Deconstructing Donation
Study Group Conference

Programme

Friday 8\textsuperscript{th} December 2023
Contents

Getting to the venue .............................................................................................................................. 3
Note for Chairs ....................................................................................................................................... 4
Itinerary .................................................................................................................................................. 5
Abstracts ................................................................................................................................................ 10
  Mixed-methods systematic review (SR) to understand factors influencing living organ donation (OD) in Black and South Asian communities ................................................................. 10
  Accessing and researching bereaved families: Rapport, trust and emotions ...................................... 10
  Towards an understanding of familial and personal relationships in organ donation: Challenging the ‘Gift of Life’ discourse in a global context .................................................................................... 11
  Public attitudes, preferences and self-reported behaviour, related to deceased organ donation before and after the introduction of the 'soft opt out' consent system in England: Implications for ethnic minority donation ........................................................... 11
  Fluid histories: Historical perspectives on power dynamics, transnational solidarity, and bioethical landscapes of blood donation at the American University of Beirut .......................................................... 12
  Beyond conventional plasma donor recruitment: empowering children and youth for a lifesaving future through plasma donation ............................................................................................ 13
  ‘Be clear’ and ‘think carefully’: Comparing the discursive framing of known and identity-release gamete donation in the UK context .............................................................................................. 14
  “There’s always that little bit of stress at the beginning of whether you have to out yourself for the millionth of time”: Politics and practices of erasure, invisibility, and hypervisibility for trans, nonbinary, Two-spirit and other gender-diverse donors in the blood donor center ... 15
  Donors and recipients: From complexity to connection through narrative analysis ............................. 16
  Medical mediators, brokers of knowledge or commercial actors? Mapping intermediaries in the new oocyte economy ...................................................................................................................... 16
  Recruiting ethnic minority blood donors: A frame analysis of blood donation on blood collection agency websites in the UK & Belgium .......................................................................................... 17
  Emotional matters: Methodological challenges of studying emotions in organ donation technologies ......................................................................................................................... 17
  Why do people say no to a donated kidney? ......................................................................................... 18
  Giving, receiving and forgetting? Face transplant patients and professionals struggling with the anonymous donation policy in France .................................................................................. 19
  Getting children on board: Using puppets as elicitation tools to explore beliefs and attitudes towards genomic research ............................................................................................................. 20
  When opposites do not attract – implementing the principle of presumed consent into an informed family consent deceased organ donation system: Learning from initial implementation of the Organ Donation (Deemed Consent) Act 2019 in England ................. 21
  Encountering the dead in anatomy units: Autoethnographic reflections as a methodological tool .................................................................................................................................................... 21
  Asked to be a sperm donor: Disclosure dilemmas of gay men living with HIV ................................. 22
What can we learn relevant to raising consent rates by comparing the current organ donation consent system in Spain and England? A qualitative content and discourse analysis

A fair exchange: Why living kidney donors in England should be financially compensated

A critical review of the United Kingdom’s role and responsibilities within the global organ market

Life after loss: Grief, community, and the donor family network

Reconsideration of the limitation and applicability of the ‘Gift Theory’ by Mauss: An examination of the post operative life experiences of Japanese heart transplant recipients

Blood, breakthroughs and bioethics: Navigating the nuances of responsible implementation of novel cell therapies for hereditary anemias

Haematopoetic stem cell donor perspectives of alternative uses of their cells beyond patients transplantation: Findings from exploratory focus groups

Redefining ‘the field’: An ethnographic study of Australian organ donation
Getting to the venue
The venue for the conference can be accessed from the main University entrance in Northampton Square and it is: Northampton Suite (B114), University Building [B] (4th Floor), Northampton Square, EC1V 0HB, United Kingdom.

The nearest tube stations are Angel, Farringdon and Chancery Lane – all within about a 10-15 min walking distance of the University just slightly varying lengths (but allow for different tube line options).

The University is also within walking distance from Euston and Kings Cross (approximately 30 minutes) for those who want a walk from the main train stations!

Campus map with the main university address is here: https://www.city.ac.uk/about/find-contact/find?_gl=1*1u2hesx*_ga*MzgwNTU3NTMxLjE2OTg4MzM0NjU.*/_ga_YLSK0292X4*MTY5OTUzMDA2MS45LjAuMTY5OTUzMDA2Ny41NC4wLjA.
Note for Chairs

Please note the room for the session you are chairing.
Please note the length of time for speaking and questions.
Please do stick to time as much as possible.
People are able to move between rooms.
Please remind presenters when they have 5 mins left of their allocated time to speak.
Do introduce yourself at the start of the session.
Ask the audience to raise their hands and introduce themselves before asking their question.
## Itinerary

<table>
<thead>
<tr>
<th>Time</th>
<th>Room A</th>
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<tr>
<td>9.00am - 9.15am</td>
<td>Registration</td>
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<td>Insecure bodies – a critical review of the United Kingdom’s role and responsibilities within the Global Organ Market</td>
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<td>9.15am - 9.30am</td>
<td>Welcome Laura Machin</td>
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<td>Jo Tanner University of West London</td>
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<td>9.30am – 10.25am</td>
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<td><strong>Time</strong> (10 mins presentation + 5 mins for Q&amp;A)</td>
<td><strong>Room A</strong> Chair: Róisín Ryan-Flood</td>
<td><strong>Room B</strong> Chair: Eva-Maria Merz</td>
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<td>9.30am – 9.45am</td>
<td>A fair exchange: Why living kidney donors in England should be financially compensated</td>
<td>Daniel Rodger London South Bank University and Birkbeck, University of London &amp; Bonnie Venter University of Bristol</td>
<td>Insecure bodies – a critical review of the United Kingdom’s role and responsibilities within the Global Organ Market Jo Tanner University of West London</td>
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<td>9.50am – 10.05am</td>
<td>Reconsideration of the limitation and applicability of the ‘Gift Theory’ by Mauss: An examination of the postoperative life experiences of Japanese heart transplant recipients’ Ikuko Tomomatsu Osaka University</td>
<td>Mixed-methods systematic review to understand factors influencing living organ donation in Black and South Asian communities Shreya Arora Kingston University, London</td>
<td>What can we learn relevant to raising consent rates by comparing the current organ donation consent system in Spain and England? A qualitative content and discourse analysis Leah McLaughlin &amp; Kate Rees Bangor University</td>
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<td>10.10am – 10.25am</td>
<td>Accessing and researching bereaved families: rapport, trust and emotions</td>
<td>Life after loss: Grief, community, and the donor family network</td>
<td>Towards an understanding of familial and personal</td>
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### Time Table

