Everyday belongings: Exploring Australian donor-conceived adults’ social, linguistic and digital practices across private and public domains

Author:
Newton, Giselle

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Everyday belongings
Exploring Australian donor-conceived adults’ social, linguistic and digital practices across private and public domains

Giselle Newton

A thesis in fulfilment of the requirements for the degree of
Doctor of Philosophy

Centre for Social Research in Health
Faculty of Arts, Design and Architecture
UNSW Sydney

August 2022
Thesis submission for the degree of Doctor of Philosophy

Thesis Title and Abstract | Declarations | Inclusion of Publications | Corrected Thesis and Responses

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Details of the publications are provided below.

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Candidate’s Declaration

I confirm that where I have used a publication in lieu of a chapter, the linked publication(s) above meets the requirements to be included in the thesis. I have also adhered to the University’s guidelines for the preparation of the thesis.
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This thesis was primarily developed on the unceded lands of the Bedegal people. I pay my respects to Elders past, present and emerging. Always was, always will be.

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ABSTRACT
From the turn of the century, social attitudes have shifted away from secrecy and anonymity in donor conception in line with broader recognition that children have a right to accurate information about their identity and family. As such, some donor-conceived people are now growing up in families who disclose and discuss donor conception openly while others are unexpectedly learning of their donor-conceived status later in life. Yet, little empirical research has explored the array of actors, processes and technologies that shape experiences of belonging for donor-conceived people. This thesis reports on exploratory research of Australian donor-conceived adults’ experiences. The project adopted an innovative interdisciplinary approach, combining methods and analytic techniques from sociology, social semiotics and media studies to explore everyday social, linguistic and digital practices. Data comprise Hansard from a public hearing of a Senate Committee Inquiry into donor conception; a national online survey with sperm donor-conceived (n=90) and egg donor-conceived (n=1) respondents over 16 years of age; and semi-structured interviews with sperm donor-conceived adults (N=28). The research is also underpinned by vignettes of personal experience to reflexively foreground my own positionality as a donor-conceived person. Findings reveal the significant role that digital technologies play in donor-conceived people’s everyday lives. Donor-conceived peers used digital platforms to exchange experiential knowledge and negotiate meanings ascribed to their collective identity, to educate (prospective) recipient parents and the general public about their perspectives, to trace family members through direct-to-consumer DNA testing, and to strategise for increased recognition in legislation. In terms of family, participants navigated complex and dynamic familial (non) relationships and the lingering consequences of anonymity. However, donor-conceived people also found strategies to help them reckon with secrecy and silence, actively responding to social conditions and challenging the institutions of medicine and the law. Indeed, donor-conceived people drew on experiential and institutional knowledges to position themselves as an authority on donor conception as people with lived expertise. I argue that belonging, for donor-conceived people, is experienced across three planes: in relation to peers, family and the State. In doing so, this thesis underscores how everyday belonging is relational and processual, and achieved through a range of momentous events, everyday encounters and humorous artefacts.
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CHAPTER 1 - Introduction

Attitudes about how to form a family and who constitutes family continually evolve. While the heterosexual nuclear family model has long been a dominant form across many cultures, creating a family according to this structure has not always been possible or desirable. For centuries, infertility has affected the ways people have created families, and many people have sought to identify contributing factors and ‘cure’ the condition (Allan, 2017). One technique used to overcome infertility since at least the early 19th century is artificial insemination with donor gametes (Beeson et al., 2011; Daniels & Taylor, 1993; Swanson, 2012). In the Australian context, donor conception was first reported in 1946 (Adams & Lorback, 2012; Fertility Society of Australia, 2010; Gregoire & Mayer, 1965). During this period, the practice was conducted in private rooms of individual doctors (Adams & Lorbach, 2012; Kelly & Dempsey, 2018). From the 1970s, donor insemination programs were set up at hospitals such as Prince Henry’s, Queen Victoria and the Royal Women’s in Melbourne, Victoria, with medical students donating the required sperm (Kelly & Dempsey, 2018). The 1970s and 1980s saw significant developments in assisted reproduction – with successful pregnancies using In Vitro Fertilisation (IVF) and progress in cryopreservation – advancements which would facilitate gamete and embryo collection, banking and transportation (Clarke, 2006; Steptoe & Edwards, 1978; Zeilmaker et al., 1984). Although unsuccessful in facilitating the first IVF birth, Australian researchers were eagerly experimenting and later orchestrated the first live birth through egg donation (Monash IVF, 2022; Trounson et al., 1983). Innovation in assisted reproduction in Melbourne led to the establishment of clinics in other Australian capital cities – Sydney, Adelaide, Brisbane and Perth – where doctors would begin assisting more families experiencing infertility using a combination of older techniques, such as donor insemination, and newer technologies, such as IVF with donor gametes (Cohen et al., 2005).

