the Games – they were new donor relatives who recently agreed to organ donation and were unsure whether they had made the right decision. He encouraged me to try to get away from the desk to see some of the medal ceremonies – another unique opportunity for donor relatives to take on a key role in handing over the medals to the recipients who won at the various events. Before he left, he told me I should also try to come along to the donor run – a non-competitive community activity during the events, where donor relatives, recipients and supporters could take part, some in fancy dress, running or just walking, to show their support in recognition of organ donors. I promised him I would be there for all the things he suggested. I felt excited. I had not been at the Games for very long yet, but I thought I was already beginning to understand why he had encouraged me to come – I could feel the sense of community and the anticipation in the air. I understood why Keith was so excited that the donor relatives were a big part of the event.

The collective excitement and buzz at the Games is intended to help deceased-donor relatives who newcomers feel part of the transplant community. Keith explained that the Donor Family Network often invites deceased-donor relatives who are unsure whether they made the right decision or what transplantation means, for example, because they did not receive a reply from recipients to attend the Games. He said that only a few donor relatives know that the Games exist but that anyone who has been before tends to come back again because "*once you go, it is addictive. The people that have been before you don't lose after that"*.Keith stressed that attending the Games and having a chance to interact with the recipient is a powerful opportunity, partially because there are very few similar gatherings where many different people from the transplant community come together during the year. The network wants deceased-donor relatives to attend because by being at the event and establishing a formal presence of deceased-donor relatives, they ensure they are linked with the rest of the transplant community as a biosocial collective. The representatives of the Donor Family Network at the event fulfil the purpose of the charity that is indicated in its name – they network and establish new connections to other donation advocates, other charities and non-governmental organisations, other deceased-donor relatives and transplant recipients.

Throughout the Games, attendees engage in both formal and playful expressions of biosociality that reaffirm their sense of belonging as part of the transplant community. As discussed in Chapter 6, for recipients, transplantation can be a confusing experience that raises questions about who they are, what they might expect from their future and how, if at all, they are connected to the donor. Beyond that, transplantation can be a very challenging experience that results in an ongoing need to take medication and further health complications that affect the daily lives of recipients. Being at the Games allows recipients to encounter a sense of belonging and of normalcy, where they can control the impact of transplantation on their lives and express themselves as athletes. Because of this, the event has been described as a "*therapeutic landscape*" for transplant recipients (Greig, 2023). The sporting event gives individuals access to a sense of community and connectedness closely linked to the transplant decision for donor relatives and the transplant hospital units comprising the recipient teams. In that community, individuals can find a sense of belonging. Through the ceremonies at the beginning of the event and whenever medals are handed out, rituals offer an opportunity for the organisers to highlight the connection between donor relatives and transplant recipients in positive ways. Details of the symbols used were described in Chapter 3.

Participation in sporting events as an identity-affirming form of social performance, in many cases in support of a community that is meaningful and important to the player (such as their team, their family, their country, or in case of the games, the people from their transplant unit and the donor relatives and donors who supported them) has previously been highlighted by Kraft and Brummett (2009). For Steffensmeier, who writes on the significance of college football for building local identities, days of sporting competition are opportunities to demonstrate a shared community identity (Steffensmeier, 2009). Opportunities that create shared excitement and offer the possibility of supporting someone competing in a sport as a team are said to help facilitate community development (Steffensmeier, 2009). In this sense, the choice to dress up in a group uniform is an act of identifying oneself as a member of the community the uniform is associated with – for the members of the Donor Family Network, these are the Donor Family Network T-shirts sold at the stall and worn during the days, for the volunteers they are the T-shirts and name tags provided by Westfield Health, and for the

Transplant Athletes and supporters, they are the T-shirts and slogans in support of their transplant unit.

Consequently, recipients don't necessarily share local but instead share hospital identities. Buechner et al. and Malcolm outline how the opportunity to begin to feel part of a new community or to discover a new facet of one's identity can be triggered by a disruption of one's view of oneself (Malcolm, 2013; Buechner *et al.*, 2020). In Malcolm's work, such a disruption is triggered in people from the Caribbean who move to Britain and experience a "*crisis of identity*" when faced with a very different way of life. He argues that by sharing the membership of a group of supporters from a similar background who cheer on their team in cricket, a new kind of identity can be produced, which is reinforced when the individual attends sporting events (Malcolm, 2013).

Figure 16: Donor relatives from the Donor Family Network at the Games

Both the transplant recipients and donor relatives I have spoken to describe a different kind of disruption of their identities. For many of the donor relatives, the death of the donor meant that their identity as a mother, father, brother or son was disrupted. For recipients, the experience of learning of the need for an organ transplant and ultimately receiving a donor organ that came out of the body of another person raises a different set of questions about their identity and their relationship with their own body. In my view, the Games provide an opportunity for both groups to be exposed to community rhetoric that actively celebrates the positive influence the organ donation could have had on their identity and offers up a robust idea of a new identity that can be found within the transplant community. That is not to say that attendee's identities would become exclusively about their membership of the transplant community, but instead, that the Games provide them with an opportunity to mend a part of their sense of self that might have become disrupted, to discover new ways of thinking about the consequences of the traumatic events they had been through. In this sense, the Games allow them to experience a form of anti-structure. Specifically, the event creates circumstances under which their usual social roles and the associated norms and hierarchies are replaced with their opportunity for transplant-related self-expression the Games create. As part of their experience in this liminal space, new identities may be found and expressed by the participants, for example, by introducing themselves as a "*donor mum*" or "*donor dad*" when somebody asked them about their reasons for attending the transplant games.

In other instances, similarities about the experiences of relatives of recipients are similarly expressed, when mothers refer to themselves as "*heart mothers*" or where children at the Games or in other transplant community spaces make friends that are sometimes described as "*heart buddies*". The sense of social connections that relate to the organs involved in the transplant process creeps into the terminology used by many of the people affected by transplantation. These expressions of identity-based on biosocial ties linked to material objects sometimes evoke notions of kinship relations that are not exclusively connected to biological relatedness, but instead arise from the kind of organ that has been donated or the familiar role a relative has as a result of their relationship to the donor, for example as mother or father, in relation to the donor.

7.5 The British Transplant and the problem of anonymity

Donor relatives and other members of the transplant community in Britain have the chance to meet up at the annual British Transplant Games, where they can strengthen transplant-related facets of their identity, reflect on the positives transplantation can achieve, escape their everyday lives and have the kind of rapport with recipients that they were perhaps missing in the standard procedure of NHS transplant communication. For deceased-donor relatives, the experience of going and feeling the gratitude expressed by recipients and seeing what the transplant organ has enabled them to do can feel cathartic for donor relatives. The deceased-donor relatives and recipients in attendance usually do not know if any of the organs that they donated/received biologically connect them to other people there. However, the anonymity of both parties is slightly blurred when donor relatives wear T-shirts marking them out as members of the Donor Family Network and recipients wear T-shirts and nametags that show that they are recipients as well.

This expresses an association with the community at the games and provides an opportunity to continue bringing the donor into the games' environment. For example, Tina explained that when she identifies herself as a deceased-donor relative during her exchanges with others, her son, the organ donor, is "*brought up*" much more frequently than during her everyday life. Scarlett said that she enjoyed the Games for a similar reason.

> *The recipient's mother wrote to me to say that her daughter had won silver at the transplant games. The Games meant I could see what good transplantation could do. At the Games,*

> *everyone can talk about transplantation, we all talk about our children. It's my time with my daughter; it's my Tracy time.*

For Scarlett, the gathering with other donor relatives at the Games and the Donor Family Network shared meal provided her with a whole weekend dedicated to thinking about and remembering her daughter and the one positive thing that resulted from her death. She stressed that being free to talk about her daughter and about what happened to her allows her to feel as though she could dedicate her whole time there to her daughter's memory. Donor relatives who attended together with the members of the Donor Family Network often found time to remember their deceased relatives explicitly as a community – to take them to the events with them in some way. The Donor Family Network newsletter includes an example of how these activities can look, albeit at an international transplant sport event (the World Transplant Games in Newcastle in 2019):

> "*There was a beach walk for donor families from all over the world, where names of the donors were written on pebbles and laid on the beach. While doing this, a rainbow appeared—our loved ones were looking down on us*!" (Donor Family Network, 2019a)

Moments of collective remembrance as a community can sometimes be experienced more powerfully together, and the sense of deeper meaning is often amplified (Durkheim, 1893). Through spontaneous acts of remembrance that involved unconventional acts of collective intentionality among deceased-donor relatives, feelings of connectedness emerged more quickly through the shared desire to meaningfully acknowledge the deceased donor's presence in the minds of the group of relatives.

The Ibbington family felt that acts of participation in the medal ceremonies in their role as deceased-donor relatives provided a sense of belonging and comfort.

> *We have been to the Transplant Games, where we had the opportunity to present medals to the recipients, and that felt really good and helpful. The first games we attended happened in Bath. Overall, our memory of our son is a separate thing, but we do remember him there. It is a chance to see the good that you have done. We agreed to help other people, but some family members did not understand right away; it took them some time to accept what had happened. Going to the transplant games is great; it really is like one big family, and everybody is sort of connected in a way.*

The experience of presenting medals to recipients and the sense that the recipients feel a donor relative is one of the most influential people who could possibly honour them for their win help donor families feel positive about the decision they have made and makes them feel as though they have a role to play and a contribution to make when attending the Games. At the Games, recipients can also choose to embody the effect the transplant had on their bodies actively. They are now "*transplant athletes*" who are taking control of their health as best they can or who choose to celebrate what their bodies can do following the receipt of their transplant. By doing that, their self-perception changes due to the chance to participate in this unique sporting event (Malcolm, 2013). Furthermore, the opportunity to express gratitude to donor relatives directly can provide a sense of closure to both the recipient and the donor relative. Such expressions of gratitude can be very meaningful for deceased donor relatives like the Ibbington family.

Figure 17: A medal is being awarded by a donor relative

> *The donor T-shirt is recognisable, and at one point, a little girl (who was a recipient) and her dad came and gave us a big hug to say thank you. Our son was able to get a sense of community out of (the games) and we are happy to discuss donation in that context.*

Many donor relatives who attend the Games wearing something that identifies them as such meet recipients who want to express gratitude. Even if the recipient is not the one who received an organ from their deceased relative, hearing a personal thank you and a sign of gratitude from any recipient affirms them having made the right choice and being a valued part of the community.

> *Certainly, with transplant sport, when they (recipients) win a medal, they give it to the donor family. Some of them don't know their donor family. They will just find a donor family at the games, and they will just give it to them and say I don't know my donor family, but you are a donor family, So the donor family community is almost a surrogate community. You read so much about everyone being so thankful to their donor. And it is sort of on social media. There is always somebody who says I am so grateful to my donor family. I would not be here without my liver transplant today. Which I think is good for the donor families; it makes them realise not that they did not know how much good their loved one has done. The gratefulness never disappears.*

Maggie speaks as a nurse who has supported recipients throughout her career and as a longtime supporter of Transplant Sport and event organisers. She explains that many recipients want to actively express gratitude to either their personal "*donor family*" or a representative of donor relatives as part of their attendance of sporting events. If recipients win something, they often feel it is essentially the result of the transplanted organ they received, and in turn, they want to give something back to those who had a part in that win that was achieved by the recipient's body. Donor relatives, in this sense, are sometimes viewed as being connected to the recipient bodies in a physical sense, as enabling their achievements – this is why the term "*surrogacy*" is often used. As with anonymity in surrogacy, the anonymity in donation often complicates a positive sense of social connectedness, but it simultaneously allows the roles of donor relative and recipient to be opened up to wider groups. In this setting, the anonymity between donor relatives and recipients of deceased donor organs can be revealed to have a positive effect when peeled back slightly. If recipients reveal that they are recipients and donor relatives reveal that they are donor relatives, many of them could hypothetically be linked by the biological connection of an organ and not know it. This hypothetical link that could exist amplifies a sense of meaningful connection between the two groups.

Beyond that, each group gets an idea of what the other group has gone through and can appreciate the goodwill and resilience that they each represent. This kind of reduced anonymity creates an opportunity for connection, belonging, and dialogue, ultimately resulting in a deeper understanding of what the other party is going through. Events that facilitate togetherness provide insight into the kinds of people who embody the roles the gift of life metaphor attributes, allowing a one-sided imagination of the other to be replaced with the idea of complex individuals who act as representatives of their communities. As explored in Chapter 6, where there may be disillusionment or a sense of uncertainty among donor relatives who have not heard from the recipients who received an organ or who were disillusioned/unsure about their decision, recipients at the games can step in and offer their gratitude and appreciation, fragments of their personal story, whereby they embody the role of the recipient donor relatives had hoped to benefit with their decision, affirming through their embodiment of an organ recipient in conversation with donor relatives that the donation was meaningful that there is gratitude and appreciation, that their decision had a positive impact and that the spirit behind the donation is recognised – in doing so, they fill some of the vacua in meaningful affirmation of transplant receipt that can result from disillusionment following a lack of meaningful reciprocity that could have been experienced post donation where members of the public took the gift metaphor literally, as discussed previously.

Ritual processes like those that occur at sporting events are thought to provide members of the sporting community with opportunities to see their identities expressed or to perform that role themselves as part of the event, allowing them to feel transformed and reassured in their identities (Bigger, 2009). In the disappointing silence that may exist between the biologically linked donor-recipient pairing, the Transplant Games open up a space where others can stand in and speak from the perspective of a donor family or recipient. In doing so, the sense of a loss of meaning in donation that the anonymous gift can create is answered through powerful symbols and the opportunity for donor relatives and recipients to speak on behalf of the biologically linked donors and recipients. The opening ceremony partly sets the tone for such conversations.

At the British Transplant Games, there are two distinct opportunities for social performance – one that is explicit in the opening ceremony and other presentations throughout the event, where attendees are passive listeners and recipients of the shared messages and stories. Simultaneously, there is a second opportunity for social performance in the implicit expression of one's stance or identity as part of the complex transplant process. Here, individuals actively step into the opportunity to identify as a transplant recipient/athlete or donor/donor relative and perform a task in appreciation and support of the other group to get a message about their feelings towards the other party across. The idea of play as a way for communities to engage in organic embodied interactions has been explored by Edith Turner as a way to strengthen social bonds (Turner, 2012). Sporting events provided opportunities for this form of play in modern English society (Guttmann, 1978). The contact between biosocially anonymous members of the donor and recipient groups at the Transplant Games provides a powerful alternative sense of connectedness within a community that can exchange shared emotions in a broader sense, which is especially powerful at the British Transplant Games. However, for many, the competition is more about conquering their ability to participate in sports and challenging their bodies to train in pursuit of better health and, at times, celebrating remaining or regaining health.