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<td><strong>Refreshment break</strong></td>
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<td>10.55am – 11.45am</td>
<td><strong>Plenary</strong></td>
<td><strong>What Donation Means to You</strong></td>
<td><strong>Professor Rosamund Scott</strong></td>
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<td><strong>Fluid Histories: Historical perspectives on power dynamics, transnational solidarity, and bioethical landscapes of blood donation at the American University of Beirut</strong></td>
<td><strong>Blood, breakthroughs and bioethics: Navigating the nuances of responsible implementation of novel cell therapies for hereditary anemias</strong></td>
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<td>Center for Philanthropic Studies in the Department of Sociology, Vrije Universiteit, Amsterdam &amp; Eva-Maria Merz, Center for Philanthropic Studies in the Department of Sociology, Vrije Universiteit,</td>
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<td>Getting children on board: Using puppets as elicitation tools to explore belief and attitudes towards genomic research</td>
<td>Gillian Martin University of Malta</td>
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<td>Redefining ‘the field’: An ethnographic study of Australian organ donation</td>
<td>Tanya Zivkovic University of Adelaide</td>
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<td>Public attitudes, preferences and self-reported behaviour, related to deceased organ donation before and after the introduction of the ‘soft opt out’ consent system in England: Implications for ethnic minority donation</td>
<td>Paul Boadu London School of Hygiene and Tropical Medicine &amp; Leah McLaughlin Bangor University</td>
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<td>Beyond conventional plasma donor recruitment: Empowering children and youth for a lifesaving future through plasma donation</td>
<td>Alexandra Ciausecu Sanquin Research, Department of Donor Medicine Research, Amsterdam; Vrije Universiteit Amsterdam, Faculty of Social Sciences, Sociology, Center for Philanthropic Studies</td>
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<td>1.00pm</td>
<td>Emotional matters: Methodological challenges of studying emotions in organ donation technologies</td>
<td>Anja MB Jensen, Sofie á Rogvi &amp; Zainab A Sheikh Center for Medical Science &amp; Technology Studies, Section for Health Services Research, Department of Public Health, Copenhagen.</td>
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<td>Recruiting ethnic minority blood donors: A frame analysis of blood donation on blood collection agency websites in the UK and Belgium</td>
<td>Lesley Hustinx Ghent University; Pierre Monforte Leicester University &amp; Toyah Van der Poten Ghent University</td>
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<td>Robert Pralat</td>
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<td>'Be clear' and 'think carefully': Comparing the discursive framing of known and identity-release gamete donation in the UK context</td>
<td>Leah Gilman</td>
<td>University of Sheffield</td>
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<td>3.45pm – 4.10pm</td>
<td><strong>'Off grid' donor identity disclosure:</strong> What happens when people trace their egg or sperm donor through social media or genetic testing?</td>
<td>Róisín Ryan-Flood</td>
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<td>Giving, receiving, and forgetting? Face transplant patients and professionals struggling with the anonymous donation policy in France</td>
<td>Marie Le Clainche-Piel</td>
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**4.15pm**  
Concluding comments  
Jessie Cooper
Abstracts

Mixed-methods systematic review (SR) to understand factors influencing living organ donation (OD) in Black and South Asian communities

Shreya Arora, Tushna Vandrevala, Ingrid Bacon & Paty Paliokosta
k2208863@kingston.ac.uk
Kingston University London

Abstract:

**Background:** Black and Asian communities are more likely to develop chronic conditions, such as high blood pressure and diabetes that predisposes them to needing a live organ transplant. Although transplantations from white donors are possible, the best transplant outcomes will be from a donor from the same ethnic background. OD rates from ethnic minorities are low in the UK and shortages in ethnically matched donors results in lengthy period on the waiting list, poorer health at the time of transplant and increased mortality for those waiting for a transplant.

**Aims/purpose:** The study aimed to systematically review and critically appraise the existing evidence to provide a comprehensive insight into how ethnic communities make decisions about live OD in terms of their attitudes, willingness, and donor behaviour.

**Methods:** This review will be conducted in accordance with the JBI methodology for SR. Studies will be retrieved by online searches from 2004 to 2023 from databases such as MEDLINE, CINAHL, PsycInfo, Social Sciences Full Text, Web of Science - Science Citation Index and Business Premier. A critical appraisal will follow, using JBI appraisal tools to identify the methodological quality of the chosen papers and a convergent segregated approach will be used for data extraction.

**Results:** The SR will provide an informed understanding of the existing evidence on attitudes, willingness, motivation, and decision making towards live OD among South Asian and Black people living in the UK. The study will inform subsequent studies which aim to develop a culturally appropriate intervention aimed at increasing live OD behaviour in the population of interest using co-design methodology.

Accessing and researching bereaved families: Rapport, trust and emotions

Lisette Aviles₁ & Stephanie Parsons₂
₁ University of Edinburgh, laviles@ed.ac.uk
₂ Anglia Ruskin University, London, stephanie.parsons@london.aru.ac.uk

Abstract:

Losing a family member in the context of organ donation often evokes a turmoil of emotional responses in both healthcare professionals and families. Emotions are socially constructed and experienced by the participants but also by the researcher when accessing and exploring bereaved families’ experiences. Methodological and ethical considerations are at the heart of the challenges
of researching donation, yet little is known about the role of researcher and its impact on rapport, trust and emotions when analysing, theorising and deconstructing donation in the global context. This paper presents the reflections of two researchers investigating the experiences of healthcare professionals, families and organ recipients in two international contexts. The paper draws on the concept of ‘methodological emotional reflexivity’ developed by Munkejord and ‘intersectionality’ by Collins and Bilge to highlight the active and reflexive role of the researcher when accessing and researching bereaved families. Authors reflect on the research process and how their global perspectives provide ethical and methodological insights into studying donation as a sociological phenomenon.