From the early days of experimentation using donor sperm to conceive, and for many decades to come, the practice of donor conception was secretive: doctors promised donors anonymity and encouraged parents to keep details of their fertility treatments from their children and others. These silences were thought to shield the parents from the shame of infertility, the donor from legal paternity and succession issues, the child from stigma, and the doctor from legal uncertainty and public scrutiny (Bennett, 1997; Daniels, 2007; Haimes & Daniels, 1998; Haimes, 1993; Swanson, 2012). Doctors used techniques such as sperm matching so that the
child would share physical resemblances with their social father, or sperm mixing where the
donor’s sperm was combined with the social father’s sperm to confuse paternity (Adams &
Lorbach, 2012). Couples were often encouraged to have sexual intercourse following the
procedure to forget the insemination had occurred (Allan, 2017; Rowland, 1985; Swanson,
2012). Further practices contributed to ongoing secrecy: some doctors did not verify donor’s
identities; used sperm from anonymous interstate donors or from donors without informed
consent; encouraged donors to use pseudonyms; encouraged patients to donate; used different
codes for the same donor; offered donors course credits, STI testing, free vasectomies, sperm
storage or payments in exchange for donation; and/or used the same donor to knowingly
create up to 30 separate families or more than 40 donor siblings (Dobby, 2010). Some doctors
also used their own sperm to inseminate patients (Dingle, 2021). From the 1970s, with
developments in IVF and cryopreservation, there was increased attention and scrutiny
towards reproductive technologies from the public, particularly in relation to the newer
technologies. However, donor conception remained a largely secretive practice.

Outside the clinical context, from at least the 1970s, same-sex couples were experimenting
with self- or home-insemination using ‘fresh’ donor sperm as a solution to social infertility
(the lack of necessary gametes to conceive a child) (Donovan, 2000; McNair et al., 2002;
Saffron, 1994). These donor conception practices within queer families paved the way for the
‘gayby boom’ in the following decades (Dempsey, 2006). As such, practices under the
umbrella of donor conception were being used by a range of families. More broadly, the
1980s and 1990s saw a proliferation of alternative relationship and family forms, reflective of
the increasing agency individuals had to make decisions about their personal and family life
(Heard & Arunachalam, 2014). This period also saw a new sense of individualism emerging,
which was articulated through the enactment of personal freedoms, including the claim to
autonomy and the right to make decisions based on personal preference (Beck & Beck-
Gernsheim, 2002; Giddens, 1992). In the context of healthcare, patients were increasingly
taking a more active position (Lupton, 1997). As such, broad shifts were occurring in
relational and power dynamics.

The technological and social developments described above are relevant to understanding
how my own parents approached having a child through donor conception. In the early
1990s, my parents were unsuccessful in their efforts to achieve pregnancy naturally and thus
sought medical advice. To participate in the ‘Donor Sperm Programme’ at the Royal Darwin
Hospital, my mother and father’s doctor presented them with a consent form that stated that
the staff would select a suitable donor and the identity of the donor would not be disclosed to them, nor their identity or the (resulting) child’s identity to the donor. Doctors’ attitudes with regards to secrecy and anonymity in donor conception had barely shifted between the 1940s and 1990s. Focused on achieving pregnancy through any means, my parents signed the documents and in doing so, agreed to a specific relational structure between the doctor, the anonymous donor, them and their hypothetical child. My mother was working at the hospital where she sought treatment and balancing arduous night shifts and invasive fertility cycles, after multiple rounds of donor insemination, she fell pregnant in April 1993.