Throughout the event, spectators regularly cheer the loudest for the slowest person running on the track or for the only competitor in a given category. There is a mix of excitement, competitiveness and ambition, and a general notion of wanting to compete to participate as an active part of the community in attendance. In that sense, one could argue that ritual plays a more significant part in transplant games than other sporting competitions. Many feel that participating in the event allows them to express their appreciation of the donor whose organ contributes to their overall performance. In that sense, they could be set to participate as a symbol of their appreciation of the organ they were given or as an expression of their determination to "*look after*" the transplanted organ they were given by the donor as best they could. After all, the charity Transplant Sport and the Games were initially founded to create a space that would motivate transplant recipients to positively impact their health and the transplant success by engaging in sports with others in a similar situation (Greig, 2023). I argue that the kind of play and immersion that is evident at the transplant games is an example of "*productive* *play*" or "*reassuring play*" – sporting competition that happens in an environment where others are aware of the health issues competitors have been through and where the general attitude is generally one of support for one another.

The kind of liminal space that is created at the Games is one where one of the most challenging things about the lives of donor relatives and transplant recipients is laid bare and normalised, not hidden and seen as a thing that makes them different from other members of the community. Keith provided a poignant example of something he had noticed in the hotel he was staying in that morning. The same hotel that housed donor relatives like Keith for the duration of the Games also accommodated several members of the recipient teams, including a group of young kids. In the morning, Keith observed all the kids dressed in their team T-shirts laughing and eating at their table, each of them with a box of medication and different pills next to their plate, which they needed to take because of their transplant-related health needs. He was pleased to notice that because they all had such a pill box in front of them, none of them seemed to care much about taking it, and they chatted on excitedly. He felt this was evidence of the escape from reality the Games provided for recipients and their families in attendance – something that would make them feel different from other members of the community in everyday life was something that made them part of the group of people they were surrounded by during the Games. Having a transplant and the circumstances of the transplant are not forgotten about; they are normalised in a sense. That is not to say that underlying anxieties about one's health or perceived responsibilities about looking after the donated organ are no longer thought about – they are merely thought about more productively because the event allows thoughts that might otherwise be repressed, unspoken worries to flow more freely within the community space. In that sense, play and competition do not mute concerns that exist in everyday life. They don't necessarily make individuals forget about them but release them into expression and contemplation throughout the event. The revelations about personal struggles and memories that the people who attend go through and strengthening bonds between Deceased-donor relatives and recipients are the most powerful arguments against abstraction and symbolism used to describe transplantation.

7.6 Organ donation as legacy

Ultimately, the experiences of deceased-donor relatives and the impact the decision to donate had on their lives after the loss can be very diverse. Because of this, I advocate for the inclusion of a broader range of symbols and metaphors that go beyond the gift of life to relay donation experiences and. Everyone affected by transplantation does not necessarily agree on how the experience should be described, and different pairings of people with similar perspectives can meet one another in online spaces or at events like the Transplant Games and have productive conversations. For some recipients, the fear of a transplant eventually failing means that organ donation can best be described as a Life 2.0 (with the potential of future transplants resulting in a life 3.0, 4.0 and so on). In this sense, organ donation creates a chance of improving another person's life for an unknown amount of time. That is not to say that organ donation cannot have an immense positive impact on recipients' lives, but it is an acknowledgement of the reality of the uncertainty involved. Alternative pragmatic takes on organ transplantation were also present among deceased-donor relatives. For example, many of my interlocutors viewed the connection with the recipient as a legacy of the donor who passed away, caused by a positive act that originated as the final act the donor contributed to, which continues to cause positive ripple effects for the recipient. However, the biological material from the transplanted organ is not always seen as a part of who the deceased donor was, as Isabel’s account illustrates.

> *Many people have said to me. “Oh, it's lovely. That she's been a donor because she's living on in other people”. And I don't think that. How could she, she is not living still. Bits of her are still alive, but I feel it's more like it's my DNA. It’s the things that I created in my womb that made her body. And so my DNA is now in other people, rather than trying to say, you know, oh, she is still alive, because it’s weird.*

Isabel stressed that she does not feel her daughter lives on in others because of the physical preservation of biological material that came from her body – instead, she explains, she feels the organ is biologically connected to herself because she was the one who gave birth to her daughter. She explained that there is a positive non-biological legacy that her daughter continues to leave when positive things happen because of the organs she donated. Tina, too, used the word legacy when she reflected on her donation decision.

> *I am very proud of that legacy. We have gained a lot out of it, obviously, with our involvement in the charity, but he left that legacy, and through that, there are people today who are still living because of that legacy. We are very proud of what our son did. We do get a lot out of it. But what we are getting out of it is that we are meeting all those amazing people who have made the same decision and have become part of that family.*

In Tina’s mind, her involvement and that of her husband in organ donation advocacy were a result of the legacy that her son left and that they both contributed to.

> *Because, and it is the way I see it, it is something that has come after our loss. So, although we are remembering our son very much so by being involved in the network, the work that we are*

> *doing has come after. This entire legacy has come for us, through the fact that he passed away and donated.*

By being involved in the transplant community, the decision to donate their son's organs continues to have an effect on both of them and that connection with their son is reinforced because when they do it, it helps them remember their son. Similarly, for Scarlett, the idea of a legacy that has been left and that organ donation is a part of is something that the surviving relatives can continue to contribute to through their support of the transplant community. She described her daughter's "*legacy*" as open-ended and continuous.

> *My daughter died 20 years ago, but her heart is still beating. I like to think about the legacy she has left behind; I feel she has now left her mark on the world*

Scarlett thought of the organs that her daughter "*left behind"* as part of the legacy, as further proof that she was part of the world and that her life made an impact. In her statement, she spoke about the continued heartbeat of her daughter who died a long time ago – the notion of a legacy and that of the continuing survival of the organ are connected. However, should the heart stop to beat one day, this would not be understood as the cessation of the legacy, as the heartbeat and the legacy are connected but not dependent on each other. Often, deceased-donor relatives described their understanding of the donation as an ongoing ripple effect, starting from the moment that consent to the donation was given. Isabel emphasised that consenting to organ donation was a decision that would continue to impact lives far into the future.

> *It's the legacy, isn't it? It's the legacy that they leave. Well, it rolls forever… You know the families who got his organs, it moves, it ripples, the ripple effect is fantastic, much more so than you ever realise, it takes a while to understand that fantastic ripple effect.*

Organ donation can be a legacy that has an impact on the lives of recipients for a long time, and on the lives of their relatives. Many recipients I have spoken to have stressed that they are often anxious for deceased-donor relatives to understand that the donation can have a very positive impact, even if the transplant eventually fails, and that it has enabled them to spend additional time with friends and family. Isabel recognises that the donation has the potential to impact many lives. The notion of legacy allows for an understanding of donation as something that comes after the death of the deceased – some of the deceased-donor relatives I spoke to did not like the idea of a gift of life because their relative had not died in order to become an organ donor. They also did not feel that their remembrance of the donor was directly connected to the organ donation decision; instead, organ donation had come after the death of the person.

The term legacy can accommodate something that was given after a loss. The etymology of the word legacy comes from *legacie* meaning "*the body of persons sent on a mission*"(Online Etymology Dictionary, 2024). The origin of the word aligns quite closely with what goes on in organ donation – the body of the donor can be understood as being sent on a mission to help save or improve the life of a recipient. The emphasis from an etymological perspective is on the intention of that mission, the cause that is being assigned. A further etymologically related term *legatia,* linked to the latin word *legatus* means "*ambassador*" (Online Etymology Dictionary, 2024). In that sense, the notion of legacy can be linked to someone being in support of a cause or giving their body to a cause. The role of the donor here would be to give their body to a cause directly, but the deceased-donor relatives are also involved under English law, as they must be the ones to allow the body to be given to the cause. Because the legacy is very much about the attention or causes behind the action, the term creates some detachment from the need for a successful outcome for the term to be applicable. Organ donation can still be part of a legacy if the mission to give the body to the cause was ultimately unsuccessful. In the colloquial use of the term legacy, the term describes "*a situation that has developed as a result of past actions and decisions"*. The term is quite broad and leaves much room for interpretation – a situation that has developed or continues to develop can be something others can become a part of. The legacy of someone who became an organ donor can include the decision of the family to honour that decision and their later work in advocacy; it can include the actions of recipients who are able to do things as a result of the donation. Notably, the term can be opened up to these contributions that are external to the donor's role, but these elements do not need to be included for the term to be relevant. In reference to the findings of this PhD, the donation as a legacy can accommodate the transplant community – multiple different people working together to expand and protect a legacy or recognise its value. Of course, there are multiple alternative characterisations of organ donation that can sit alongside the notion of legacy that is described here. Including the idea of a legacy in organ donation campaigns and discourses constitutes merely one way of many possible options to broaden donation discourses. Crucially, the idea of organ donation as a legacy left behind attributes the roles of the different parties involved less firmly, allowing a wider breadth of different transplant identities to be represented and expressed in interactions between members of the transplant community.

7.7 Conclusion

The Donor Family Network Memorial Event and the British Transplant Games run by Transplant Sport are two examples of events that have been organised to welcome attendees into the wider deceased-donor relative and transplant community. Where experiences of loss and donation-related anxieties can cause uncertainty and a sense of isolation among deceased-donor relatives, both events create spaces that are intended to help relatives understand what their decision to donate meant. Simultaneously, they offer acceptance and solidarity in the grief experienced by deceased-donor relatives and want to allow a climate of mutual understanding based on the shared experience of having been impacted by organ donation in a meaningful way. In this sense, these spaces are intended to give people a break from the social norms and conventions that may cause them to hide their grief or not address their loss in a way that is intended to feel therapeutic and reassuring. Additionally, the British Transplant Games, in particular, help give flesh to the otherwise anonymous and imagined counterpart involved in the organ donation process – the transplant recipients. The use of symbols casting donation in a positive light is intended to give closure. Events like the Games and the memorial ceremony in the minds of some manage to give flesh, face and story to the preceding anonymity, by peeling it back slightly but also opening it up into larger groups and people less bounded by biological connection, they aim to create a space with a sense of belonging and coexistence.

The British Transplant Games act as a space where donor relatives and recipients in the transplant community can come together. Transplantation, which can act as a reality-disrupting experience, either following a loss on the donor side or the transplantation of another person's organ on the recipient side, can be reclaimed as a positive in the lives of both deceased-donor relatives and recipients, despite its complexities. The British Transplant Games provide opportunities to build a connection routed in abstract ideas of gratitude and mutual recognition for deceased-donor relatives, where the donation of the organ as a gift is symbolically presented as the thing that made the Games possible. Simultaneously, playful performances of exchange during the Games begin to make the abstract relationality promised by the gift of life narrative real. As donor relatives and recipients continue to spend time together, at the Games and in private instances of donor-relative and recipient contact, they get to know one another as people and begin to appreciate the personal struggles and complexities the other is experiencing. Through these experiences, the sense of complete anonymity of the other party involved in the donation is slightly peeled back, giving the respective parties an impression of why the biologically connected deceased-donor relatives or recipients may not feel able to communicate. This often leads to a deeper appreciation for the other party's strength amid great challenges and introduces meaning into a previously unclear and, at times, unsettling relationship. The British Transplant Games only happen once a year and are a lot less publicised and known about compared to events like the Paralympic Games[7]. Because the Transplant Games are a charity run, relatively few deceased-donor relatives know about them, and even fewer benefit from the capacity

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[7] Sporting event modelled after the Olympic Games which holds competitions for disabled athletes

of the Games to introduce greater tangible meaning to the deceased-donor relative-recipient connection.

Under the veil of the opening ceremony and more minor acknowledgements of the meaningful connection between recipients and donors of the gift of life promises, the Games provides opportunities for members of the two anonymised sides to hear powerful stories about how the other side feels. The opening ceremony is akin to a performative dialogue between the two sides intended to guide interactions between the groups at the Games and in life in general. From the beginning of the games, the discourses do not avoid the complexities and struggles experienced by both sides. Instead, they acknowledge what deceased-donor relatives and recipients have gone through but emphasise the resilience that all members of the community have shown and the mutual support that is available. The British Transplant Games are full of more organic opportunities to express mutual support and appreciation that can bring closure to both donor relatives and recipients, creating opportunities for participation and contribution for deceased-donor relatives to the "*legacies*" that the donors left behind. Being a part of a community and being able to experience the anti-structured space the Games provide gives deceased-donor relatives a sense to develop a sense of what their decision to consent to organ donation meant to themselves and others. Additionally, it provided them with a space in which they could share stories about the deceased donor and the loss they experienced in a positive context, in a way that the social conventions of their daily lives did not permit.

8. Sharing One’s Story and Educating the Public

8.1 Introduction

Once deceased-donor relatives decide to join the transplant community, they think more about the impact the experience of organ donation had on them, the desire to share their stories and join volunteer donation education and advocacy initiatives can emerge. Having become aware of the role volunteer-run organisations play in donation promotion and advocacy or having become invested in one’s role as a deceased-donor relative can increase the willingness to participate in advocacy. NHSBT strategies on donation welcome this desire and, more generally, strategies by the Department of Health indicate that communities and members of the public should feel increasingly empowered to share their own stories in public spaces (Department of Health, 2011). The trends towards individual and community responsibilisation trends discussed in Chapter 5 about neoliberal support provision to deceased-donor relatives thus also surface in donation advocacy and promotion (Rosol, 2012; Jugović Spajić, 2020; Small, 2023).

To understand this development, it is necessary to consider what possible effect the telling of one’s story can have on deceased-donor relatives. This short vignette has been written reflexively on the basis of accounts by my interlocutors about what it was like to share their experience of organ donation with others. The vignette draws out the different ways in which my interlocutors felt it helped them get used to recounting how they became deceased-donor relatives.