**Towards an understanding of familial and personal relationships in organ donation: Challenging the ‘Gift of Life’ discourse in a global context**

Lisette Aviles₁ and Stephanie Parsons₂
₁ University of Edinburgh, laviles@ed.ac.uk
₂ Anglia Ruskin University, London, stephanie.parsons@london.aru.ac.uk

**Abstract:**

Official discourses associated with ‘gift of life’ and ‘saving lives’ has characterised organ donation literature on a global scale. These narratives have shaped the understanding of this complex phenomenon that intertwines donors and recipients in ways that have drawn little attention. Organ donation, from the perspective of the sociology of emotions, is limited and recent studies under this perspective are challenging those narratives. This paper presents the findings and reflections of two researchers investigating the experiences of healthcare professionals, donor families and organ recipients in two international contexts. The paper employs the concept of ‘social scripts’ to highlight the ways in which families approached for organ donation authorisation engaged with the dominant narratives of organ donation. In doing this, we show how these global experiences are similar in nature and call for further investigation into the lived experiences of organ donation on a global scale.


**Public attitudes, preferences and self-reported behaviour, related to deceased organ donation before and after the introduction of the 'soft opt out' consent system in England: Implications for ethnic minority donation**

Paul Boadu₁, Leah McLaughlin₂, Jane Noyes₂, Mustafa Al-Haboubi₁, Lorraine Williams₁, Jennifer Bostock₁, Stephen O’Neill₁, & Nicholas Mays₁
₁ London School of Hygiene and Tropical Medicine, Policy and Innovation Research Unit

₁.mclaughlin@bangor.ac.uk
Abstract:

**Background:** In the UK, over 7,000 people are on the waiting list for a transplant and there are inequalities in need, access and wait time for organs, notably between different ethnic groups. In May 2020, England introduced a soft opt-out system of consent to organ donation to help the situation. We aimed to learn more about the impact of the changes on factors likely to be relevant to consent to deceased organ donation between different population sub-groups.

**Methods:** Mixed-methods design involving latent class analysis of data from twelve repeated cross-sectional surveys collected from 2015 to 2021 (n=19,011); additional interviews with purposively selected members of the public (n=30) focussing on nuanced minority perspectives (e.g., Islam); parallel survey and interview analysis followed by synthesis.

**Results:** Support for the principle of organ donation remained high and stable (80%) but was 20% lower among ethnic minority groups. While 58% of the general population were aware of the law change, this was lower among ethnic minorities (31%). We identified four subgroups of the population (cooperative donors, predominately white (24%); sensitive donors, predominately ethnic minority (22%); ambivalent donors, no dominate ethnicity (46%); and non-donors, predominately ethnic minority (9%)). Interview themes included the challenges of discussing organ donation decisions, balancing autonomy with family relations, targeted (harmful) misinformation, frustrations at the lack of consensus between community leaders, limited understanding of what happens in the processes of deceased organ donation and whether this aligns with cultural values and preferences.

**Discussion:** Implementation of the law change has had little impact to date on factors influencing consent or helped to address inequalities in deceased donation that particularly affect minority ethnic groups in the population. Ambivalent donors may benefit from encouragement to express their organ donation decision, and sensitive donors to address mis/information, confusion, and uncertainty. Interventions need to take account of the (significant) role of the family as well as wider community influences on attitudes, preferences, and decision-making among certain ethnic minority groups.

**Fluid histories: Historical perspectives on power dynamics, transnational solidarity, and bioethical landscapes of blood donation at the American University of Beirut**

Samira Chatila₁ & Eva-Maria Merz₂

s.chatila@vu.nl₁ E.Merz@sanquin.nl₂

₁ Center for Philanthropic Studies in the Department of Sociology, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

₂ Department of Donor Medicine Research, Sanquin, Amsterdam, the Netherlands
In 2018, a thought-provoking query emerged within a Lebanese blood bank as a medical laboratory scientist pondered, “Should I accept blood from him?” The question arose when a Palestinian donor, armed with legal identification, sought to contribute blood to a patient in need. This incident serves as a gateway to a vital inquiry: Does the racialization of blood donation stand as an isolated occurrence, or does it possess historical underpinnings? Our proposed study delves into the historical landscape of blood donation and donor recruitment at the American University of Beirut (AUB) between 1934 and 2023. As the oldest university in the Middle East, founded in 1866, and home to the pioneering Faculty of Medicine, AUB serves as a captivating case for exploration. By meticulously scrutinizing an extensive collection of AUB student newspaper clippings, our investigation plunges into the discourse and practices surrounding blood donation and donor recruitment. Through this comprehensive analysis, we unveil the multifaceted nature of blood, which not only fostered political solidarity among diverse Arab communities transcending borders but also perpetuated enduring power differentials. Furthermore, our research unearths how these dynamics fortified classism and racism, ultimately influencing the well-being of blood donors. Our study yields invaluable insights into the evolving theoretical perspectives and practices encompassing blood donation. Significantly, we emphasize the methodological importance of archival studies within the blood donation context. By conducting a content and discourse analysis of historical documents, we attain profound comprehension of the intricate relationships woven among blood products, the individuals involved (including their legal identities), the technologies employed, and the disciplinary landscapes that shape our understanding. These findings make substantial contributions to the broader discourse encompassing the bioethics of blood donation, healthcare disparities, and the urgency of equitable practices that empower both individuals and communities.