Despite advice to the contrary from their doctor, my parents approached the circumstances of my conception with openness within our nuclear family unit. Sprinklings of age-appropriate detail like being a ‘special’ baby were integrated into my family narrative which was developed into a complete and truthful set of conception facts once I had reached sufficient maturity to understand. And my parents were not the only parents opting to disclose. For example, in 1993, a group of parents of donor-conceived children formed a support group to discuss how to tell children about their conception, and how to negotiate relationships with clinics, donors and siblings (Donor Conception Support Group of Australia Inc., 2010).

These careful negotiations were reflective of broader shifts in parenting norms at this time, in which transparency and openness were valued over ideas about the privacy and the protection of children from information previously considered the jurisdiction of adults (Frith, Blyth, Crawshaw, & Akker, 2018; Grace et al., 2008; Indekeu et al., 2013; Smart, 2007). Moreover, attitudes towards the rights of the child were evolving too, in line with the tenet within Western law that the best interests of the child should always be paramount (Daniels & Taylor, 1993; United Nations, 1989). The United Nations Convention on the Rights of the Child in 1989, for example, outlined a number of rights of relevance to the donor-conceived child, such as: the preservation of identity, nationality and family relations; to know, be cared for by, and not be separated from parents; to maintain direct and regular contact with both parents; to express views, be heard and receive and impart information in all matters affecting the child (United Nations, 1989).

The donor conception support group established in 1993 later expanded their scope to include an advocacy agenda (Donor Conception Support Group of Australia Inc., 2010). The group advocated for the rights of all donor-conceived people to accurate information about their conception and family. In 1996, in the first event of its kind, ‘the Donor Issues Forum’, was
Chapter 1: Introduction

held in Sydney and brought together stakeholders in donor conception including donor-conceived young people and adults (Donor Conception Support Group of Australia Inc., 1997). This event also led to larger donor conception conferences in Australia in 2001 and 2004. Later, an advocacy group, TangledWebs, was formed by donor-conceived people and allies in Melbourne and built upon the work of the Donor Conception Support Group of Australia in Sydney. This advocacy work on donor conception was contemporaneous with broader social patterns in which the value of engaging with people with lived experience was increasingly being recognised (Charlton, 2000; The Consumer Focus Collaboration, 2001). While in donor conception, the needs and perspectives of parents, donors and doctors had been foregrounded since the beginning of the practice, it was becoming increasingly clear that the best interests and rights of ‘donor offspring’ should be prioritised (Blyth, 1998).

In the first 10 years of my life, other technological changes were occurring that would allow donor-conceived people to discover many more people ‘like them’ (see also Blyth, 2002b; Cushing, 2010). The internet was entering the private home and becoming an everyday technology that would reshape the ways people accessed information and interacted (Livingstone, 2005). In 2000, an international Yahoo group was created called People Conceived Via Artificial Insemination (PCVAI) which allowed donor-conceived people to directly seek out and make contact with their donor-conceived peers (Adams & Lorbach, 2012; Crawshaw et al., 2015; Cushing, 2010). Later, in 2006, came the Australian Donor Conception Forum which was superseded by a Facebook group, the Australian Facebook Group for Donor-conceived People, created in 2012. In a similar vein, another online initiative, developed by a mother of a donor-conceived person, Wendy Kramer, for donors, parents, and donor-conceived people, was the Donor Sibling Registry (Donor Sibling Registry, 2022). From 2000, this registry began matching individuals and families using donor codes for an annual fee. As such, ‘Web 2.0’, with its emphasis on user-generated content, brought with it distinct relational possibilities for donor-conceived people and their families.

In 2012, as I finished high school and was transitioning to adulthood, I felt increasingly curious about my conception and capable of navigating a route to additional information. Outside the family home, beyond my parents’ oversight and sensitivities, and with the internet, I began searching. With the information my mother had provided, I made enquiries to the hospital where I was conceived. As though I was speaking another language, staff were bemused by the idea that there had been a donor conception program and my interactions
with staff required a lot of explaining on my behalf, which was awkward given I was also trying to reconstruct the details of my conception myself. A tactic which functioned to both dissuade me and buy them more time, staff at the hospital suggested they required patient consent to begin searching for records. The way they positioned me as a secondary party to the information about my conception left me feeling disheartened, and my mission to pave my own path as a capable adult had been disrupted. Through more conversation with my mother and her cooperation to access additional information, it became clear that the sperm had likely been donated, frozen and sent from a clinic over 3000km away from the Northern Territory hospital, in another jurisdiction, Western Australia. Internet searches revealed that there was a voluntary register in that state, and so I filed an application.