For a long time, you felt powerless after the loss of your relative. You found yourself looking for different ways in which you could have spent more time with your loved one in the days and weeks before they died, you wish you could speak to them again. Thoughts of them are in your mind everyday and you worry that if you expressed them outside your family, they would make other people feel uncomfortable because other people never seemed to know what to say to you when you brought up your loved one. You want to talk about the decision to donate and think more about what it meant to you, you feel you have a lot to process but you know that the rest of your family does not feel ready to speak more about this topic – they still feel very overwhelmed. Last weekend, you visited the British Transplant Games, and found an unexpected opportunity to speak about your relative when you tentatively introduced yourself to other donor family members you met at the events. It felt strange at first to speak to a group of strangers about something so personal that you had scarcely spoken about in your own home after the day of donation. When the faces of the other donor family members moved with sympathy and interest as you shared what organs you had agreed to donate and when the donation happened, your *concerns eased. Encouraged, you shared that you did not know whether your relative wanted to be an organ donor when you had to make a decision, but that they were always a kind and generous person who would have liked the idea of being able to help someone. Your conversation partners nodded and smile in agreement, for two of them, your explanation resonates. You learned that they consented for similar reasons. Quickly, they pointed out that the organ recipients rushing back and forth between competitions around you as you stand in their midst and chat were there because they received the same kind of help you gave someone on your relative's behalf. In the conversation that followed, speaking about the kind of person your relative was felt comforting and natural. You did not stay for long because you found the experience overwhelming and new at first, but you are glad you went. The event sparked a new-found curiosity about organ transplantation in you. You were impressed by the resilience the recipients you saw competing and touched by seeing their relatives cheer each other on. You think that your relative would have wanted to help them and to give others like them the same opportunity for a life-changing transplant. Suddenly, you wonder whether there is a way that you could do more to help recipients in memory of your relative…*

The vignette provides an example for one set of circumstances in which sharing the story of one's donation experience in the transplant community can begin the process of thinking about the death of the deceased in a new light through finding opportunities to recount the donation narratively. In Behar's work, the potential of narrative for shaping individual and collective identities is emphasised, particularly in storytelling and how subjective experiences are differently recounted (Behar, 1996). She shows that narratives can powerfully develop understanding. In the context of organ donation, the telling of one's story has been highlighted as an opportunity for healing that can help display the death of the donor in a more positive light, because the positive effect organ donation had can infuse an otherwise senseless loss with a degree of meaning (Simpson, 2001; Árnason, 2020). Additionally, the act of engaging in a show of solidarity with organ recipients or future recipients in need of a life-changing transplant organ can feel like the individual is a meaningful part of the wider transplant community (Behar, 1993, 1996). In this context, I have noticed an emerging trend in the public sharing of a bereavement or personal hardship since moving to England, namely the tendency for individuals to share their struggles publicly when they are engaging in a charitable fundraising effort to support a community in need they have some connection with. Courpasson and colleagues have shown in their work that there are instances where neoliberal responsibilisation trends that drive cost-effectiveness and place a higher demand on communities and result in the desire of communities to take back control and to band together in support of one another (Courpasson, Younes and Reed, 2021). However, when charities, non-governmental organisations and other groups that act as intermediaries between members of the public and official organisations take on the responsibility of facilitating public health education, this can be met by an increasing fragmentation risk that can make sense of national universal solidarity more challenging to establish (Coderre-LaPalme, Greer and Schulte, 2023). While the need to emphasise the potential of volunteer efforts to address global health disparities and to lift up communities through advocacy has been highlighted (Farmer, 2003), concerns about the potential negative implications of volunteerism in health education that need to be reflected on have also been raised (Mitchell and Marnie, 2018).

Efforts to raise awareness of the newly deemed consent law in social messaging campaigns have struck a positive tone and shared individual stories, mainly to raise awareness of the need for more donors from ethnic minority backgrounds. However, concerning responses that placed excessive blame on members of these groups were one of the unexpected and unwelcome consequences of the stories shared (Faherty *et al.*, 2022). Consequently, community mobilisation in donation education and particularly the opportunity to engage in advocacy work championing the transplant community are among the positive elements of the life after loss some of my interlocutors build themselves. This chapter addresses the healing potential in coming to terms with the donor's death and establishing a sense of belonging for deceased-donor relatives among members of the transplant community. Simultaneously, it illustrates the risks associated with increasingly volunteer-run organ donation education and promotion.

8.2 The role of stories in public understanding

The Organ Donor Ambassador Programme organised by NHSBT works with trained volunteer ambassadors who are given information materials to act as a volunteer public information workforce. Chapter 3 outlined information on the rationale behind the founding of the Organ Donor Ambassador Programme and stressed that one main reason it was set up was to educate people nationwide about the change in the organ donation law. Chapter 3 stressed that the power of personal stories from the people who have lived experience were highly valued by NHSBT, and that they greatly appreciated the volunteers who shared their stories to educate the public about organ donation. Additionally, it touched on the ways in which the ambassadors are semi-professional volunteers who provide a highly compelling low-cost opportunity to make progress in promoting conversations about organ donation amid resource shortages in the health service. To ensure ambassadors communicated an accurate and positive message aligned with official narratives about organ donation, they had to undergo some "*initial training*" and some "*additional training*" run by NHSBT. For many of the deceased-donor relative ambassadors, the law change seemed like an opportunity for conversations about organ donation to become a topic of higher priority in the public health discourses driven by the government.

Recent training included material to prepare ambassadors to speak in schools to educate pupils about organ donation, because organ donation had become a part of Key Stage 3 and 4 in England[8], and ambassadors could now be invited to come to schools to provide this training using NHSBT-designed materials for teachers. When Keith and Tim[9], two of the ambassadors whom I had met, first told me about this change, they were very excited. They explained that speaking about organ donation had now become a mandatory part of the school curriculum. Indeed, a statement by Alex Cullen, the head of marketing at NHSBT, announced that NHSBT were delighted that donation had been made part of the national curriculum because young people made "*such a difference*" and could become "*lifesavers*" by encouraging others to donate. They wanted to consider "*the types of donation*" as part of a "*rite of passage to becoming an adult*" (Blood.co.uk, 2021). Young people who became interested in donation due to this change were expected to potentially become influential advocates for organ donation. However, as Keith and Tim later realised, the change meant that discussing organ donation had merely become one of the possible topics that could be addressed and was not mandatory. Neither of them knew of an ambassador who had been asked to speak about organ donation in schools during our conversation in July 2023.

> *Organ donation is now part of the curriculum in schools, but it is still not mandatory; it is in competition with other general education subjects on the curriculum. When speaking to people, often everyone thinks they are on the register now (because of the opt-out law). It has muddied the waters rather than made it clearer.*

Based on their experience of speaking as ambassadors, Keith and Tim expressed doubts that the change to a deemed consent law had clarified the process among members of the public. Both often found that they needed to correct misconceptions or misinterpretations about the transplant process when they spoke to different people. They each expressed that they enjoy working as volunteers to provide this clarification and to discuss what organ donation has meant to them. Tim explained that he was an ambassador because organ donation was important to him.

> *We are here because we want to be – it is very rewarding, we would not want to be paid.*

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[8] The learning materials are intended for students in year 7 to year 11. Additional information on what is covered by the materials can be found here: https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/donation-teaching-resources/

[9] I cannot provide additional information on who Keith and Tim are in relation to their ambassador role as this would compromise the degree of anonymity for both.

> *Being an organ donor or donor family member provides a chance to give something back – I value any opportunity to promote it (organ donation). Many people have misconceptions, I tell people "look into organ donation – you can still be donors if you have a health condition"*

Tim was very proud of what he does and explained that neither he nor many other volunteers would be comfortable being paid for something they are passionate about. He knew he convinced many people to register as organ donors and found his advocacy work very fulfilling. Tina said the chance to talk about the donation was especially meaningful for deceased-donor relatives like herself.

> *I think the ambassador programme is a positive experience for donor families. In a way, ambassadors and trustees of the Donor Family Network are all actually keeping the memories of our loved ones alive because we are using our experience in what we hope is a positive way. Inevitably, by talking in that capacity, you are sharing your story. When I speak to people, they need to know that I lost a child, so in a way, you are always keeping their memory alive.*

She feels that different examples of advocacy or education work, inside and outside the programme, create opportunities for the donor's story to be shared, allowing her to keep the donor's memory alive. Tina's comment indicates that telling one's story over and over again gets deceased-donor relatives used to discussing the donation and helps them reflect on their experience.

One of the things that can make the death of the person very difficult to talk about for the deceased-donor relatives is the fact that the person died in a way that was considered a bad death. For example, they might have died too soon, younger than expected, after a violent accident or otherwise unexpected incident, and the death of the donor frequently came as a shock to my interlocutors (Árnason, 2020). To understand this phenomenon, it is helpful to draw on the idea of canonical narratives. Research on canonical narratives suggests that the analysis and development of narratives can help the people recounting events reflect on a particular event and their role in it, and by repeatedly revisiting the issue, allows them to form a more sophisticated sense of how they were affected by the event (Emerson and Frosh, 2004). Consequently, re-telling of the donation story and what happened and what it meant, characterised mainly by the positive impact of the decision to donate, can allow people to arrive in a more comfortable mental space when thinking about their loss. Initially, adverse or demanding circumstances can be reflected on and adapted until a comfortable moral space is discovered in an increasingly established narrative (Simpson and Douglas-Jones, 2017). Research on deceased-donor relatives in similar situations has differentiated between the activities of meaning-making and adapting, seeing the death and the processes involved in it differently depending on whether you are an individual or a collective and whether or not you feel conscious of the attitudes of those surrounding you (Silverman, Baroiller and Hemer, 2021). This process combines a sense of care and compassion from a personal connection with volunteer work in neoliberal informal care systems (Hoffman & St. John, 2017). Volunteering to promote something "*good*", like organ donation, can sometimes be seen by deceased-donor relatives as an opportunity to do something positive to take back control after the experience of the loss.

For example, efforts to "*find all the positives*" were central to Isabel's response to the loss, and she counted every opportunity to engage in advocacy or to lend the insights she had gained through her experience that now made her an "*expert*" about deceased organ donation of sorts as a positive. Volunteers are beneficial as a part of the health workforce that operates between the professional service and the public community because they are seen as connected with both and can generate significant symbolic meaning and a sense of representation (Morris et al., 2017). In this sense, the Organ Donor Ambassador programme is part of the general trend within the government strategy communicated by the Department of Health in 2011, which underlines the desire to "*nurture and release the capability, capacity and assets that exist within our communities*" (Department of Health, 2011, p. 6). Here, the personal stories of people affected by organ donation have been semi-formally incorporated into official government communication, lending themselves to promoting organ donation and seemingly serving as a chance for community representation. However, the frustration about the limited impact of both the new organ donation law and limits to how mandatory conversation about organ donation has become indicates the limited control over the processes governing both donation itself and the information about how the processes involved unfold. Regarding the positive potential of discussing one's experience with others, deceased-donor relatives and other ambassadors cannot exclusively share their stories in line with the guidelines they are asked to follow as ambassadors. If they discuss the donation story independently and not as a part of a wider organisation, the freedom on what aspects of the process to highlight may be more significant, and the benefits of the re-telling of narratives can be similarly high.

8.3 The Organ Donation Ambassador Programme

As described in the introduction of the programme in Chapter 3, ambassadors are encouraged to consider their objectives and those of the ambassador programme in communicating. Therefore, there are instances where the statements they make may be different because they are made in the capacity of a person as an ambassador rather than only a donor relative, as Keith explains.

> *It can be tricky to know what hat to put on – the ambassador hat or the donor family hat.*

Additionally, Maggie feels that the programme responded to a need that was already known to and being responded to by specialist care staff in hospitals in the past.

> *Donor families have done it all along, and recipients have done all sorts because they are so grateful and know that the public needs to know because people die waiting. So all the joe publics who have been touched by a donation and transplantation have always been very keen to share. So it has been going on for many years but not through the national agency, the government agency whose job it is to sort this out. So now they have us lot for free and they had us lot anyway. So when I did my one day's training it was quite funny because when I got my certificate it said Organ Donation Ambassador but I had been doing that anyway all my life talking about it. It is a long title, and I am not a title person. So I think it is funny I have a name badge that says Organ Donation Ambassador.*

Maggie highlighted that in the past, before the government created a dedicated programme for the sharing of donation stories, it was common for many of the people involved in transplantation to work as volunteers and raise awareness. In her eyes, the main thing that changed was that ambassadors now did so following the framing of the programme in more official terms and with an associated title.

> *But to be honest, we did so much education of the public for years; it is just the simple thing that we need to educate the public because those are the persons that sit next to the bed in intensive care when you go to ask for their consent and you will notice that when they don't understand it, it is very difficult to discuss that and discuss their wishes because their loved on did not know their wishes. In the old days, they used to educate the public, they used to go to schools and the different groups, and because it is the public who are the donors – so if you do not educate the public you are not going to have donors. It is fairly black and white to me. But NHSBT, in their "wisdom" at some point, stopped all that, so they just had to educate hospital people. This is them now realising – saying this is what we are doing, and we like all these good stories, these real-life stories of people who have been ill and who have now had a transplant, all because of the donor and the press. Yes, it is so simple, and it has taken them years to work it out.*

Maggie was in favour of the idea that volunteers need to educate the public and explained that in the past, there had been programmes to tell the public about organ donation until that initiative was stopped and charities took over that role. She explained that the same people who have now been asked to come forward and work as ambassadors were already working as advocates in different capacities and having those rewarding experiences because they chose to share their stories. Now that the programme had been brought back, she felt that the activities of existing advocates were merely rebranded in a sense.

> *But NHSBT, which is a government agency, and they are all paid to do this job, they are not doing it. So now they have worked out we have to somehow teach the public. So they have this Organ Donation Ambassador programme that they started, and we do it for nothing, but we will go and have a stand outside and educate the public.*

While Maggie was happy to be an organ donation advocate and to engage in advocacy for free, she thought that the idea that NHSBT acted as the initiator of the advocacy itself was strange, considering that most ambassadors were already working in a similar capacity before they joined the programme. All the ambassadors I spoke to were proud of their work and would not want to have accepted any payments because they deeply cared about organ donation. However, there was little transparency on how they had been recruited and how the recruitment of new ambassadors would work in the future. This raises questions about the diversity of the programme and the insights it represents – the voices of a smaller number of representatives are frequently amplified in organ donation messaging, but the full breadth of perspectives is not consistently being represented.