Beyond conventional plasma donor recruitment: empowering children and youth for a lifesaving future through plasma donation
Alexandra Ciausescu₁,₂, Eva-Maria Merz₁,₂, Rene Bekkers₂, & Arjen de Wit
a.ciausescu@vu.nl
₁Sanquin Research, Department of Donor Medicine Research, Amsterdam, The Netherlands
₂Vrije Universiteit Amsterdam, Faculty of Social Sciences, Sociology, Center for Philanthropic Studies

Abstract:
The contemporary European landscape is witnessing a pressing shortage of plasma, which seriously threatens the provision of life-saving medicine for numerous patients. A possible explanation for insufficient plasma donors could be a lack of awareness among potential plasma donors. Many individuals remain uninformed about plasma and its crucial role in medical treatments. In the Netherlands, this issue may stem from a systematic educational gap, where the topic of plasma donation remains largely unexplored in children's educational curricula. As critical scholars, we challenge the conventional approach to donor recruitment, which primarily focuses on adults aged 18 and above. We argue that ineligibility for donation should not limit the acquisition of knowledge on this vital subject. To address this issue, we have developed an
innovative pedagogical method targeted at an often-overlooked group – children and youth under the age of 18. We designed a serious game to disseminate knowledge about plasma donation to this potential future donor demographic. Additionally, we provided our research subjects with the opportunity to share their views on the topic.

The effectiveness of our game in increasing and, co-producing, knowledge about plasma will be tested at NEMO, a Dutch science museum in Amsterdam (July 22 – August 4, 2023). The study results will greatly enhance our interdisciplinary understanding of donor recruitment and hold vital significance for youth, children, blood banks, potential donors, patients, and curriculum designers. Beyond the Netherlands, this project’s far-reaching implications recognize the significance of children and youth as study subjects. Their involvement serves as a catalyst for dedicated educational programs targeting non-donors. This strategic step is crucial to secure the long-term plasma donor pool, with children and youth shaping the future of plasma donation. It will strengthen the plasma supply chain in the Netherlands and across Europe.

‘Be clear’ and ‘think carefully’: Comparing the discursive framing of known and identity-release gamete donation in the UK context

Leah Gilman
University of Sheffield
l.gilman@sheffield.ac.uk

Abstract:
Contemporary UK egg and sperm donation exist in two predominant forms: clinic-based, identity-release donation, and known donation, which can take place either inside or outside of the clinic context. Through analysis of policies and online communications produced by UK regulators, fertility clinics and third-sector organisations, I demonstrate that discussions of known donation, where present at all, frame known donation as uniquely risky. In contrast, identity-release donation is positioned as safe, straightforward and the default route to donor conception. With reference to previous research with donors and families through donor conception, I draw attention to what is absent within these texts, namely any recognition of the perceived and potential benefits of known donation or the possible risks of identity-release practices. These absences are particularly intriguing given that known donation appears to support the belief (now dominant in many Euro-American cultures) that donor conceived children have a ‘right to know’ the donor (Guichon, Mitchell, and Giroux 2012). Thus, the binary framing of known and unknown donation as good/bad, safe/risky represents something of a puzzle. However, I show these donation discourses are explicable when situated within their broader cultural, economic and historical contexts. I consider, for example, the rationale for historical practices of donor anonymity (Haimes 1992), the forms of gifting expected of bodily donors (Shaw 2015), the ‘financialisation’ of fertility medicine (Van de Wiel 2020) and moral panics about the quality of ‘online’ connections (Baym 2015).

References
Abstract:
Donation is a complex social process that is not only specific to the type of bodily material donated and its purpose, but also to the person who is donating. For example, many trans, nonbinary, Two-Spirit, and other gender-diverse blood donors face challenges in the donor centre, including registering their gender in systems limited to binary gender (or sex assigned at birth) options only. That is, all donors are limited to “female” or “male” registration options only. Trans and gender studies scholars argue that bureaucratic systems based on cisnormative assumptions that neglect to include trans identities and bodies is a form of institutional erasure and can lead to inadequate healthcare and social services for trans people (e.g., (Bauer et al., 2009). Others suggest that in addition to erasure, or invisibility, trans people and bodies may be rendered hypervisible and thereby objects of governance and surveillance technologies (Kia, 2016). Drawing on qualitative data from a community-based study with 85 gender-diverse donors in Canada, this presentation explores the experiences and practices of gender-diverse blood donors in the donor centre through the concepts of invisibility and hypervisibility. I demonstrate how instances of erasure, invisibility, and hypervisibility emerge, navigated, and contested by trans and gender-diverse donors during the donation process and with centre staff. I argue that the politics of invisibility and hypervisibility in the donor centre can only be understood by situating blood donation within the broader political and social context that both challenges and affirms the rights and personhood of trans and gender-diverse people.

References

“There’s always that little bit of stress at the beginning of whether you have to out yourself for the millionth of time”: Politics and practices of erasure, invisibility, and hypervisibility for trans, nonbinary, Two-spirit and other gender-diverse donors in the blood donor center

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Donors and recipients: From complexity to connection through narrative analysis

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Abstract:
This paper is a reflection on the methodology of narrative analysis in the context of an applied study meant to promote plasma donation. I consider how to promote plasma donation while also representing complexity, contradiction, difficulty and uncertainty of recipients’ lives. Human plasma supplies over 25 therapeutic proteins to treat bleeding, haemostatic, immunological and metabolic disorders. The plasma protein product in highest demand is immune globulin (Ig). In a study of whole blood donors who converted to source plasma donation in Canada, I found that the story of how plasma has an impact on a recipient is not well understood. Indeed, the process involves multiple steps; plasma is collected through apheresis, manufactured by a commercial entity, and sold back to a blood service or health authority. It treats multiple conditions, sometimes rare, with names that are difficult to remember like hypogammaglobulinemia and chronic inflammatory demyelinating polyneuropathy. Donors want to be able to understand how plasma has an impact so they can encourage their friends and family to donate (Holloway, 2022).
To respond to this interest, I conducted a study with recipients of Ig. I used narrative analysis to understand the recipient’s story from illness to treatment and beyond and communicate how donation has helped a recipient. I completed 44 narrative interviews with 23 recipients of immune globulin (most participants were interviewed twice), and with participants, co-created narrative accounts that can communicate the impact of a plasma donation on a recipient. While narrative analysis gives us access to recipient stories, it has also revealed the complexity of recipients’ lives. I draw on the sociological literature on contested illness, chronic illness, and unexplained illness to analyze participant stories, and ultimately suggest that humanizing the complexity of the recipient story is a powerful act that could resonate with potential donors.