Around that time, in 2012, I also found out about a Facebook group for donor-conceived Australians. After proving details about my conception, I gained access to the private, hidden group. “Welcome Giselle!” the moderator posted to the group of around 60 people, accompanied by my introductory post. From then I began being exposed to donor-conceived people’s experiences on an everyday basis. I could ask if others had dealt with the donor conception register and whether waiting for months was ‘normal’. By the end of my first year in the Facebook group, donor-conceived people had begun discussing DNA testing kits being newly offered by companies like 23andMe and FamilyTree DNA for less than one hundred Australian dollars (see also Adams & Lorbach, 2012; Cushing, 2010). Databases on these platforms were still growing but donor-conceived people were reporting 4-7th cousin matches. These technologies were viewed as an alternative to accessing medical records, and as a way to find out reliable information about one’s biological family.

Not only did social media provide a platform for disseminating information and exchanging support, it also afforded a channel to strategise. Donor-conceived people were increasingly raising awareness about their difficult quests to access information more publicly, for example, in government inquiries and public hearings, and in the media (Australian Broadcasting Authority, 2014; Dingle, 2014; Parliament of Victoria Law Reform Committee, 2012; The Senate Legal and Constitutional Affairs References Committee, 2011; Tomazin, 2013). In speaking out in public, donor conceived people were drawing attention to hitherto hidden dimensions of donor conception practice. More broadly, they were challenging dominant narratives which portrayed parents’ difficult infertility journeys and heroic fertility practitioners who created ‘miracle babies’ (Burns, 2022). Indeed, the ‘miracle babies’ had
grown up and were keen to make their voices heard. Additionally, as donor-conceived people appeared in the media, membership of the donor-conceived Facebook group grew.

In 2010, five donor-conceived people, Damian Adams, Lauren Burns, Myfanwy Cummerford, Kimberley Springfield and Michael Williams, gave evidence at the public hearing of the Australian Parliament’s Legal and Constitutional Affairs References Committee Inquiry into Past and Present Practices of Donor Conception in Australia (henceforth the Inquiry). In 2011, following the Inquiry, the committee remarked that: “there would be significant benefit in having records relating to donor conception, particularly personal information about donors and donor conceived people, stored in a single national register” (The Senate Legal and Constitutional Affairs References Committee, 2011, p. 94). While no national register was ever created, the Inquiry provided a platform for donor-conceived people – through their testimonies and recommendations to the committee – to draw attention to their experiences, and position themselves and their needs in novel ways (explored more in Chapter 4).

In Victoria, a state-based inquiry ran in parallel with the national Inquiry. Several members of TangledWebs tirelessly advocated for reform. The lived experience of one donor-conceived person in particular had a major impact on the course of events. Narelle Grech, a donor-conceived woman who had been searching for her donor for half of her life, was diagnosed with stage 4, likely inherited, bowel cancer in 2011 (Grech, 2011). In her submission and statement at the public hearing to the Victorian Inquiry into Access by Donor-Conceived People to Information About Donors, Grech pleaded for access to medical records about her sperm donor, ‘T5’, in order to inform her donor siblings and meet her donor before her death. Grech advocated for reform that would allow all donor-conceived people accurate information about their biological and medical histories. As Grech was referred to palliative-care services, the Law Reform Committee chair Clem Newton-Brown referred Grech’s case to the premier of the state, Ted Ballieu, who intervened and authorised the Public Record Office to release records to the Attorney-General’s Office so that staff could contact Grech’s donor. During the final six weeks of her life, Grech’s biological father, Raymondo ‘T5’ Tonna, travelled to visit Grech in hospital almost every day. It also became clear that while the fertility practitioner had insisted for many years that he had reached out to Grech’s donor, no letter was ever received by Tonna.
Narelle Grech did not survive to see the introduction of world-first legislation in Victoria from 2014 and 2016 (*Reproductive Treatment Further Amendment Act 2014* (Vic), *Assisted Reproductive Treatment Amendment Act 2016* (Vic)); retrospective legislation which entitled all Victoria donor-conceived people access to identifying information about their donor. The introduction of the Victorian legislation marked a major tipping point: the rights of donor-conceived people to know their biological identity were being centred and privileged over the rights of donors to retain anonymity. Donor-conceived people’s voices were finally being listened to and acted upon.