For example, some ambassadors were aware that others also had a "*transplantation story*" to share but would not be able to do so on a volunteer basis, for example, because of time or financial constraints. Furthermore, some were reportedly reluctant to lend their personal story to the purpose of free donation promotion for NHSBT, because although they were happy that they consented to organ donation, they worried their story could be instrumentalised in some way.

> *Some people choose to engage in advocacy on their own terms – they don't want to speak to a charity; they want to control their own story and their narrative – they are worried that if the story was used by someone else, they would focus on something it is not about. Some people from other organisations who educate the public about organ donation ask for money because they say, "Why should I be exploited to educate you?"!*

The "*real-life*" stories that are used as powerful tools to communicate information about organ donation are coupled with the NHSBT communication aims when ambassadors are trained. Most of them do not feel restricted in what they share, but they know that they may need to phrase some things in a particular way if they speak on the NHS's behalf. That is something that others are not comfortable with, preparing to speak through privately created channels, where they have greater control over the way their story is used. The widespread existence of social media communication channels broadens the opportunities to do this. Many would only share their story, if they were being renumerated for it because they do not view volunteer work to educate the public on behalf of the NHS as appropriate and feel that they have already done a lot to support the transplant service. NHSBT has pushed for the sharing of accounts that explain how knowledge of the deceased's donation preference having had helped relatives make a decision, or how not being certain had subjected them to additional strain. This is because personal stories about organ donation shared on social media and mainstream media platforms have been shown to have greater resonance and a more powerful persuasive effect on members of the public (Shi and Salmon, 2018).

8.4 Promoting organ donation through regional, ethnic and faith-based communities

There is an emerging trend in the overall shift towards neorealist approaches to healthcare which is evident in emerging programmes to promote organ donation education: a shift to appeal to regional groups and faith-based communities. The rationale for community-targeted outreach is explained in the government strategy. The three main arguments in support of such an approach are the notion of "*voice and control*", which views community-based programmes as opportunities to give people a greater say in their care provision; "*equity*", which is said to reduce inequalities by mobilising community resources and energy; and "*social connectedness*", which is meant to be promoted through community-based approaches (Public Health England, 2015). Providing funds or vocal support to community-based initiatives and working with them allows the health-service to reduce costs. Additionally, it is thought that programmes can be more likely to work if they are "*sustainable*" and delivered using resources already available. There is also a presumed chance for the health service to better understand the needs of communities. Regional and faith-based initiatives have recently emerged to help prepare their members for the possibility of becoming an organ donor. The example of the Yorkshire Donor Card launch, which happened at the British Transplant Games in Leeds in 2022, and the NHS supported work the Jewish Organ Donor Association has done so far illustrate these trends.

The community that gathers at the Transplant Games is often encouraged to help promote organ donation through community initiatives. The space to do so and to stage introductions for these initiatives is similarly made possible by charities and sponsors, like the Games themselves. When I was working on the track field, in front of a section of stalls for spectators filled with competitors and supporters at the 2022 Games in Leeds, we were informed that we would need to keep the supporters from running onto the field, as there was a "*big surprise*" on its way to the pitch in the centre. Once we had cleared the area, an announcement was made over the speakers. The "*Yorkshire Donor Card*", a local initiative that encouraged individuals to pledge to speak to their families about their organ donation preference, was to be launched. A large version of the card would be flown in on one of the helicopters from the Yorkshire Air Ambulance. Soon after, the helicopter appeared in the sky and descended onto the field, the noise from its propellers falling just short of completely drowning out the enthusiastic cheers that had erupted from the spectators watching from the stalls. Once the helicopter was landed, a group of representatives from different transplant charities and NHSBT present at the event approached the aircraft to collect the Yorkshire Donor Card from its pilots to emphasise the importance of the initiative and its intended benefits were outlined over the speakers (Yorkshire Times, 2022). The Donor Card was celebrated as a legacy of the community of the Games and its efforts to promote conversation and raise awareness about organ donation to increase rates of consent in the UK. The sporting event, in this case, was used to recruit the personally affected potential advocates for the Donor Card initiative who were in attendance and used them as a symbol of the good donation can do. Here, the people affected by a health need who hope for a rise of rates of consent to organ donation because it could have helped them, someone they were close to, or might be needed to help them again in the future are being mobilised as health advocates. The launch appealed to regional

Figure 18: The Yorkshire Donor Card is being introduced at the Games in Leeds

identity, to the notion of taking action as a community, to help others in the community. This does not reflect the reality of donation, as the place where an organ is donated is not necessarily the place where a person came from. Nevertheless, there was an assumption that locals may be more likely to take an interest in the initiative, if they feel it is part of their regional identity. Here, a person's connectedness with the people they are surrounded by and the place where they live is being used to produce a sense of responding to the responsibility to discuss organ donation for the people of Yorkshire.

The approach for the initiatives promoted by the Jewish Organ Donor Association (JODA) is different in that it appeals to religion and cultural identities. I draw on this organisation's work to highlight opportunities for future research into the way different organisations beyond groups like the Ambassador Programme and the attendees at the Transplant Games are being mobilised to encourage conversations about organ donation. While an in-depth exploration of the questions that arise is beyond the scope of this thesis, the material discussed raises wider questions about the way in which collaborations between third sector organisations and the health service drive particular narratives and direct the emphasis for change in particular directions. I reached out to several organisations who promote conversations about organ donation among members of their religion or community group and received a response from JODA.I had a conversation with one of the founders where I learned more about JODA's mission. He explained that he became interested in organ donation after the law changed, because of his background in marketing – he was intrigued by the way nudge theory and behavioural change theory seemed to play into the campaign approach. He gradually became more interested in volunteering and became curious about the reasons why people did not donate. When his rabbi held a talk about the permissibility of organ donation in Judaism, he was interested to hear that the rabbi interpreted the guidance of the teachings in a more nuanced way than he expected. Eventually, he and his co-founder decided to run a survey about organ donation attitudes among Jewish people living in England. They received a very large number of responses, from around 15000 Jewish people and were struck by a high willingness to discuss the subject alongside a high prevalence of misconceptions.

The results of the survey were shared at the British Transplant Conference – the organisation was then awarded funding by NHSBT to continue its work. Additional initiatives included a Zoom-based discussion later shared on YouTube, to raise awareness of the topic of organ donation and to encourage others in the community to discuss it. Long-term development goals that have since emerged include educational programmes targeting young people and tactical campaigns. As part of those campaigns, the NHSBT messages on organ donation were also being taken into discussions within Jewish Communities. This was a change to "*test social marketing messages*" in the market. One of the organisations preliminary findings was that tailored messaging worked well, but that some communities should not be approached, because they have their "*own independent way of doing things".* In some spaces, JODA does not feel it has the authority to comment – for examples, they do not target the Haredi community. Instead, JODA are trying to help "*the mainstream liberal to modern orthodox base*" to better understand the law and its implications for Jewish people – because JODA feels it can understand that community and is better positioned to communicate those messages. Even within that mission, the advice JODA gives is centred around medicine and the law, and the language used reflects that. JODA are keen to "*not use religious language"* because they are not qualified to do so, they only challenge misconceptions from the medical perspective. The only way in which religious authorities are involved is in a dialogue with the founders – JODA wants to ensure it is supported by the religious authorities and the founders try to be as well informed as possible. The statements by the founder implied that more liberal takes on the religious tradition viewed organ donation as a virtue in the sense that it was a selfless way to relieve the suffering of others. However, he implied that orthodox groups like the Haredi Jewish community adhered more strictly to their requirements for correct burial practices and were reluctant to compromise the completeness of the body. For JODA, negative feedback was usually used as a chance to create a dialog – a discussion of different views and an increase in conversation is the central aim. Additionally, the founders received help from advisors from other communities who have spread a similar message and can provide guidance, such as the need to take into account the structure of different communities. By doing that, JODA used the fact that the "*Jewish community is slightly more centralised, making it easier (…) to navigate. Different communities in the country are also characterised by different levels of trust in the government".*

JODA wants to help ensure that communities have the necessary resources to speak with their families and friends about organ donation - – funding grants through the NHS are thought to be a helpful way to achieve this goal. Here too, the members of a community are encouraged to take the initiative to speak to people who are part of that community. There is a belief that Jewish people speaking to other Jewish people and communicating some of the NHS information/encouraging conversation, is likely to yield wider reach of the organ donation education message. The emphasis is placed on finding out what the community attitudes are and how they could be changed and improved. The response to lower rates of organ donation among community members is to encourage community members to educate themselves, the likelihood of success in attempts to do this is thought to be higher if people "*speak to their own*". Importantly, there is funding support available from the NHS to help achieve this.

However, the notion of representation can easily be oversimplified, which is why JODA's co-founder stresses the need for the association to not presume to speak from a Jewish religious perspective or on behalf of all Jewish communities. According to the Department of Health, community representatives often have a more sophisticated understanding of what their members need and how support can best be provided (Department of Health, 2011). Authentic personal stories and a willingness to act as a representative or intermediary exchanging information between the general public and professional bodies can happen through semi-professional routes and public organisations. The discourses that are situated around personal responsibility and personal choice are increasingly no longer being led by the health service, but by intermediaries. The network of regional, faith-based and national charities, community organisations and semi-professional organisations are complex, and more research could be beneficial to help unpack how rhetoric flows between the different organisations. This opens up questions about whether this trend drives an implicit responsibilisation of people who are being grouped together based on characteristics such as religious beliefs, ethnicity, or the location in which they live. Further research is needed to determine whether there are inequalities in terms of the internal resources, time and energy, readily available in different communities. Additional research could reflect on whether it is appropriate to task with a higher burden of disease that leads to a greater prevalence of the need for transplanted organs with raising rates of consent. In some cases, there may be a risk for such a task to place a disproportionately greater burden on groups with lower resources and higher levels of transplant need, and future research could investigate the reasons behind the greater transplant needs among people from minority ethnic backgrounds. If funding and support are made available by NHSBT to provide support with the task of raising levels of donation awareness among particular groups, transparency is needed to demonstrate how the support allocation was determined and why, to ensure that health inequalities are reduced and not amplified by such initiatives. Additionally, a more transparent structure could help members of the public navigate different sources of information and support as well as understand through which avenues they can contribute their own views to the conversation. At the moment, both the messaging providing deceased-donor relatives with information on avenues through which they can share their stories and different advocacy groups point to a trend towards multiple different fragmented support sources. Through this process, questions about the validity of extrapolating information about parts on the transplant community shared by the intermediaries onto the whole become increasingly pressing for researchers to address. Where advocacy and representation become the responsibility of intermediaries who have the capacity to work on a volunteer basis, underlying structural issues that would usually be the responsibility of the government to address can fade into the background (Farmer, 2003).

8.5 Conclusion

In a fragmented neoliberal system of donation advocacy and communication, the need for organ donation conversations is being pushed by different kinds of representatives - local representatives, faith representatives, community representatives and deceased donor representatives. This is because of an assumption that these people have extensive knowledge or that they can lend particularly persuasive accounts to the promotion of organ donation. For some deceased-donor relatives, the opportunity to be proactive following their loss and to find a cause in speaking about their donation experience that allows them to move forward is a positive experience. Upon first contact with other people impacted by transplantation, many of my interlocutors expressed a sense of relief that they had been provided with an opportunity to speak about the donor or about the way the donation impacted them. Where donation and the donor were not a topic that was ordinarily brought up outside their private lives, more public forums for opportunities to recount their experiences or to remember the donor in light of the donation provided a chance to come to terms with the loss. Gradually, some became more used to talking about what had happened and were able to receive advice or engage in mutually supportive exchanges of the ways in which donation impacted them. Importantly, such opportunities to construct narratives that were more familiar and less painful to recount about the donation experience over time existed in and outside the work on official programmes such as the Ambassador Programme. Where donor relatives and other people with lived donation experiences did begin to work as donation advocates, there was limited transparency of how they were selected and prepared for the role. Additionally, many deceased-donor relatives recounted how difficult to find the initial access points into spaces where they could share their stories were, and that they would have not had the opportunity to do so had they not had the personal capacity and taken the independent initiative to do so. This is because the organisations and events that provide relevant opportunities were dispersed and regionally fragmented. Support is somewhat decentralised and utilises non-governmental, charitable and semi-governmental communication channels that form a patchwork, which can at times limit the transparency of the system for people wishing to access it. In particular, there is limited clarity concerning the completeness of the different perspectives that are being represented.

The material from my fieldwork and contextual information shows a disconnect between donor relatives' expected needs and motives for donating that dominate donation promotion discourses and their lived experiences throughout the donation process. Importantly, the number of donor relatives I spoke to was relatively small; almost all of them were put in touch with me with the Donor Family Network acting as an intermediary, and they were all from similar backgrounds. Despite this, their reported experiences were much less heterogeneous than donation care guidelines suggest. Conversations with donor relatives about their reasons for agreeing to organ donation showed that the consideration that impacted the decision could rarely be predicted based on the ethnic group or age of the donor, nor religious beliefs, although in some cases, ideas about the afterlife came into play.

Consent to donate did not equate to support for the transplant process or necessitate a willingness to promote organ donation when speaking to others. Given the tendency of organ donation information materials, promotional campaigns and process guidelines to simplify the donation process, the establishment of initiatives like the Organ Donor Ambassador programme could be seen as positive instances of the diversification of donation stories that are told. However, this effect is reduced in the minds of some by training ambassadors to speak on behalf of NHSBT, using similar overall messages, and by a lack of transparency into who is given a chance to become an ambassador. The reliance on volunteer work in multiple aspects of care provision makes it difficult for people who cannot work as volunteers because they do not have the time or financial resources to communicate their perspectives. Furthermore, some people do not have the willingness to volunteer because their experiences are not optimistic enough to help promote organ donation. The emphasis on volunteer work and community-based advocacy could lead to inadvertent fragmentation. More research is needed to establish the presence of structural factors that contribute to the variations in donation need and rates of consent to make an analytical move beyond community responsibilisation. While the sharing of one’s story to educate members of the public can help deceased-donor relatives reflect on the death and come to think of donation as a positive thing that counteracts the memory of a bad death somewhat, the way in which proliferating intermediary organisations amplify voices needs further research. A better understanding of the diversity of different perspectives and information preferences about organ donation could reveal novel concerns and dimensions in the donation experience. Such details may be missed if the same largely positive themes are publicly emphasised.