Medical mediators, brokers of knowledge or commercial actors? Mapping intermediaries in the new oocyte economy

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Abstract:
Whilst there is a growing scholarship that explores third party involvement in the brokerage of medical travel, less attention has been paid to other forms of commercial medical facilitation. In the context of egg donation, what work does exist comes from the US where it is argued market
forces shape practice. More recently, a range of intermediaries has begun to emerge in the European context; offering new forms of mediation between egg providers, clinics and egg recipients, and giving rise to a more diverse and increasingly commercialised geography of provision. Since these intermediaries often operate outside the medical field, they pose pressing questions related to their governance and oversight.

This paper considers the reasons for these developments in the European context and maps the new configurations of mediation and exchange they represent. Taking three national case studies – the UK, Spain and Belgium – it examines how the traditional link between the donor and the recipient that underpins most of the existing national regulations in Europe, is being disrupted. Drawing on policy mapping, online marketing analysis and interview data from across the three national study sites, we illustrate how these developments have significant implications for egg donation policy and egg provider welfare, as well as for wider understandings of the fragmentation of traditional healthcare pathways and their co-ordination by a range of commercial and non-commercial actors.

**Recruiting ethnic minority blood donors: A frame analysis of blood donation on blood collection agency websites in the UK & Belgium**

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**Abstract:**

People from ethnic minority groups are less likely to donate blood compared to the majority population in Western countries and are underrepresented in donor populations. In policy documents on the matter, these groups are coined ‘Missing Minorities’. Blood donation is usually framed as an anonymous altruistic gift, that is given voluntarily and without remuneration. The gift discourse envisions donation as a morally worthy act, and even one of the purest examples of solidarity and good citizenship. Previous research has mostly focused on individual motivations to donate blood and neglects contextual factors such as the social, cultural, religious and institutional systems in which blood donation is embedded. Such one-sided focus risks depicting ‘Missing Minorities’ as not willing to donate, hence as less contributing citizens. In this paper, we argue that there is an urgent need to also question the organizational basis of the blood procurement system, in order to discern mechanisms of exclusion in donor recruitment and blood collection practices.

Healy’s seminal work on ‘blood collection regimes’ (2000) provides an apt perspective to go beyond individual motives and more systematically understand organizational factors that affect donation rates and donor populations. Healy observed important cross-national differences in donor populations, depending on the blood collection agencies (BCA’s) providing differing opportunities for donation. Building on Healy, Coveney et al. (2022), in a study on egg donation campaigns of fertility clinics, further coined the term ‘recruitment regimes’ to signal more specifically how these different BCA’s use varying modes of donor recruitment strategies.
This paper aims to explore how recruitment regimes of blood donation differ, focusing on a comparative case study between Belgium, where the Red Cross has a monopoly in blood collection, and the UK, where blood collection is state led by the NHS. Strikingly, while the NHS very actively and visibly addresses ethnic minorities in its recruitment campaigns, the Belgian Red Cross has no distinct recruitment strategies towards this underrepresented donor segment. Based on a frame analysis of their websites, we examine how these distinct BCA’s actively use different frames and hereby in-or exclude ethnic minority groups in European donor populations.

**Emotional matters: Methodological challenges of studying emotions in organ donation technologies**

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**Abstract:**
Transplant technologies are accelerating towards new futures in the never-ending quest to eliminate organ shortage. Recently, it has become routine to transplant organs from both brain dead and circulatory dead patients, organs are transported, perfused and improved in ex-vivo machines, children are born in donated uteruses, and the scientific ambition to transplant organs from animals to humans have moved from science fiction to actual clinical experiments. We explore how technological breakthroughs in pioneering transplant medicine evoke and depend on emotional responses. Technology shapes how humans live, die and are cared for/treated. Thus, it affects experiences, perceptions and emotions. On the other hand, new technological practices cannot be implemented and legitimated in the clinic, without the cultural and emotional acceptance of the public, patients, families, and professionals involved.

Doing fieldwork on the implementation of DCD in Denmark (Anja), the hopes and concerns regarding uterus transplantation in Denmark (Zainab) and the experimental practices and ethical dilemmas regarding xeno-transplantation in the US (Sofie), we invite methodological discussions. We would appreciate input on how to operationalize our analytical focus on technology and emotion, and how to systematically observe, talk about, record, and analyze emotions among medical professionals, researchers, policy makers, patients and families in these fascinating fields. Based on earlier anthropological research in organ donation, we know emotions are everywhere and among all actors. Paradoxically, emotions are also sometimes nowhere. They are managed, disguised, used actively, strategically downplayed or emphasized. So far, we have taken inspiration from “emotional practices”, how emotions are done and how they matter in practice (Scheer 2012). However, how do we methodologically study intersections of emotion and technology, what emotions should we look after, what are emotions anyway, how might a focus on emotion contribute with new knowledge, and how do we avoid discriminating on whose emotions deserve anthropological attention.
Why do people say no to a donated kidney?

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Abstract:

Introduction:
Kidney transplantation is considered the ‘best’ kidney replacement therapy for people with end stage chronic kidney disease. To maximise potential organ transplantation in the UK, the Organ Utilisation Group has published recommendations to make best use of available kidney donors. The aim was to develop an in-depth understanding of the lived experiences of people living with kidney disease, their experiences of decision-making and the reasons which led them to decline a kidney transplant.

Methods:
Thirty people were recruited from 6 regional nephrology units within the United Kingdom. Semi-structured interviews were digitally recorded, transcribed verbatim and subjected to Interpretative Phenomenological Analysis. The Theory of Planned Behaviour and the Adaptive Decision Maker Framework were used to develop an understanding of decision-making.

Findings:
People have socially constructed understandings of what is considered the right and best kidney replacement treatment for them. Pre-conceived ideas and negative perceptions towards kidney transplantation regardless of age, gender, or kidney replacement treatment influenced their decision. Being adjusted on dialysis and being able to lead a ‘normal life’ that did not carry the uncertainties and burden of receiving a donated kidney. People felt pressured to consider living kidney transplants. Three participants had previously been on the transplant list had refused the offer of a donated kidney when called by their transplant centre because the timing was inconvenient, or they wanted the kidney to be given to someone else to lead the best life they could.