Following this reform, governments in several Australian jurisdictions conducted reviews or began considering pathways to the introduction of legislation (Australian Capital Territory, Queensland, South Australia, Tasmania, Western Australia). Across Australian states and territories, legislation continued to shift in an evolving patchwork (Allan, 2017) (see Table 1). The significant disparity between the rights afforded to donor-conceived people depending on jurisdiction and year of birth grew. For example, Victoria introduced legislation on donor conception in 1984 and from 2016, all donor-conceived people conceived in Victoria were granted access to identifying information about the donor via the central register despite year of birth. In contrast, the jurisdictions of Queensland, Tasmania, the Australian Capital Territory and the Northern Territory to date have not introduced legislation on donor conception, and thus donor-conceived people have been left to negotiate information via the clinic or hospital where they were conceived. Those jurisdictions without legislation have been guided by the National Health and Medical Research Council (NHMRC), Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research, which have existed since 1996, although the importance of protecting the identifiability of the donor for the wellbeing of donor-conceived people was only outlined from the 2004 edition (NHMRC, 1996, 2004). Moreover, as guidelines they do not have the legal force of legislation.

*Table 1: Overview of legislation, reform and access to information across Australia*

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Legislation as of May 2022</th>
<th>Abstract of Review/Inquiry</th>
<th>Access to information/Donor Conception Register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>State/territory-based legislation</td>
<td>2010 Legal and Constitutional Affairs References Committee Inquiry into Past and Present Practices of Donor Conception in Australia</td>
<td>Access to information varies by state/territory of conception and year of conception. Some states/territories have a donor conception register to facilitate access to</td>
</tr>
<tr>
<td></td>
<td>Assisted reproductive technology is guided by the National Health and Medical Research Council (NHMRC) Ethical guidelines on the use of</td>
<td>Recommended the</td>
<td></td>
</tr>
</tbody>
</table>


Chapter 1: Introduction

<table>
<thead>
<tr>
<th>State</th>
<th>Assisted Reproductive Technology Act</th>
<th>Assisted Reproductive Technology Regulations</th>
<th>Legislation/Inquiry/Review</th>
<th>Information Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td>None</td>
<td></td>
<td>In 2021, politician Marisa Patterson proposed establishing a regulatory framework and a donor register in the ACT.</td>
<td>None</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>None</td>
<td></td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>New South Wales</td>
<td>Assisted Reproductive Technology Act 2007 (NSW)</td>
<td>Assisted Reproductive Technology Regulation 2009</td>
<td>2013 Inquiry into managing information related to donor conception</td>
<td>Those conceived after 2010 can access identifying information via a central register. Those conceived before 2010 can join a voluntary register.</td>
</tr>
<tr>
<td>Queensland</td>
<td>None</td>
<td></td>
<td>2022 Inquiry into Matters Relating to Donor Conception Information</td>
<td>Currently being deliberated</td>
</tr>
<tr>
<td>Tasmania</td>
<td>None</td>
<td></td>
<td>2016 Inquiry into Donor Conception Practices in Tasmania</td>
<td>None</td>
</tr>
<tr>
<td>Victoria</td>
<td>Assisted Reproductive Treatment Act 2008 (ART Act)</td>
<td></td>
<td>Amendments in 2016 allowed for full retrospective release of information for all donor-conceived people regardless of the donor’s consent</td>
<td>All donor-conceived people can access identifying information via a central register.</td>
</tr>
</tbody>
</table>