The increasing push for minority groups who have statistically higher needs for donated organs and lower rates of consent to mobilise their communities to create support should be accompanied by research into the underlying reasons for the greater degree of need among them. An overemphasis on community subgroup responsibilisation obscures the need to look at underlying factors and places great demand for action often on a voluntary, unpaid basis on people who are members of groups with lower donation rates. Some people who already supported the transplant service by consenting to donation or who are experiencing health struggles can struggle to find the energy and resources to advocate for themselves. While the initiatives by NHSBT that allocate grand money to community groups to help them with their endeavours counteract the concern over resource scarcity somewhat, additional research is needed to improve transparency about how these resources are being distributed and allocated.

9. Conclusion

My research set out to investigate how the decision to consent to organ donation influences the lives of donor relatives after the loss they experienced. In this thesis, I have argued that the focus of current public health education campaigns has limited capacity to prepare deceased-donor relatives for the experience of deciding about organ donation in hospital. Through close attention to the experiences of organ donation for donor relatives I have been able to highlight the support that is available to guide them through the decision-making process as it is found in England. The research provides insights into the support and recognition which is in place for relatives who consented to organ donation and what is positive and negative for them in the transplant experience. Particular attention was paid to the rhetoric that surrounds organ donation and to what extent these are deemed appropriate. My research has identified tensions between the intended effects of donor relative care and the outcomes and contradictions between reported support needs and support availability.

This project has shed light on the way donor relative support services are co-created by volunteers and charity members who have themselves been affected by organ donation and offered reflection on positive and negative experiences of donor relative – recipient interactions. These interactions frequently occur in the context of terminology describing organ donation which often foregrounds the gift of life metaphor and the narrative cast that it generates for the organ donation process. Volunteer and charity initiatives have been found to make up much of the available transplant related support once donor relatives leave the hospital. This has been linked to a neoliberal trend towards community care delivery and the idea of representative advocacy on behalf of affected parties by intermediaries working with and sometimes around the professional transplant service. The research has shown that the transplant community in England has the capacity to act as a positive and supportive resource that can provide reassurance and closure to donor relatives who reflect on the significance of organ donation. However, much of the quality of the donation experience rests on the personal experiences of donor relatives and their capacity to seek support independently. The intended effects of the various education, care, recognition, support and representation services in place fail to be universally beneficial and similarly helpful for all deceased-donor relatives.

The public health campaigns for organ donation education and promotion frequently emphasise guidance on religious and moral considerations that could play into the donation decision or identify a lack of education on the transplant process as the dominant reasons against consent to donation. Additionally, they frequently assume that the deemed consent law provides reassurance to grieving relatives who are unsure about the donation preference of the deceased. In practice, deemed consent that the relatives are being asked to honour can create the sense that relatives cannot offer donation freely. There is an implicit assumption that relatives who know that the deceased had the desire to donate earlier in life would still want to donate given the choice in the moment – instead, there is sometimes a lingering degree of uncertainty when the moment arises. Despite this, relatives frequently reflect on the characteristics of the potential donor to determine whether they would have wanted to consent but can run into further uncertainty when they are being asked to decide which of the organs to offer up for donation. This can give rise to a sense that some organs may hold significance for the donor in the afterlife, while others may preserve something of the person if they were to be donated. In some cases, the decision to donate is not carefully considered and instead reactive – it can be an instinctive response to the question. Donor relatives can consent because they may feel this gives some purpose or meaning to a death that is otherwise senseless or because they feel donation is the only proactive choice they have left to make. Others, having experienced the feelings the loss evoked in them, are compelled by the potential to spare another person the same experience. For some, moral convictions or practical considerations such as the organ's lack of usefulness for the donor after their death can cause relatives to consent.

Because of the complexity of these recollected experiences, ethnographic research approaches are well-suited to understand how the hospital environment and the context of interaction with staff could influence the decision. Information disclosed when donor relatives are in hospital, including what to expect following organ removal, recipient contact, the reasons why some organs may not be transplanted, and support process is often not well-recollected. The news of the death and the subsequent transplant process frequently mean that information materials and complex procedural information are forgotten. The definition of the death although legally understood may not be immediately translated into relatives' perceptions of the donor body. Often, kinship and authority over other people has become fragmented. Many of my interlocutors felt cautious about the prospect of making the decision the deceased would have wanted and were anxious about whether they had made the right decision. In many cases, the time between giving consent and organ removal is experienced as the last amount of time relative can spend with the donor. The donor's status as a person can be characterised differently in medical terminology used by medical professionals and in the experiences of donor relatives. Additionally, being separated from the body of the donor for organ removal in the hospital environment can be difficult. The hospital environment is not designed to offer bereaved relatives comfort and privacy and can be challenging. Together with the prospect of organ removal it is frequently recollected as traumatising. Fears can be reduced, and discomfort alleviated when hospital staff find ways to align their perception of the donor with the perceptions of relatives – expressions of care and recognition of the donor relatives' needs and the donor "*as a person*" can in some cases be beneficial. Indeed, many specialist nurses and transplant surgeons take great care to ensure they express their respect and care for the donor and their family and are actively involved in the wider transplant community. In the hospital setting, there can be important opportunities to embed demonstration of care and recognition for the donor into routine hospital process. Examples in this thesis include walking the donor to the operating theatre or the closing of the body with stitches that have little bows in them. Where possible, the incorporation of last rites into the transplant process could be a chance to make the hospital experience less dissonant. The introduction of elements of care and support from external support sources such as the Hugga blankets that have been developed by the Donor Family Network create a further chance to express that care. However, organ donation is an invasive process and can be challenging for relatives in any case, although some require very little support. To better understand this, the idea of dividual personhood of donor bodies as they go through the transplant process can be helpful. This is because dividual personhood allows researchers to recognise the contradiction between a body that looks alive and belongs to a person the relative is closely connected to and paperwork that requires that body to be seen as holding a collection of organs that could be used by someone else.

Following organ removal, relatives receive prompt communication about donation outcomes and, if they do not opt out, a gold heart pin to recognise the donation. Symbolic, one-off acts of recognition can be positively received but can also create frustration and a sense that a bereaved relative who has just been through a loss is immediately being asked to publicly reaffirm their presumed support for organ donation in general. In a symbolic sense, donor relatives are included in the recognition of the health service, however, special bereavement support and follow-up meeting with transplant care professionals if so desired are not routinely made available. The health service may send out surveys reaching out to donor relatives to reflect on their experience and the service they used as one of many routine healthcare services the hospital delivers. For bereaved relatives who are navigating the impact the death of the donor had on their lives, this can create a sense of frustration and a lack of appreciation for the impact that the loss had on their life. Frequently, services delivered to respond to grief and self-reported needs of the people affected do not align. In some cases, relatives recall having been offered counselling support that they felt they did not need or received too soon, in other cases, relatives could not access support despite attempting to find it. Support needs are difficult to determine based on the nature of the death of the donor and timescales of grief differed greatly. In many cases, relatives had to take personal initiative to look for transplant specific support and found the Donor Family Network as the only national provider. The provision of support that meets the diverse needs of bereaved relatives is not easy and, in many cases, symbols and rhetoric that are intended to have a comforting effect were met with disillusionment and frustration, highlighting the challenges that support providers must overcome in their attempts to help effectively.

Transplant-related support was frequently needed because the relatives had in hindsight thought of further questions or because they felt that no one understood the way in which the transplant decision was affecting them. Many donor relatives reported feeling comforted by the Donor Family Network support. The helpline, whilst universally recognised as positive, is in English and staffed by volunteers who provide support based on their experience working with the charity and having gone through some aspect of donation process. Those who already consented to donation are the main source of support for others who did the same. Two of the notable reported advantages of the Donor Family Network phoneline are that the people who have been personally affected have a deeper understanding of how others feel and that they can provide ongoing support grounded in community. Attendance at community-run events like the Memorial Ceremonies and online memorial and information resources can reinforce the notion that there is support and remembrance available. However, some donor relatives did not feel the emphasis on grief and loss at the events reflected their own support needs and did not feel comforted by the events because they did not click with the members of the charity. The Memorial Event used some imagery and practices of collective expressions of grief that referenced religious imagery, which resonated more with some donor relatives but was less apt in the minds of others. Here, personal comfort needs, and support preferences are difficult to be universally covered by the support the Donor Family Network provided. However, for many of the attendees, the ceremony was a very meaningful experience.

The use of rhetoric describing organ donation as the “gift of life” as a means of portraying organ donation emphasised the anonymous connection with a recipient. In the experiences of many donor relatives, there was disappointment or frustration about a lack of contact with the recipients of the organs they had donated, or a sense of curiosity of who the people were who had received the organs. For some, a lack of communication from recipients contributed to doubts about the donation decision. The rhetoric intended to comfort served to emphasise this effect in the eyes of some. Simultaneously, the idea of the gift of life presented organ donation as a cure, not a treatment, which gave many donor relatives an insufficient understanding of some of the challenges recipients can experience. Meeting other recipients at events like the British Transplant Games and attending as “donor mums” or “donor dads”, sometimes wearing “Donor Family Network” T-shirts, gave deceased-donor relatives the chance to see the good that donation can do for recipients and recipient resilience. In many cases, the significance of the donation can feel unclear in its impact on the person after transplantation takes place, and the links that are formed to other people. When people affected engage with the transplant community, the transplant connection begins to be normalised and acknowledged through terminology that deceased-donor relatives and recipients use to refer to themselves or others. These elements of connection are expressed positively in spaces like the Games' opening ceremony and the Donor Run that included acts of gratitude, support and recognition for donor relatives felt comforting for many and filled them with pride about the role of the deceased in enabling recipients to compete. The British Transplant Games created a space where many donor relatives positively reflected on the impact of the donation decision on their lives and where a sense of reduced anonymity allowed them to form comforting connections with recipients. Additionally, their attendance at the event was connected to their remembrance of the deceased and for some, being able to openly speak about the donor, their reason for being at the Games, created a positive experience of receiving support from the community. A useful concept in understanding how the generation of positive experience achieved is the notion of "*surrogacy groups*" that appear at the event, where members of one group can feel connected to all members of the other and where closure can be gained by positive interactions with the other group. An increasingly close connection with recipients raised awareness among many donor relatives of the challenges recipients go through and their involuntary reliance on a donor organ. As an abstract image of the other party involved in the organ donation is replaced with a notion of a person as involuntarily involved in the transplant process as the other (donor relatives because a relative died and recipients because of ill health), expectations are frequently lowered and opportunities for mutual support arise. However, here too, a desire to connect with the biological relative that the organ is linked to can persist, or discomfort at the idea that the donated organs can one day fail. The event is charity run and not well-known among members of the general public or donor relatives, which means that few have access to the positive sense of a supportive community they generate. Many of the services that exist for donor relatives after transplantation has taken place are provided by volunteers and charities, and frequently donor relatives take initiatives based on their own experience to help others. While this means that there are opportunities for advocacy and tailored care by people who have been personally affected, and who can tell their stories and reflect on memory of the donor, and while the support that is generated is personable and sustainable, there are several concerns and limitations.

The results of my research suggest that the experiences of donor relatives are more personal and diverse than the dominant messaging can encapsulate, and that people who do not have the financial and temporal resources to provide their insights as volunteers, or the willingness to do so for free, are less likely to be represented. Many volunteers are very supportive of organ donation and want to help the health service wherever possible but would have received the benefits of sharing their story about organ donation outside an NHS associated capacity. The trustees of the Donor Family Network are one group which engages in such activities outside the NHS organ donation education initiative. However, there is sometimes little transparency in how representative impacts are taken into consideration in the development of laws and funding is often made available for projects that have the capacity to reach out to "*hard-to-reach*" groups for organ donation education and promotion. Similarly, the NHS sometimes works with charities and services working to provide support to donor relatives after the transplant process takes place, but transparency and consistency as to what support is allocated could be greater. The greater diversity of accounts of the donation experience within a small group of deceased-donor relatives I have spoken to compared to the dominant themes in public information campaigns suggest that the dialogue about organ donation is currently limited. The dominant rhetoric of the gift of life is well received by some but does not resonate with many others and can amplify a risk of disappointment and confusion relating to the donor relative- recipient interaction or lack thereof. There are alternative ways of describing organ donation that are similarly prevalent in the accounts of deceased-donor relatives who have been through the process, and in some instances less restrictive in their impact on how the process is imagined. The idea of organ donation as part of donor's *legacy* is one of them. Incorporating a wider variety of ways of thinking and speaking about organ donation, emphasising the notion of a supportive and active transplant community and acknowledging some of the tension that deceased-donor relatives can experience could broaden the discussion about organ donation.

Several of the concepts and insights discussed in this study were previously touched on but rarely explored in the contemporary UK context. However, this thesis contributes several novel insights. My research presents an overview of deceased-donor relative sources of care and support and the roles of deceased-donor relatives in the transplant process. This research questions the validity of education on moral, religious and procedural elements of thinking about organ donation in preparing members of the public for having the conversation about organ donation that is widely encouraged. Indeed, a more complete account of how the donation experience might feel for relatives should it arise and the elements that became important when others were in that situation may help prepare members of the public for what to expect. This thesis built on the suggestion that notions of dividual personhood can help unearth the tensions that can exist between the perception of donor relatives of the donor in hospital and the medical jargon used by some hospital staff and legal documents that regulate the process. While some dissonance will likely remain, hospital environments can be adjusted to become more fit for grieving relatives spending final hours with the donor body. There are opportunities to embed novel forms of last rites and expressions of care for the donor when interacting with relatives into the routinised medical processes that exist in hospitals. Additional research could produce details on what such processes might look like, building on the ones already outlined here and used by specialist nurses. My research raises a concern around the delivery of information and the times at which that information is most needed.