Discussion:
This study is one of the first to explore reasons for declining a donated kidney. Peoples’ social constructions of what was ‘best treatment’ for them was often at odds with clinical practice recommendations that aimed to increase the numbers of people transplanted to improve clinical outcomes. Understanding peoples’ perspectives is imperative to developing future policies underpinned by better shared decision-making.

Giving, receiving and forgetting? Face transplant patients and professionals struggling with the anonymous donation policy in France
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Abstract:
This presentation stems from a research project on the emergence of face transplants, in which I followed two teams and their patients between 2010 and 2018. I analyzed the historical and social process by which the face has become an interchangeable organ in France – in contrast to the UK, for example, where the project arose but was never implemented. From this case study I argue that what an organ represents – from the medium of the donor’s personal identity to an interchangeable organ – is never fixed. It emerges through the policies regulating organ sharing, the hospital practices, the interactions between medical professionals, patients and their relatives. Anonymizing faces of the dead has been a key process to make them interchangeable in France, but it is not done without resistance and the process can be questioned at any time. Even through the postoperative time, which I am particularly going to focus for this talk, I show that patients receive potentially contradictory recommendations about how to integrate the organ, revealing the tensions at work in this process. They are invited to consider the organ theirs and forget the donor, but at the same time to thank the donor for the donation and never forget the origin of the graft. Based on the plurality of relationships developed by the patients with their donor, I revisit Maussian interpretative analyses of organ reception, the forms of reciprocity and effects on personal identity.

Getting children on board: Using puppets as elicitation tools to explore beliefs and attitudes towards genomic research
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Abstract:
The presentation will offer an outline of work in progress exploring beliefs and attitudes of children towards biobanking for genomic research, with particular focus on the consenting process. Qualitative data are being generated with 9 -15 year olds in Malta, using a specially commissioned puppet show as an elicitation event upon which focus group discussions are developed. The puppet show is delivered using professional performers in different settings (schools, community events etc). It introduces the basic concepts of genes, DNA, blood sample, research, but it does this within a story line of superhero (Mr Mustaccio) and villain (Haemo Goblin) which the children readily relate to, and always thoroughly enjoy. Focus group discussions are audio-recorded and transcribed verbatim. Thematic and narrative analysis will be used to explore the process of embodiment related to blood/DNA in young children, and their attitudes and expectations in relation to the ethicality of donating their blood/DNA to biobanking for genomic research.
When opposites do not attract – implementing the principle of presumed consent into an informed family consent deceased organ donation system: Learning from initial implementation of the Organ Donation (Deemed Consent) Act 2019 in England

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Abstract:
Background: As a result of the Alder Hey scandal which damaged public trust in the organ donation system and reduced consent rates for deceased organ donation in the UK in the 1990s, the Human Tissue Act (HTA) was overhauled. To restore public trust, an ‘appropriate consent’ model was implemented for the removal, storage and use of human tissue, whereby individual organs, tissues and their use requires (various types) of informed consent. Over 20 years later, England implemented a ‘soft’ opt-out system of consent, whereby citizens are presumed donors unless they state otherwise and which removes the right of their families to decide on their behalf after their death. We aimed to evaluate the effects of the changes on the organ donation system following implementation.

Design and methods: A mixed-methods study involving interviews and surveys of healthcare professionals, and interviews with family members who were approached about organ donation after their relative had died.

Results: For healthcare professionals, formal and intuitive practice continued to align with family consent. As a result, the new law added further layers of complexity to an already highly complex system. Families found the consent process too long, convoluted and overwhelming, and most retained little detailed knowledge of what they were asked. The consent documents remained modelled on informed family consent.

Discussion: We found a legacy of consent which has proved resistant to the principles in the newer opt-out legislation. The HTA and ‘soft’ opt-out are almost entirely contrasting pieces of legislation. The two together have created additional uncertainty and frustration, and brought nothing new to help staff support the acutely bereaved. Families feel no more supported or less burdened with their decision-making. Until the HTA is updated to align with the new system, it is unlikely that any modifications to the newer Act will lead to the desired impact.

Encountering the dead in anatomy units: Autoethnographic reflections as a methodological tool

Zivarna Murphy

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Abstract:
Zivarna will discuss her emotion management while encountering the dead within Medical School Anatomy Units while researching the work that anatomy unit staff did with the families of body donors. These encounters were due to her ethnographic approach—Although this approach allowed her to witness the process of body donation first-hand, it was her autoethnographic reflections while encountering cadavers that allowed her to empathise with her participants and understand their work, including how they managed their emotions. Zivarna too experienced the psychosocial challenges of encountering the dead and learned to manage emotions using coping strategies, such as: avoidance, dehumanisation and ‘tactical objectification’, dark and gallows humour, and dealing with the ontological duality of the corpse, which are both ‘persons’ and ‘things’. Autoethnography thus became an integral part of her methodology which enabled her to reflect on adopting similar strategies to her participants. In this paper Zivarna will demonstrate how autoethnographic reflections can be used as a methodological tool to better understand the research context and participants’ roles within it. She will also discuss the lack of recognition and support for such researchers and call for their emotion management to be recognised.