As this brief outline of donor conception in Australia demonstrates, over the last three decades the everyday lives of donor-conceived people have been significantly impacted by a range of social, technological and legislative changes. In 2018, fascinated by how donor-conceived people were negotiating digital technologies, community, family and change, I deliberated on whether this topic would be a suitable focus for a PhD. Exploring this topic would likely mean being more open and public about my own conception story. My mother supported my decision, believing that my personal involvement and investment in the issue...
would likely drive my interest in and commitment to the study. However, other members of my family felt exposed by my decision to focus on donor conception, reflecting how the topic entangled sensitive and personal stories beyond my own. And indeed, more than once throughout my doctoral study I asked myself where the limits of my personal story end and the terrain of others’ stories begin. While I have sought to do justice to many of my own truths in this thesis, I have tried to do so without causing harm to others or overlaying my own experience over theirs. Donor conception is a sensitive topic both within my family and broader cultural context in which I am enmeshed. Speaking about donor conception involves a de-coupling of sex from reproduction, and framing family both in terms of its biological and its social dimensions. Discussing donor conception often involves talking about infertility and individuals’ perceived right to a child, issues which continue to be emotionally charged and difficult to discuss within our culture. Research on donor conception, then, as I became increasingly aware, could be both an extremely personal and political domain to be working in.

As I have sought to demonstrate in the initial paragraphs of this introduction, my positionality as an ‘insider’ in this research affected all aspects of this thesis: from topic choice, research design, coding, analysis and writing. My personal experience can be interpreted within a specific socio-historic moment, and through this doctoral study I sought to extend beyond my experience to trace the social, legal and technological processes that have impacted Australian donor-conceived people’s lives.

**Literature review**

Stepping into my doctoral program, I began considering the magnitude of infertility and assisted reproductive technologies, and how these issues had been described and conceptualised within the peer reviewed literature. Biological infertility is defined as a condition in which an opposite-sex couple engages in unprotected sexual intercourse over a 12-month period and does not achieve pregnancy, and may be caused by a range of lifestyle, sexual, psychological or physical issues, including diseases, infections and disorders, chromosomal or gene abnormalities or age-related fertility decline (Babakhanzadeh et al., 2020; Vander Borght & Wyns, 2018). Biological infertility is experienced by one in six couples, amounting to approximately 186 million individuals globally (ESHRE, 2018; World Health Organisation, 2022). Throughout history, one solution to biological infertility has been to conceive using donor gametes. The other form of infertility which drives people to donor conception is social infertility, where an individual or couple want to have a child but do not
have all of the necessary gametes. For at least five decades LGBTQ+ people and solo parents
have forged avenues to parenthood via donor conception in a private/home-based or clinical
setting (Crouch et al., 2013; Dempsey, 2015; Kelly & Dempsey, 2017; Power et al., 2020).
Today, solo mothers and same-sex mothers represent the dominant family type accessing
donor conception (Linara-Demakakou et al., 2020; VARTA, 2021).

Another issue leading to infertility for people of diverse genders and sexualities is delayed
parenthood. In Australia, like many developed nations, a range of factors have contributed to
delays in parenthood, including increased control over family planning through access to
reliable contraception and abortion, prioritisation of professional trajectories, an increasing
focus on being emotionally and financially ready for a child, and limited fertility-related
knowledge (ABS, 2020; Berrington, 2004; Cooke et al., 2012; Frejka & Sardon, 2006;
Hammarberg & de Silva, 2022). Yet delaying parenthood can have consequences for
individuals’ fertile capacities, and many couples facing age-related infertility are turning to
cryopreservation or donated gametes or embryos as a solution (Baldwin et al., 2019; Sartorius
& Nieschlag, 2010; Waldby, 2019). It is therefore unsurprising that assisted reproduction is a
rapidly-growing, multi-billion dollar industry, expected to reach US$41 billion by 2026
(Stewart, 2021). Globally there have now been more than 8 million babies conceived using
assisted reproductive technologies, with 2.5 million cycles and 500,000 births achieved
annually, and the number of families accessing assisted reproductive technologies to conceive
increasing year after year (Chambers et al., 2021; Fauser, 2019). While the provision of
(in)fertility treatment was interrupted by the Covid-19 pandemic, reproductive care has
subsequently been gradually resumed (ASRM/ESHRE/IFFS, 2021; Smith et al., 2020). This
evidence suggests that donor conception will continue to be a key mode to creating a family
into the future, including across diverse family forms.