Deceased-donor relatives were rarely able to recollect details of what was shared with them in hospital, especially concerning procedural details about the transplantation process or about general information in recipient contact. Similarly, awareness of and access to support services and transplant specific support often depended on personal initiative. Consequently, a central hub of information including visual and auditory information materials and transparent information on the different possible sources of information and support, including regional and local charities would be appropriate. Such an information hub could also include videos by the charities and organisations introducing themselves and what they do and perhaps recipient testimonies and even video footage from the Transplant Games and other events that may be difficult to attend. The current Donor Family Care Service Webpage could be used as a basis for this and expanded to act as more of a window into the wider transplant community for those who need it. An alternative or complementary event/meeting to the existing ceremonies to honour the donor could be set up to introduce relatives to this resource and to answer any additional support needs or questions in-person. This would also act as an act of recognition in support of the charity and volunteer-run services and provide deceased-donor relatives with a wider set of choices. Additionally, such a support hub would not be faith-based and information could be presented in different languages if necessary. The material provided could be presented in multiple different formats to suit different levels of digital literacy and any accessibility needs, including in the form of audio recordings, an app, a website, perhaps a DVD or book. Information would need to be well-structured and easy to navigate. There may also be an opportunity to incorporate a channel through which anonymised feedback could be given in different formats. In the current system, charities like the Donor Family Network that seek to contact deceased-donor relatives to provide support that is not available through the NHS, have to be innovative and imaginative, investing charity resources and relying on personal conversations to introduce information and support materials to deceased-donor relatives. I have introduced the term "*moral navigation*" to encapsulate the experience they face to provide meaningful support based on their own experiences and outreach within the health service as a charity situated outside it, with limited access. The notion of moral navigating underlines the dynamic in play between charities and volunteers and official organisations. This dynamic is generated because of the different degrees of access to information and abilities to change processes among key participants. There is consequently an imbalance of power in what initiatives are possible. If community-based care and neoliberal support systems are intended to be used to support deceased-donor relatives post-transplant, that balance of power could shift to enable them to work more effectively on the support side and invest less energy into attempts to influence and navigate the health service. Such a shift would reduce the reliance on the support of individual supporters within it who can act as access facilitators. Additionally, much of the long-term impact of the donation decision is reflected on along very different timelines, calling into question the usefulness of time-limited and centrally regulated standardised government support provision. Often, questions arise some time after donor relatives have left the hospital setting, and in the current disconnected system there is little that can be done to evaluate what impact donation has on the lives of deceased-donor relatives after hospital contact ends. Such an evaluation could include further research into the effects of the usage of rhetoric like that or organ donation as the "*Gift of Life*" to offer comfort and a positive sense of the organ donation to relatives.

In this thesis I have built on previous critical evaluations of organ donation campaign messaging, identifying some of the confusions and ambiguities that can arise. In particular, I have focussed on the metaphor of the gift and the way that it operates within the donation experience donors, their families and donor recipients. I have identified major conceptual issues arising from the desire for personal connection and narrative meaning implicit in the gift metaphor when it is used as a trope to make sense of the anonymous relations that are at the heart of organ donation. Additionally, the ethnographic accounts have shown that disappointing interactions with recipients or no recipient thank you at all can lead to a sense of incompleteness following the donation for some deceased-donor relatives. In such circumstances, though, I have demonstrated that informal community gatherings like the British Transplant Games, where the roles of recipients and deceased-donor relatives are symbolically acknowledged and recognised through personal acts of connection and mutual understanding, can act as spaces of reduced anonymity. Within these spaces, organ donation can be experienced as something special and positive. Some of the hardships experienced as a result of a loss or a transplant can be openly discussed and understood by others, and the memory of both donors and recipients who were part of the community but passed away is present and part of the legacy of the event. The event strikes a balance between formal celebration of organ donation through rituals establishing its significance and personal acts of spontaneous expressions of support that can result in meaningful connection. The support for a charitable cause can frequently create opportunities for deceased-donor relatives to speak about a loss that they would otherwise not discuss as openly. Through work with charities or private fundraising and advocacy, the donor is publicly mentioned and remembered. Because of this, many of the donor relatives I spoke to for this project found that donation advocacy was a positive experience for them and a big part of their lives after the loss they experienced.

In summary, the overall findings discussed in this thesis demonstrate the impact that a conversation about organ donation with the donor during their lifetime that clarified their donation preference can have upon the relative’s experience of the donation process and its long-term implications. Not being unprepared for the possibility of being asked to donate and having a perceived clear sense of what the deceased would have wanted can help alleviate doubts and provide a sense of agency connected to fulfilling the potential donor’s wishes at a time that is often otherwise characterised by a sense of powerlessness. The reason for the donation comes to shape the donation narrative that evolves in the minds of deceased-donor relatives in the long-term, however, this evolving narrative is also impacted by the way the procedures of preparing for organ removal and subsequent contact with the healthcare system and any direct or indirect contact with the recipients are experienced. The complexities impacting these emerging ways of making sense of the donation are not fully captured in the dominant rhetoric about organ donation that is being shared through health campaign messaging. Current dominant messaging provides a small selection of the many kinds of meaning that donation can assume in the minds of donor relatives, and a more complete account of the processes that take place in the context of different kinds of donation and how they might impact the relative and recipient could be shared. Similarly, more diverse symbolic narratives of assigning meaning to the donation beyond the gift of life could be shared to broaden the rhetoric with alternative ways of making sense of the donation and to reflect the heterogeneity that exists.

Beyond the factors that impacted the consent decision, organ donor relatives can look to the transplant community as a source of support who can provide a sense of community and offer opportunities for mutual understanding and shared remembrance in addition to the further support the NHS can provide. For many, the donation gives rise to further questions or a need for additional reflection to process its implication for the recipient, the memory of the donor and in some cases about whether donation was the right decision. Some struggle to cope with the experience, the shock, the stress and the hurt caused by the bereavement and hope for an offer of additional care. However, further information and support is most readily available during the donation process itself, when many deceased-donor relatives are struggling to process the implications of what has happened and are not able to anticipate the questions and needs that might arise later on. Neoliberal trends of responsibilisation of individuals to fulfil their own care needs and to seek out the support that they need are often at odds with the expectations of deceased-donor relatives, many of whom take a more passive approach of waiting for further information and offers of support. For many, actively searching out sources of information and bereavement support resources is an additional challenge with variable results depending on the circumstances of the death, the donor-relatives geographical location or the characteristics of the donor. For some, the challenges and unmet needs they faced or the strong feelings about donation they developed leads to the founding of charitable organisations and advocacy groups, in which they often find a sense of purpose and an opportunity for rewarding remembrance of the donor, but also respond to a shortfall in capacity for support within the health system. Due to their third-sector status, such volunteer organisations rely on networking and innovative initiatives like the Hugga blankets to spread awareness about their work and to gain access to the people and policy conversations they seek to interact with. The dominant argument for their involvement and the reason why volunteers with lived experience are invited to become part of NHSBT organ donation information campaigns is the volunteer- and health service recognised power and relevance of deceased-donor relatives' stories.

For many of the donor relatives who interact with recipients at transplant events, who learn more about the ongoing health challenges recipients continue to face, or who become aware of expressions of gratitude from recipients, the opportunities to see the positive impact that organ donation can have is comforting. However, despite the overall improvement in health and wellbeing that donation can achieve, donor relatives can face several challenges as a result of the donation. Among these is the hope and search for something positive that can accompany donation which can be challenged when donation cannot go ahead or cannot achieve an improvement in the recipients' life. Additionally, many donor relatives hope for a sense of closure or thank you from the recipients and feel disappointed in the absence of communication, especially when they have no further information on why no communication was received or why recipients may feel hesitant to write. However, the findings in my thesis show that raising awareness of the complexities and variable factors that can impact on the possibility to donate and shape the possible impacts on the recipient and potential deceased-donor relatives would better enable relatives to give informed consent. There is a disjuncture between the heterogeneity of the impact donation had on my group of interlocutors despite the limited diversity of my participants and the aspects of the impact of donation on donor relatives that are widely shared through organ donation information campaigns. Overall, a more complete level of awareness of the donation law, the needs of recipients before and after donation, and the processes that shape the experiences of deceased-donor relatives need to become more widely known to better prepare members of the public for the eventuality of a donation decision. Consequently, research and public health information and promotion messaging need to move beyond an emphasis on the donation decision itself and lean into investigating the post-donation implications of the decision and expanding the long-term support opportunities for deceased-donor relatives in more robust ways. Members of the transplant community frame donation by drawing on diverse symbols and reflect on the decision in complex ways. These symbols and terminologies could be shared akin to a spectrum of perspectives rather than one dominant narrative of the gift of life and may constitute opportunities to create deeper reflection on organ donation both for members of the transplant community and among members of the general public.

My findings have a number of important implications for future research. The most important one is that deceased-donor relatives should not be perceived as a homogenous group whose needs can be managed and supported in universalised ways. It is therefore necessary to re-examine where current messaging makes assumptions that indicate an overgeneralisation and presumptions about donation attitudes that overemphasise the relevance of factors such as religion and ethnicity. The support delivered to deceased-donor relatives is currently reliant on community care provision and service delivery, and a condition of the success of such a management strategy is ensuring that new deceased-donor relatives become aware of the requirement for them to take personal initiative and have help in identifying what sources of support are available. The groundwork to locate deceased-donor relative support opportunities and community settings that this thesis has laid needs to be expanded on to develop a sense of the patchwork of non-professional resources that are available and a more comprehensive understanding of their effectiveness in providing the support and information to deceased-donor relatives that is needed. Ultimately, such research needs to determine whether the trends towards support delivery and advocacy provided by increasingly non-governmental intermediary organisations supported by volunteers, if continued, would offer support that is equitable. Research into the experiences of deceased-donor relatives and the wider transplant community provides a rich tapestry of opportunities for further ethnographic exploration. Such research would benefit from being co-designed with donor relatives and could deepen our understanding of donor relative perspective's which are currently underrepresented in the literature.

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Appendices

Appendix 1: Ethics documentation

Generic Paragraph

"My name is Johanna Thren and I am a PhD student in Anthropology at Durham University. I am writing to you because your experiences and views are relevant to my project. Any information you might choose to share with me will be completely confidential, fully anonymized and stored securely.

I am interested in learning more about the way charities and non-governmental organizations provide support to people who have agreed to donate the organs of a loved one who has passed away. I want to understand how the decision shapes donor family attitudes towards organ donation in the long-term and whether it affects the way the person is remembered or how grief is experienced. Beyond that, I am interested in anything else you wish to share with me - it has come to my attention that research is often prone to focusing on the experiences of donor families on the day of donation and less so in the months and years that follow. My project aims to change that.

You can share as much or as little as you like. You can contact me via E-Mail at johanna.r.thren@durham.ac.uk, via WhatsApp or over the phone via [redacted], and I would be happy to arrange a zoom call if you would be comfortable communicating in that way. I am looking forward to receiving your message."

Participant Information Sheet

Project title: Charity, Grief and Community in Organ Donation Campaigning – An ethnographic study in England

Researcher(s): Johanna Thren

Department: Department of Anthropology

Contact details: johanna.r.thren@durham.ac.uk

Supervisor name: Professor Bob Simpson, Professor Hannah Brown, Professor Andrew Russel
Supervisor contact details: robert.simpson@durham.ac.uk, hannah.brown@durham.ac.uk

You are invited to take part in a study that I am conducting as part of my PhD at Durham University.

This study has received ethical approval from the Ethics Review Team at the Department of Anthropology at of Durham University. Prior to commencing her PhD Johanna completed at Bachelor of Arts in Philosophy, Politics and Economics at Durham University and a Master of Science in Public Health at the University of Bristol.

Before you decide whether to agree to take part, it is important for you to understand the purpose of the research and what is involved as a participant. Please read the following information carefully. Please get in contact if there is anything that is not clear or if you would like more information.

The rights and responsibilities of anyone taking part in Durham University research are set out in our 'Participants Charter': https://www.dur.ac.uk/research.innovation/governance/ethics/considerations/people/charter/

What is the purpose of the study?

The following paragraph will briefly describe the project aim and the purpose of the research you participated in:

There are not enough organs being donated by people after their deaths, to meet the increasing need for transplant organs to treat seriously ill people who could be helped with an organ transplant. This project looks at the existing public health challenge of a need for more organ donors after the onset of the Covid-19 pandemic, which has seen an increase in universal awareness of collective health issues among the public, government policy that restricts citizen autonomy on the basis of a health issue, and the increased sharing of contrasting messages and communication via the internet.

What I want to find out from this research is how charities and non-governmental initiatives provide support to people who have been affected by organ donation, and the effect that additional support has on their lives. Beyond that, I want to learn more about how the wording of messages within discussions about organ donation and the background of people receiving/distributing them affects public opinion on organ donation. I want to see what role people see themselves in relating to other public groups in this context and what affects their personal attitudes toward the problem. I want to find out how people perceive the different interest groups involved in organ donation campaigns in the context of the recent Covid-19 pandemic and the current acute awareness of public health and health policy in that context.

The rationale for this approach is that the field of public health has been significantly impacted as a result of the pandemic and the legislation it has engendered. This research investigates these impacts using organ donation campaigns as a case study.

This project is not supported by explicit funding, the project is completed as part of my PhD, which is expected to take place between September 2020 and September 2023.

Why have I been invited to take part?

You have been invited because I am interested in talking to you about conversations about organ donation/organ donation campaigns/organ donation legislation/ any personal relationship you may have to any of the above. Your views are relevant to this project and will be very important to the overall success of this project. You will be asked to share some of your personal views and values if you feel comfortable doing so.

Do I have to take part?

Your participation is voluntary, and you do not have to agree to take part. If you do agree to take part, you can withdraw at any time, without giving a reason. Your rights in relation to withdrawing any data that is identifiable to you are explained in the accompanying Privacy Notice.

What will happen to me if I take part?

If you agree to take part in the study, you will be asked to participate in a focus group discussion/ fill in a questionnaire/ participate in a face-to-face interview/ participate in an online video chat or audio-based conversation/ or continue to go about your day as normal within the setting you have been approached in.

The questionnaire will contain a brief set of questions however, you will be able to provide as much detail as you like in your answers. The interviews are expected to last between 30 – 50 minutes. In most cases this will be a one-time interview. I would ask that you think openly and honestly share any information you feel comfortable with. Please ensure that you ask for clarification should anything be unclear to you. You can share or omit any details depending on your personal preferences. There is no need to answer any questions you do not wish to.

As this project is not supported by funding there are no reimbursements or incentives for your participation in this research project.

Are there any potential risks involved?

Carefully think about whether you feel comfortable discussing the topic of post-mortem organ donation as well as related campaigns, language and legal or institutional factors. Consider that all information you provide will be anonymised and that the questions intended to guide discussions will be well-prepared, clear and respectful. Be aware that if you do become upset during the conversation, you are able to request to pause or not to comment on a question. This research ultimately aims to understand how different groups of people perceive each other's statements and interests and how they view the different groups involved in organ donation. It is my hope that a better understanding of possible friction points or areas of interest within these discussions could help ensure that communication on this important subject happens as smoothly as possible, thereby helping ensure that individuals feel educated on the subject and able to make an informed decision for themselves.