Asker to be a sperm donor: Disclosure dilemmas of gay men living with HIV

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Abstract:
Drawing on interviews with gay men living with HIV, conducted in four clinics in London, this paper explores narratives of men who have been asked by their female friends about the possibility of being a sperm donor. The narratives highlight layers of complexity which have received little attention, not only in studies of sperm donation but also in research on HIV. The paper advances dialogue between these two largely separate bodies of work. Our data suggest that reluctance to share an HIV-positive status with others can be an important factor in deciding how to answer the ‘sperm donor question’. As the data show, it is not unusual for gay men to be asked by female friends about being a sperm donor, especially if the man is single. When gay men live with HIV, responding to questions about sperm donation involves decisions about openness and secrecy with regard to the virus as well as considerations about parenthood. Our findings demonstrate that reproductive decision-making is sometimes not primarily about having children. In some cases, a male friend’s negative answer to the sperm donor question might be motivated by factors other than feelings about parenthood. It is possible to envisage that some reproductive arrangements between women and gay men fail to materialise because of decisions about keeping HIV secret – which may not be how the motivations of a man declining to be a sperm donor are understood by the woman who has asked him to consider it. Examining reproductive relationships of a specific kind – those based on friendships between women and gay men – we call for future research to explore perspectives of a wider range of men who are asked by their female friends to donate sperm in order to understand what other considerations shape responses to such requests.
What can we learn relevant to raising consent rates by comparing the current organ donation consent system in Spain and England? A qualitative content and discourse analysis
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Abstract:

**Background:** Since England switched to an opt-out system of consent in May 2020, consent rates have remained much the same. However, Spain also operates an opt-out system yet has a higher consent rate, and almost twice the organ donations per million per population. We aim to identify both differences and similarities in the consent policies, documents, practice and procedures between the two countries.

**Design:** Documentary analysis using comparative qualitative content analysis and key principles from discourse analysis.

**Methods:** We have identified, obtained and translated key policy and procedural documents and consent forms from websites of the ‘Organizacion Nacional de transplantes’ in Spain and NHS Blood & Transplant in England. Qualitative content analysis is being used to analyse the content of text and diagrams, and to identify and compare concepts, patterns and larger themes related to norms of good practice, with a specific focus on consent, within the Spanish and English documents. Principles from critical discourse analysis are being used to make additional interpretations of the text based on both the details of the material itself and on contextual knowledge through engagement with an expert on each of the two systems. We will explore, for example, the often opaque relationships between what is written (i.e. policies, guidance) and what happens in practice in a frequently highly emotive context, with multiple stakeholders and potentially conflicting agendas.

**Results:** Analysis is ongoing. Key finding and insights will be presented at the meeting.

**Discussion:** By comparing the two countries, we will understand more about mechanisms underpinning the success of the Spain consent pathway, and extrapolate learning and recommendations which may be applicable with adaption to England and the UK.

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**A fair exchange: Why living kidney donors in England should be financially compensated**

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Abstract:
Every year, hundreds of patients in England die whilst waiting for a kidney transplant, and this is evidence that the current system of altruistic-based donation is not sufficient to address the shortage of kidneys available for transplantation. To address this problem, we propose a monopsony system whereby kidney donors can opt-in to receive financial compensation, whilst still permitting individuals to donate without receiving any compensation. A monopsony system describes a market structure where there is only one ‘buyer’—in this case the National Health Service. By doing so, several hundred lives could be saved each year in England, wait times for a kidney transplant could be substantially reduced, and it would lessen the burden on dialysis services. Furthermore, compensation would help alleviate the common disincentives to living kidney donation, such as its potential associated health and psychological costs. The proposed system would also result in significant cost savings that could then be redirected towards preventing kidney disease and reducing health disparities. While concerns about exploitation, coercion, and the ‘crowding out’ of altruistic donors exist, we believe that careful implementation can mitigate these issues. Therefore, we recommend piloting financial compensation for living kidney donors at a transplant centre in England.

A critical review of the United Kingdom’s role and responsibilities within the global organ market

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Abstract:

The UK’s organ donation narrative is based within a legislative framework which promotes altruistic donation and prohibits the sale of organs within illicit markets. Data presented by the NCA (National Crime Agency) report (2019) suggested there was no evidence of harvesting of organs (p5). However, empirical evidence since the late 1980’s has suggested a universal shortage of human organs for transplant. This global shortage has a symbiotic relationship with organised crime and transplant tourism confirming that an organ trade exists while also being part of the larger human trafficking narrative. For this study, the ‘Organ Trade’ has been divided into four strands; Human Organ Trafficking, Transplant Tourism, Commercialised Human Organ Sales and lastly State Acquired Organs (associated with China). The UK shares the same profile as other organ buying western nations. While also being one of the poorest performing nations in terms of organ donation with high waiting times for transplant. Statistics show that our BAME (Black African Minority Ethnic) communities drive these trends with high rates of disease, and low rates of donation reported to be caused by religious and cultural non engagement (Chugh:2016). This research used the UK’s modern slavery narrative of supply chain management as a foundation to examine the different actors and drivers which affect the supply and demand of organs. The intent was not to reproduce available statistics on donation and organ harvesting. The aim was to explore the lived experience of those moving within these spaces and examine the possibilities that there was more to tell. By utilising a thematic analysis approach to examine the emerging themes of racial iatrogenesis, relationships of insecure environments, poor statutory oversight, and access to health. It became apparent that a metanarrative based in the relevance of history was essential.
in understanding the risks presented within the organ supply chain and form a gap analysis, while considering the ‘unknown’ relationships which draw the UK into the human organ trade. This raised the prospect that the research could create a greater dialogue and understanding of the part the UK plays in the global organ trade and provide a contribution to knowledge and understanding.

**Life after loss: Grief, community, and the donor family network**

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**Abstract:**

My project “Life after Loss: Grief, Community and the Door Family Network” looks at the way in which families who have agreed to organ donation in the past can proceed to drive organ donation and education in and outside the transplant community. Rather than focusing on the donation decision and the motives for the decision itself, I explore how the decision to say yes to organ donation can influence the lives of people after they experience the loss. The thesis outlines various degrees of engagement a person can show with the transplant community after they experience the loss, and what significance such engagement can have for that individual, other donor families, other recipients, the National Health Service and the national conversation about organ donation. To do this, I worked closely with the Donor Family Network, a charity run by organ donor families for organ donor families, attended memorial and transplant sport events and had long conversations with donor family members. I explain why my research has shown me that there are more ways of making sense of organ donation than the prevailing rhetoric of the “gift of life” or “the precious gift” that is currently used in campaigns suggests. The thesis presents alternative ways of telling the story of organ donation, which could have the potential to resonate with a wider group of people. My thesis shows the homogeneity of the way the story of organ donation is often told in public messaging, and contrasts this with the multi-faceted, complex reality that many donor family members face as a result of their decision.