The number of people donor-conceived people in Australia or other countries is unknown.
Estimates in 2011 suggested there may be between 20,000-60,000 donor-conceived people in
Australia (Commonwealth of Australia, 2011), although numbers have increased dramatically
in the last decade (Newman et al., 2019). This lack of information on the prevalence of donor
conception is due to a range of factors, some of which have already been alluded to. Firstly,
worldwide there has been a history of clinicians delaying reporting on donor conception,
keeping poor or incomplete records, and modifying and destroying records (Allan, 2017;
Cox, 1991; Haimes, 1993; Hewitt, 2002; Klotz, 2016; Rowland, 1985; The Senate Legal and
Constitutional Affairs References Committee, 2011). To date there has been a lack of
standardised procedures for reporting donor conception worldwide, further complicated by
the prevalence of private arrangements with a known donor or donor sourced through social
media, as well as a rise in reproductive tourism whereby individuals or couples travel
overseas to access fertility treatments (Canzi et al., 2019; Crouch et al., 2013; Hudson et al.,
2011). Finally, given many parents do not disclose to their children that they are donor-
conceived, the number of people that are able to self-identify as donor-conceived is limited
(Macmillan et al., 2021). Since 2002, the Australia and New Zealand Assisted Reproduction
Database has collected information on all assisted reproductive technology treatment cycles
within fertility clinics (National Perinatal Epidemiology and Statistics Unit, 2022). In 2019
alone, 3,010 donor (sperm) insemination cycles and 3,532 donated oocyte/embryo cycles
were reported across clinics in Australia and New Zealand, cycles which resulted in 395 and
829 births respectively (Newman et al., 2019).

Turning to social research on assisted reproductive technologies, while there has been
increased academic attention in recent decades, many scholars have focused on IVF, and
other techniques have often been overlooked. For example, within the “new interdisciplin ary
field of reproductive studies” much research has framed assisted reproduction in relation to
its so called “inception” in 1978 (Franklin & Inhorn, 2016, p. 2; see also Ferber et al., 2020).
In doing so, researchers not only ignore a longer global history of experimentation and
discovery, but also erase those conceived prior to this period and/or with reproductive
techniques other than IVF, such as donor conception.

Donor conception as a field of study is a relatively small and recent, and research with donor-
conceived people has been limited (Macmillan et al., 2021). For example, in terms of
empirical studies, prior to 2000 no studies had been published on donor-conceived people’s
experiences (Blyth et al., 2012). In contrast, from 2000-2011, 19 empirical articles were
published representing 12 distinct studies, eight of which included donor-conceived adults
(Blyth et al., 2012). In the last decade, approximately 40 articles have been published
involving donor-conceived people with sample size ranging from N=6 to N=741, revealing a
growing interest in the topic and in line with increased popular and political attention (Canzi
et al., 2019; Indekeu et al., 2021).

Within this emerging field, scholarship on donor conception has largely focused on familial
dynamics. In much early research on donor conception, like scholarship that focused on other
non-normative families, researchers sought to show that donor families were capable of
“positive parenting and well-adjusted children” (Golombok, 2018, p. 239). In order to do so, research has been focused on understanding processes of disclosure of donor-conceived status to donor-conceived people and the impact of this disclosure on relationships between parents and their donor-conceived child/ren (Freeman & Golombok, 2012; Golombok, 2018; Golombok et al., 2002, 2013). This research has demonstrated that donor-conceived people who find out about their conception during early childhood have more positive attitudes towards their conception and more positive psychosocial outcomes (Golombok, 2021; Ilioi et al., 2017; Jadva et al., 2009; Scheib et al., 2005; Turner & Coyle, 2000; Vanfraussen et al., 2003). In contrast, late disclosure has been found to be associated with a broader range of negative emotional responses, such as anger, shock and distrust (Jadva et al., 2009; Lampic et al., 2022; Turner & Coyle, 2000). However, in cases of late disclosure, donor-conceived people report that they are glad to know the accurate details of their conception despite the difficulties associated with integrating this information into their identities (Jadva et al., 2009).

While the ‘turn to openness’ has resulted in more people learning that they were donor-conceived, there is a significant gap between parents’ intent to disclose and actual disclosure rates (Readings et al., 2011). Recent studies have shown that the majority of heterosexual parents do not disclose donor conception status to their child (Lassalzede et al., 2017; Tallandini et al., 2016), suggesting that although it has become more socially desirable to be open with children about their origins, finding ways to disclose remains difficult or unclear and as a result, parents either avoid or postpone disclosure. For the significant portion of parents that maintain secrecy, there is a considerable risk that alternative actors or processes may reveal the person was donor-conceived, such as extended family members or friends of the family, government authorities, the donor, or DNA testing (Allan, 2017; Klotz, 2016; Macmillan et al., 2021).