Will my data be kept confidential?

All information obtained during the study will be kept confidential. If the data is published it will be entirely anonymous and will not be identifiable as yours. If there are publicly available quotes or statements being used in the project which can be linked to your person or if you are referred to as a person from a relatively small team there may be a risk that the anonymisation of your data cannot be ensured with absolutely certainty. Where such a risk exists, this will be explicitly stated, and you will be asked whether you wish for any such information to be included in project outputs accessible to someone other than the research team. If a public quote should be used, this would be reworded to prevent it from being easily identifiable and linkable to you. In such cases steps to ensure you remain anonymous and some of your data can still be used for the project can be discussed and you will once again be asked to provide your explicit consent to indicate that you are happy with the arrangement.

Full details are included in the accompanying Privacy Notice.

What will happen to the results of the project?

The primary output for this research will be in the form of a PhD thesis to complete the doctoral research at Durham University. The findings may also be discussed for publication further down the line. The results could also be shared within the space of a professional conference or in conversations with a research group interested in the same subject area. At this stage all data will have been fully anonymised, making you as a participant unidentifiable.

No personal data will be shared, however anonymised (i.e not identifiable) data may be used in publications, reports, presentations, web pages and other research outputs. At the end of the project, anonymised data may be archived and shared with others for legitimate research purposes.

If there are publicly available quotes or statements being used in the project which can be linked to your person or if you are referred to as a person from a relatively small team there may be a risk that the anonymisation of your data cannot be ensured with absolutely certainty. Where such a risk exists, this will be explicitly stated, and you will be asked whether you wish for any such information to be included in project outputs accessible to someone other than the research team. Should any such public data be included, it will be rephrased so as to increase the author's privacy and protect them from being easily identifiable. In such cases steps to ensure you remain anonymous and some of your data can still be used for the project can be discussed and you will once again be asked to provide your explicit consent to indicate that you are happy with the arrangement.

All research data and records needed to validate the research findings will be stored for 10 years after the end of the project.

Durham University is committed to sharing the results of its world-class research for public benefit. As part of this commitment the University has established an online repository for all Durham University Higher Degree theses which provides access to the full text of freely available theses. The study in which you are invited to participate will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published with open access.

Who do I contact if I have any questions or concerns about this study?

If you have any further questions or concerns about this study, please speak to the researcher or their supervisor. If you remain unhappy or wish to make a formal complaint, please submit a complaint via the University's Complaints Process.

Thank you for reading this information and considering taking part in this study.

Privacy Notice

PART 1 – GENERIC PRIVACY NOTICE

Durham University has a responsibility under data protection legislation to provide individuals with information about how we process their personal data. We do this in a number of ways, one of which is the publication of privacy notices. Organisations variously call them a privacy statement, a fair processing notice or a privacy policy.

To ensure that we process your personal data fairly and lawfully we are required to inform you:

- Why we collect your data
- How it will be used
- Who it will be shared with

We will also explain what rights you have to control how we use your information and how to inform us about your wishes. Durham University will make the Privacy Notice available via the website and at the point we request personal data.

Our privacy notices comprise two parts – a generic part (i.e. common to all of our privacy notices) and a part tailored to the specific processing activity being undertaken.

Data Controller

The Data Controller is Durham University. If you would like more information about how the University uses your personal data, please see the University's Information Governance webpages or contact Information Governance Unit:

Telephone: (0191 33) 46246 or 46103

E-mail: information.governance@durham.ac.uk

Information Governance Unit also coordinate response to individuals asserting their rights under the legislation. Please contact the Unit in the first instance.

Data Protection Officer

The Data Protection Officer is responsible for advising the University on compliance with Data Protection legislation and monitoring its performance against it. If you have any concerns regarding the way in which the University is processing your personal data, please contact the Data Protection Officer:

Jennifer Sewel

University Secretary

Telephone: (0191 33) 46144

E-mail: university.secretary@durham.ac.uk

Your rights in relation to your personal data

Privacy notices and/or consent

You have the right to be provided with information about how and why we process your personal data. Where you have the choice to determine how your personal data will be used, we will ask you for consent. Where you do not have a choice (for example, where we have a legal obligation to process the personal data), we will provide you with a privacy notice. A privacy notice is a verbal or written statement that explains how we use personal data.

Whenever you give your consent for the processing of your personal data, you receive the right to withdraw that consent at any time. Where withdrawal of consent will have an impact on the services we are able to provide, this will be explained to you, so that you can determine whether it is the right decision for you.

Accessing your personal data

You have the right to be told whether we are processing your personal data and, if so, to be given a copy of it. This is known as the right of subject access. You can find out more about this right on the University's Subject Access Requests webpage.

Right to rectification

If you believe that personal data we hold about you is inaccurate, please contact us and we will investigate. You can also request that we complete any incomplete data.

Once we have determined what we are going to do, we will contact you to let you know.

Right to erasure

You can ask us to erase your personal data in any of the following circumstances:

- We no longer need the personal data for the purpose it was originally collected
- You withdraw your consent and there is no other legal basis for the processing
- You object to the processing and there are no overriding legitimate grounds for the processing
- The personal data have been unlawfully processed
- The personal data have to be erased for compliance with a legal obligation

- The personal data have been collected in relation to the offer of information society services (information society services are online services such as banking or social media sites).

Once we have determined whether we will erase the personal data, we will contact you to let you know.

Right to restriction of processing

You can ask us to restrict the processing of your personal data in the following circumstances:

- You believe that the data is inaccurate and you want us to restrict processing until we determine whether it is indeed inaccurate
- The processing is unlawful and you want us to restrict processing rather than erase it
- We no longer need the data for the purpose we originally collected it but you need it in order to establish, exercise or defend a legal claim and
- You have objected to the processing and you want us to restrict processing until we determine whether our legitimate interests in processing the data override your objection.

Once we have determined how we propose to restrict processing of the data, we will contact you to discuss and, where possible, agree this with you.

Retention

The University keeps personal data for as long as it is needed for the purpose for which it was originally collected. Most of these time periods are set out in the University Records Retention Schedule.

Making a complaint

If you are unsatisfied with the way in which we process your personal data, we ask that you let us know so that we can try and put things right. If we are not able to resolve issues to your satisfaction, you can refer the matter to the Information Commissioner’s Office (ICO). The ICO can be contacted at:

Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

Telephone: 0303 123 1113

Website: Information Commissioner's Office

PART 2 – TAILORED PRIVACY NOTICE

This section of the Privacy Notice provides you with the privacy information that you need to know before you provide personal data to the University for the particular purpose(s) stated below.

Project Title:

Life after Loss: Grief, Community, and the Donor Family Network

Type(s) of personal data collected and held by the researcher and method of collection:

Personal data will be collected using a questionnaire as a stand-alone piece of research or as preparation for an interview. This will include your name, a contact address, a preferred email address, contact number and a section on your age and profession. You will only be asked to provide a minimum of one piece of contact information. Special category data will be collected on a voluntary basis which includes information on religion, ethnic origin and race. This means that you should not provide any information on any of these points if you do not feel comfortable doing so. You will be asked to describe your experience of thinking about post-mortem organ donation and discussing it with others. You will be asked about your views on policies such as opt-out laws for organ donation and whether you would personally want to be an organ donor and why. You may be asked to provide details relating to any of these points.

If you are participating in an interview which is conducted through a secure video chat platform you will be asked whether you consent to the video being recorded, or the audio of that video being recorded for future analysis. Where interactions via the internet are concerned, there is a possibility that surveys which were filled out online can be connected to the IP-address from which you completed the survey. Should this be the case that information would not be sought out or pursued in any way.

Lawful Basis

Under data protection legislation, we need to tell you the lawful basis we are relying on to process your data. The lawful basis we are relying on is public task: the processing is necessary for an activity being carried out as part of the University's public task, which is defined as teaching, learning and research. In addition to relying on public task within Article 6 of the GDPR regulation we are also relying on the following additional conditions for processing special category data as stated in Article 9. The special category data is listed as a matter of your explicit consent. Your data will be fully anonymised and is collected for research purposes, the project is understood as being the public's interest. The collection of this data is necessary for the scientific purpose of the project.

How personal data is stored:

All personal data will be held securely and will be strictly confidential to the research team. Your data will be anonymised. You will be allocated an anonymous number for data collection. Information that identifies you will be kept separate from the anonymised data.

All personal data in electronic form will be stored on a password protected computer, and any hardcopies will be kept in locked storage. Data will not be available to anyone outside the research team. The conversation will be recorded and stored on an encrypted device until it has been transcribed by the researcher. No-one else will have access to the recording, and it will be erased once the transcript has been completed. Personal information will be stored separately to interview transcripts and recordings. Interview recordings will be encrypted and stored on the University One Drive.

How personal data is processed:

Your data will be used to provide insights into your views relating to the areas of interests for the project, for example to see why you may be in favour of or against post-mortem organ donation or why you may be in favour of or against opt-out laws for organ donation and how you present your perspective.

The information you provide will be entered into a database for analysis. After six months the data will be completely anonymised and original records, including any information which identify you personally, will be destroyed.

The recorded conversation will be transcribed by the researcher and personal information will be coded and anonymised. The original recording will then be erased.

If publicly available quotes or statements are used in the project which can be linked to your person or if you are referred to as a person from a relatively small team, there may be a risk that the anonymisation of your data cannot be ensured with absolutely certainty. Where such a risk exists this will be explicitly stated and you will be asked whether you wish for any such information to be included in project outputs accessible to someone other than the research team. To reduce the risk of someone identifying the author of a quote online through the use of the exact wording in their search, any such quotes will be reworded before being included in any publicly available research output relating to this research. In such cases steps to ensure you remain anonymous and some of your data can still be used for the project can be discussed and you will once again be asked to provide your explicit consent to indicate that you are happy with the arrangement.

Withdrawal of data

You can request withdrawal of your data until it has been fully anonymised. Once this has happened it will not be possible to identify you from any of the data we hold. The research team will consider requests to delete data on a case-by-case basis and should explain when and why it would not be possible to withdraw data. Where data is held on the basis of consent given by you, you may withdraw this identifiable data and your request will be complied with.

Who the researcher shares personal data with:

With the exception of the below exception no identifiable personal data will be shared outside the research team, any data shared as part of collaborative discussions that may emerge during the course of the project will be fully anonymised, personal data will be anonymised and it will be ensured that it is no longer identifiable prior to its inclusion in any project outputs. You will be asked for your permission where the inclusion of public statements or quotes made by you is considered for inclusion as part of the project outputs. Details on this can be found in your consent form.

No identifiable data will be shared outside the EU/UK.

Please be aware that if you disclose information which indicates the potential for serious and immediate harm to yourself or others, the research team may be obliged to breach confidentiality and report this to relevant authorities. This includes disclosure of child protection offences such as the physical or sexual abuse of minors, the physical abuse of vulnerable adults, money laundering, or other crimes covered by prevention of terrorism legislation. Where you disclose behaviour (by yourself or others) that is potentially illegal but does not present serious and immediate danger to others, the researcher will, where appropriate, signpost you to relevant services, but the information you provide will be kept confidential (unless you explicitly request otherwise).

How long personal data is held by the researcher:

We will hold personal data for six months, after which it will be anonymised. The consent form may be kept separately and held without being anonymised for up to 18 months, where this may be necessary for auditing purposes.

How to object to the processing of your personal data for this project:

If you have any concerns regarding the processing of your personal data, or you wish to withdraw your data from the project, contact Johanna Thren via jkzp64@durham.ac.uk.

As some of the research for this project will be conducted online, there may be links to other websites, or you may visit different webpages as part of your participation in the research. Where this is the case, you should ensure your have read the cookie policy and privacy statement for those pages and that you have taken care when selecting your preferences.

Further information:

If you require further information, please contact the lead researcher Johanna Thren via jkzp64@durham.ac.uk or the supervisor Bob Simpson via robert.simpson@durham.ac.uk.

Consent Form

Project title: Charity, Grief and Community in Organ Donation Campaigning – An ethnographic study in England

Researcher(s): Johanna Thren
Department: Department of Anthropology
Contact details: jkzp64@durham.ac.uk

Supervisor name: Professor Bob Simpson, Professor Andrew Russel
Supervisor contact details: robert.simpson@durham.ac.uk, Andrew.russell@durham.ac.uk

This form is to confirm that you understand what the purposes of the project are, what is involved and that you are happy to take part. Please initial each box to indicate your agreement:

I confirm that I have read and understand the information sheet dated and the privacy notice for the above project.	
I have had sufficient time to consider the information and ask any questions I might have, and I am satisfied with the answers I have been given.	
I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	

I agree to take part in the above project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	
I understand that anonymised (i.e. not identifiable) versions of my data may be archived and shared with others for legitimate research purposes	
I consent to being audio recorded / being video recorded / having my photo taken, and understand how recordings / photos will be used in research outputs	
I understand that my words may be quoted in publications, reports, and other research outputs. *Please choose one of the following two options* ▪ EITHER I agree to my real name being used in the above ▪ OR I do **not** agree to my real name being used in the above	
I understand that I will not be formally reimbursed for my time and I confirm that I have not been coerced into participating in this project.	
I understand that I may be asked to provide optional details on special category data (formerly 'sensitive personal data') on contextual details such as religion, ethnicity, race or other sensitive information. I understand that sharing this information is voluntary and hereby give my explicit consent to this information being requested and safely stored for legitimate research purposes.	
Please choose: • *Either* I consent to being contacted for follow-up information or requests to partake in further work within this project. • *Or* Following my participation as part of this interaction I do not wish to be invited to participate in any further data collection for this project.	