**Reconsideration of the limitation and applicability of the ‘Gift Theory’ by Mauss: An examination of the post operative life experiences of Japanese heart transplant recipients**

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**Abstract:**

**Aim and background:** Mauss argues that gift-giving is a form of social cohesion. The gift theory has often been applied for examining the cultural meaning of organ transplantation. However, it is not clear what constitutes the formation of social cohesion related to organ transplantation, especially in Japanese society. This study reconsider how ‘gift theory’ by
Mauss is applicable to examine the relationship between a heart organ donor and the recipient and the limitation.

**Method:** The two heart transplant recipients were recruited from participants in a previous study. More than 15 years had passed since the last interview. They were interviewed about their emotional and physical experiences as heart transplant recipients and how their attitudes toward their relationships with their organ donors and donor families had changed or not changed. Semi-structured interviews were used. All interviews were recorded and transcribed, and interview data were thematically analysed.

**Results and Discussion:** Gradually, their thoughts and ideas about donors and donor families were changing. The two recipients often had different perspectives and thoughts about the donor. Rather than talking about them with someone else, they would often repeat them in their own thoughts. In such a situation, for a while after the transplant, the main thought was gratitude for the donor and the donor family. Over a longer period of time, they had more diverse and complex thoughts and feelings. In light of these, the following may tentatively be said: Mauss's gift theory may be applicable to discussions in the short or medium term after transplantation, especially with regard to social cohesion. However, from a long-term perspective, it would be necessary to consider a theory that focuses more on the individual's inner experience.

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**Blood, breakthroughs and bioethics: Navigating the nuances of responsible implementation of novel cell therapies for hereditary anemias**

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Stichting Sanquin Bloedvoorziening

**Abstract:**

With the aim of improving the lives of patients and families affected by sickle cell anemia and Diamond-Blackfan anemia syndrome, new cutting-edge cell therapies are being developed. These therapies revolve around creating induced Pluripotent Stem Cells (iPSCs) sourced from blood donations of healthy individuals and patients, and offer curative potential, but also raise social and ethical questions surrounding responsibility. The therapies form a crossroad between society, donors, patients, researchers, technology, and engineered body material.

Our research delves into the values, relationships, and normative dimensions associated with donating, culturing, processing, editing, and treating patients with iPSCs. Besides this and in line with the requirements of Responsible Research & Innovation (RR&I), we introduce an ethical framework of four criteria to guide the development of the therapies: Availability, Acceptability, Accessibility, and Affordability (the 4A framework).

In our research we establish the connection with all relevant stakeholders: the researchers who first must make the therapies Available; patients, their families, patient organizations, donors and clinicians for whom the therapeutic options must be Acceptable, healthcare organizations for whom the therapies must become legal and Accessible, and the parties involved in making the therapies Affordable.
To achieve our goals, we conduct a systematic literature review on the state of the art of the 4A’s in the current development of the therapies. We also conduct non- and semi-structured interviews and focus groups involving all stakeholders. However, in our research we centralize the patients’ perspective.

The research outcomes will guide the development of scenarios for applying iPSC-derived products to treat hereditary anemias in a socially and ethically responsible way. These scenarios undergo rigorous evaluation through an open and ongoing dialogue with all stakeholders. This collaborative approach ensures the creation of safe, widely accepted therapies, built on informed and voluntary donations.

Haematopoetic stem cell donor perspectives of alternative uses of their cells beyond patients transplantation: Findings from exploratory focus groups
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Abstract:
Bone marrow, or haematopoietic stem cell (HSC), registries were established to provide unrelated donor HSC for transplants to treat serious blood disorders, including blood cancers. Registries now comprise nearly 41 million adult volunteer donors, enabling thousands of lifesaving transplants annually. Emergent treatment modalities, referred to as ‘cell and gene therapies’ (CGT), are becoming increasingly central in this context. CGTs, developed predominantly by pharmaceutical companies, require cellular material for development. Some have come to market, offering alternative treatment options to HSC transplant for patients. Some registries, including UK-based Anthony Nolan (AN), increasingly see part of their role as facilitating safe, ethical provision of cellular material for CGT development. A recent survey of AN’s registered donors noted that most participants (87%) would be willing to donate cells for CGT research (Hamad et al. 2023).

The current study aims to explore in more depth donors’ perspectives on donation for research. Exploratory focus groups were undertaken with 14 active AN donors who were recruited to donate for ‘traditional’ clinical transplant. Key themes included: how CGT research donation was framed by donors as another means of engaging with the registry; how ethical challenges were perceived by donors (e.g., that research donation should be as inclusive as possible to ensure different demographics of donors are enabled to participate in donation, and ambivalence in relation to their generation of genetic information being fed back to them). The findings suggest that CGT might be more effectively described and communicated about with prospective donors at the recruitment stage but also with registered donors, to enhance the sense of ongoing participation with the registry. Moreover, findings can support registries to design research donation practices that centre donor welfare, with particular focus on limiting barriers to involvement and exploring how/whether genetic information should be provided to donors.
Redefining ‘the field’: An ethnographic study of Australian organ donation
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Abstract:
This presentation will offer a reflection on some of the methodological considerations and contingencies that emerged in a research project about deceased organ donation in Australia during the coronavirus. In following the bumpy trajectory of a project funded (and due to commence in February 2020) to ethnographically examine organ donation in ICU settings, I will speak to the divergent concerns of – and requests from – donation agencies, hospitals, clinicians, ethics committees, funders, universities, researchers, and research participants. By way of a brief overview of the research and research relations formed over this 4-year Australian Research Council study, and vis-à-vis varied positionings (as researcher, hospital volunteer, confidant), I consider how and why projects may, or may not, gain support from the people and organisations involved. While it may be particularly difficult to gain access to ‘the field’, especially for ethnographic research involving organ donation, thinking through and with the obstacles and opportunities that arise can offer productive possibilities for remaking research projects, for revising the contours of ‘the field’, and for asking what is ethnography anyway?