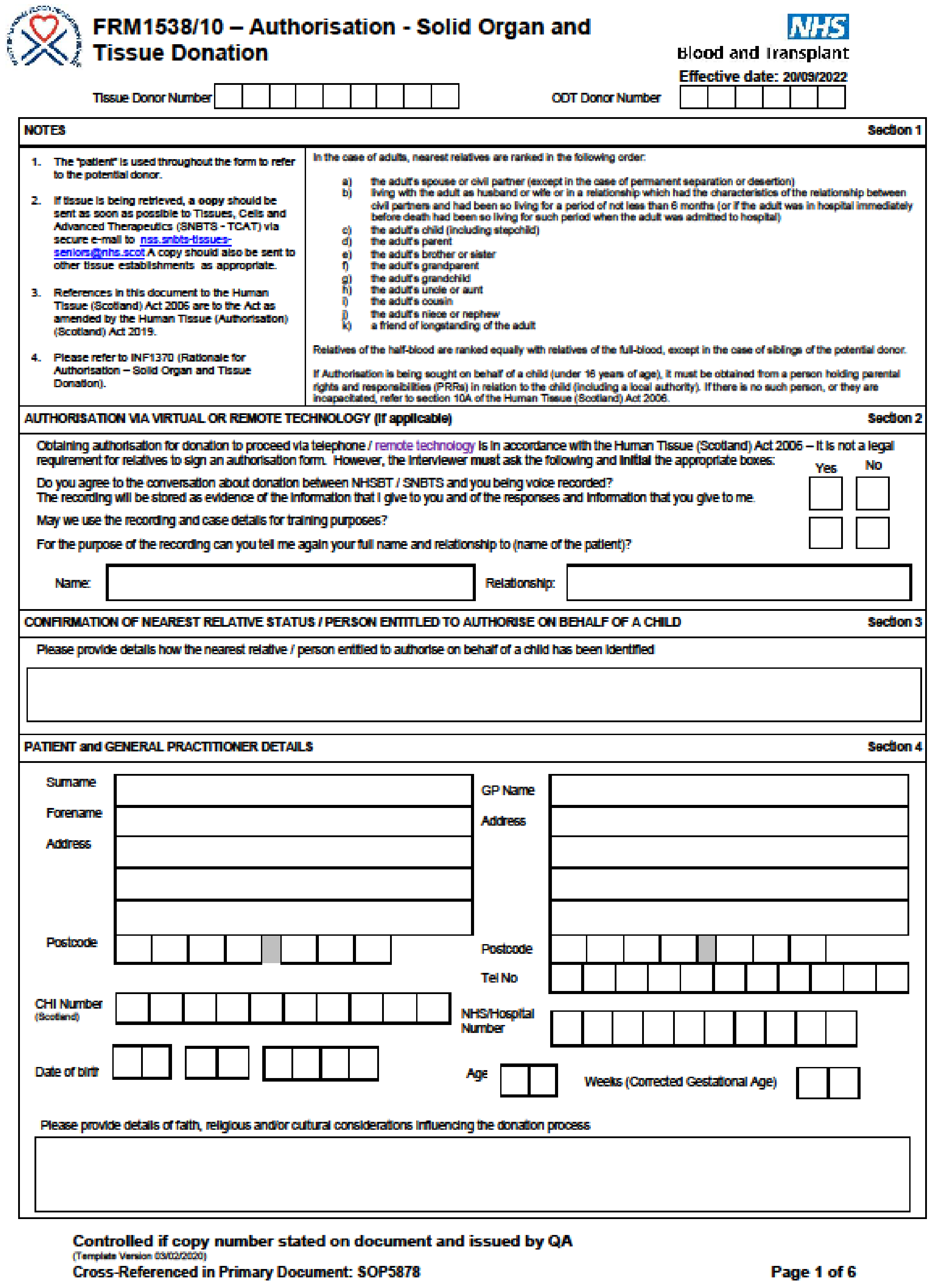
Participant’s Signature_______________________________ Date______________

(NAME IN BLOCK LETTERS)____

Researcher’s Signature_____________________ Date 14.03.2022

(NAME IN BLOCK LETTERS) JOHANNA THREN

Appendix 2



FRM1538/10 – Authorisation - Solid Organ and Tissue Donation

NHS Blood and Transplant

Effective date: 20/09/2022

Tissue Donor Number ☐☐☐☐☐☐☐☐☐ ODT Donor Number ☐☐☐☐☐☐

NOTES **Section 1**

1. The "patient" is used throughout the form to refer to the potential donor.
2. If tissue is being retrieved, a copy should be sent as soon as possible to Tissues, Cells and Advanced Therapeutics (SNBTS - TCAT) via secure e-mail to nss.snbts-tissues-seniors@nhs.scot A copy should also be sent to other tissue establishments as appropriate.
3. References in this document to the Human Tissue (Scotland) Act 2006 are to the Act as amended by the Human Tissue (Authorisation) (Scotland) Act 2019.
4. Please refer to INF1370 (Rationale for Authorisation – Solid Organ and Tissue Donation).

In the case of adults, nearest relatives are ranked in the following order:

a) the adult's spouse or civil partner (except in the case of permanent separation or desertion)
b) living with the adult as husband or wife or in a relationship which had the characteristics of the relationship between civil partners and had been so living for a period of not less than 6 months (or if the adult was in hospital immediately before death had been so living for such period when the adult was admitted to hospital)
c) the adult's child (including stepchild)
d) the adult's parent
e) the adult's brother or sister
f) the adult's grandparent
g) the adult's grandchild
h) the adult's uncle or aunt
i) the adult's cousin
j) the adult's niece or nephew
k) a friend of longstanding of the adult

Relatives of the half-blood are ranked equally with relatives of the full-blood, except in the case of siblings of the potential donor.

If Authorisation is being sought on behalf of a child (under 16 years of age), it must be obtained from a person holding parental rights and responsibilities (PRRs) in relation to the child (including a local authority). If there is no such person, or they are incapacitated, refer to section 10A of the Human Tissue (Scotland) Act 2006.

AUTHORISATION VIA VIRTUAL OR REMOTE TECHNOLOGY (If applicable) **Section 2**

Obtaining authorisation for donation to proceed via telephone / remote technology is in accordance with the Human Tissue (Scotland) Act 2006 – it is not a legal requirement for relatives to sign an authorisation form. However, the interviewer **must** ask the following and **initial** the appropriate boxes:

	Yes	No
Do you agree to the conversation about donation between NHSBT / SNBTS and you being voice recorded? The recording will be stored as evidence of the information that I give to you and of the responses and information that you give to me.	☐	☐
May we use the recording and case details for training purposes?	☐	☐

For the purpose of the recording can you tell me again your full name and relationship to (name of the patient)?

Name: ☐ Relationship: ☐

CONFIRMATION OF NEAREST RELATIVE STATUS / PERSON ENTITLED TO AUTHORISE ON BEHALF OF A CHILD **Section 3**

Please provide details how the nearest relative / person entitled to authorise on behalf of a child has been identified

PATIENT and GENERAL PRACTITIONER DETAILS **Section 4**

Surname

Forename

Address

Postcode ☐☐☐☐ ☐☐☐

GP Name

Address

Postcode ☐☐☐☐ ☐☐☐

Tel No ☐☐☐☐☐☐☐☐☐☐☐

CHI Number (Scotland) ☐☐☐☐☐☐☐☐☐☐

NHS/Hospital Number ☐☐☐☐☐☐☐☐☐☐

Date of birth ☐☐ ☐☐ ☐☐☐☐

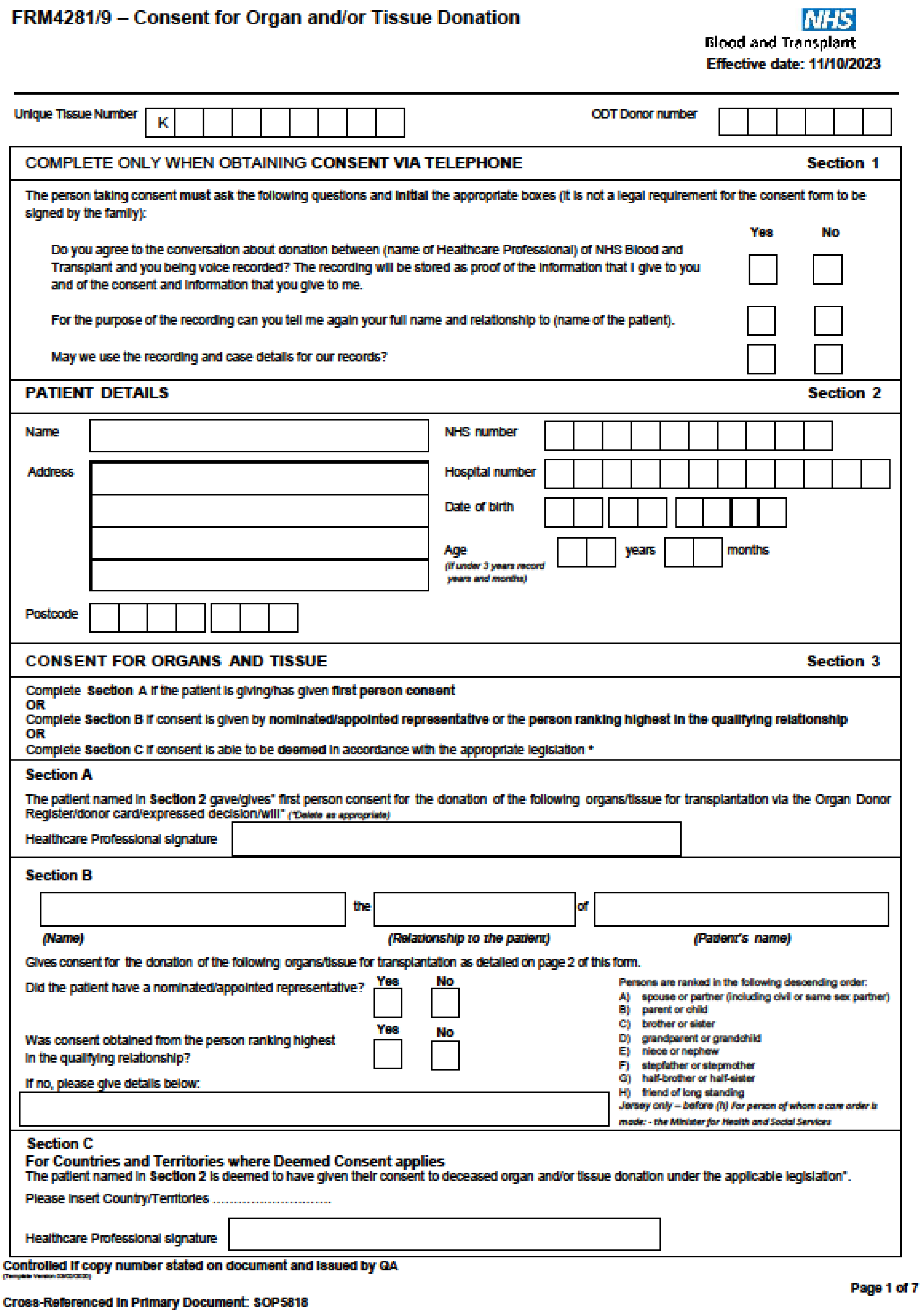
Age ☐☐ Weeks (Corrected Gestational Age) ☐☐

Please provide details of faith, religious and/or cultural considerations influencing the donation process

Controlled if copy number stated on document and issued by QA
(Template Version 03/02/2020)
Cross-Referenced in Primary Document: SOP5878 **Page 1 of 6**

Figure 19: Authorisation Form (ODT Clinical, 2022)(ODT Clinical, 2022)(ODT Clinical, 2022)(ODT Clinical, 2022)(ODT Clinical, 2022)(ODT Clinical, 2022)(ODT Clinical, 2022)(ODT Clinical, 2022)

Appendix 3



FRM4281/9 – Consent for Organ and/or Tissue Donation

NHS
Blood and Transplant
Effective date: 11/10/2023

Unique Tissue Number K☐☐☐☐☐☐☐☐ ODT Donor number ☐☐☐☐☐☐

COMPLETE ONLY WHEN OBTAINING **CONSENT VIA TELEPHONE**	**Section 1**

The person taking consent **must** ask the following questions and **initial** the appropriate boxes (it is not a legal requirement for the consent form to be signed by the family):

	Yes	**No**
Do you agree to the conversation about donation between (name of Healthcare Professional) of NHS Blood and Transplant and you being voice recorded? The recording will be stored as proof of the information that I give to you and of the consent and information that you give to me.	☐	☐
For the purpose of the recording can you tell me again your full name and relationship to (name of the patient).	☐	☐
May we use the recording and case details for our records?	☐	☐

PATIENT DETAILS	**Section 2**

Name ☐
Address ☐
Postcode ☐☐☐☐ ☐☐☐
NHS number ☐☐☐☐☐☐☐☐☐☐
Hospital number ☐☐☐☐☐☐☐☐☐☐☐☐
Date of birth ☐☐ ☐☐ ☐☐☐☐
Age *(If under 3 years record years and months)* ☐☐ years ☐☐ months

CONSENT FOR ORGANS AND TISSUE	**Section 3**

Complete **Section A** if the patient is giving/has given **first person consent**
OR
Complete **Section B** if consent is given by **nominated/appointed representative** or the **person ranking highest in the qualifying relationship**
OR
Complete **Section C** if consent is able to be **deemed** in accordance with the appropriate legislation *

Section A

The patient named in **Section 2** gave/gives* first person consent for the donation of the following organs/tissue for transplantation via the Organ Donor Register/donor card/expressed decision/will* *(*Delete as appropriate)*

Healthcare Professional signature ☐

Section B

☐ the ☐ of ☐
(Name) *(Relationship to the patient)* *(Patient's name)*

Gives consent for the donation of the following organs/tissue for transplantation as detailed on page 2 of this form.

	Yes	**No**
Did the patient have a nominated/appointed representative?	☐	☐
Was consent obtained from the person ranking highest in the qualifying relationship?	☐	☐

If no, please give details below:
☐

Persons are ranked in the following descending order:
A) spouse or partner (including civil or same sex partner)
B) parent or child
C) brother or sister
D) grandparent or grandchild
E) niece or nephew
F) stepfather or stepmother
G) half-brother or half-sister
H) friend of long standing
Jersey only – before (h) For person of whom a care order is made: - the Minister for Health and Social Services

Section C
For Countries and Territories where Deemed Consent applies
The patient named in **Section 2** is deemed to have given their consent to deceased organ and/or tissue donation under the applicable legislation*.

Please insert Country/Territories ....

Healthcare Professional signature ☐

Controlled if copy number stated on document and issued by QA

Page 1 of 7

Cross-Referenced in Primary Document: SOP5818

Figure 20: Consent Form (ODT Clinical, 2023b)