Researchers have also sought to understand whether and to what extent donor-conceived people are motivated to seek contact with donors and donor siblings. A range of studies have illustrated that the majority of donor-conceived people view information about their donors as important, and useful for understanding themselves and for illuminating similarities between themselves and their donors (Beeson et al., 2011; Blyth, 1998; Dempsey et al., 2019; Hertz et al., 2013; Jadva et al., 2010; Kelly et al., 2019; Koh et al., 2020; Macmillan et al., 2021; Mahlstedt et al., 2010; Rodino et al., 2011; Scheib et al., 2005; Scheib et al., 2017; van den Akker et al., 2015; Vanfraussen et al., 2001, 2003). Many donor-conceived people also desire
contact and/or an ongoing relationship with their donor (Beeson et al., 2011; Hertz et al., 2013; Jadva et al., 2009; Kelly et al., 2019; Macmillan et al., 2021; Mahlstedt et al., 2010; Nelson et al., 2013). However, research has also highlighted that many donor-conceived people avoid discussing their curiosity towards their donor and delay contact to avoid upsetting their parents, particularly social fathers in heterosexual-parented families or non-biological mothers in lesbian parented families (Beeson et al., 2011; Harrigan et al., 2014; Jadva et al., 2010; Mahlstedt et al., 2010; Vanfraussen et al., 2001). In families in which the donor-conceived person had a strong relationship with their social father, this positive dynamic did not lessen donor-conceived person’s curiosity about the donor (Mahlstedt et al., 2010) and in families without a co-parent, donor-conceived people were more comfortable indicating they were curious about the donor and more likely to seek contact (Beeson et al., 2011; Macmillan et al., 2021). Negotiating relationships can evidently be complex for donor-conceived people.

In terms of donor siblings, research has suggested that many donor-conceived people have a strong interest in meeting others conceived with the same donor and have sought to establish ongoing relationships (Cushing, 2010; Frith, Blyth, Crawshaw, & van den Akker, 2018; Hertz et al., 2013, 2017; Jadva et al., 2010; Mahlstedt et al., 2010; Nelson et al., 2013; Persaud et al., 2017; Rodino et al., 2011; Scheib et al., 2005; Scheib et al., 2020; van den Akker et al., 2015). In a similar vein to motivations to learn about and have contact with donors, donor-conceived people seek relationships with their siblings to have a more complete sense of who they are in relation to genetic family members, and also to avoid consanguineous relationships (Frith, Blyth, Crawshaw, & van den Akker, 2018; Hertz & Mattes, 2011; Nelson et al., 2013; Persaud et al., 2017). Despite this evidence on donor-conceived people’s attitudes towards relationships with donors and donor siblings, how donor-conceived people initiate and maintain everyday relationships with donors and donor siblings is less clear.

Scholarship has also explored the meanings donor-conceived people ascribe to family, kinship, relatedness, resemblance and genetics (see Blyth, 2012a; Frith et al., 2018; Harrigan et al., 2014; Hertz et al., 2017; Indekeu & Hens, 2019; Martin, 2019). For example, Harrigan and colleagues (2014) have underscored how donor-conceived people understand family, both in terms of nature (connection to family based on shared genetics) and nurture (connection to family based on love and care), and as something that could be constructed from either or both. In particular, the researchers point to how donor-conceived people resist
dominant discourses that often favour the role of nurture and minimised the role of nature. Further, the article highlights how donor-conceived people redefine family through definitions that encompass and legitimate both nurture-based family members (such as their social father) and the biological-based family members (to include the donor/biological father and siblings). Thus, as individuals are increasingly invested in information about genealogy, genetics and the body, donor-conceived people’s experiences offer timely insights into who matters in terms of family, the role of familial narratives in identity formation, and how individuals position themselves in familial webs.

A handful of studies on donor-conceived people have been conducted in the Australian context. These studies have focused on donor-conceived people’s health and mental health outcomes (Adams et al., 2021a; Adams et al., 2021b), donor-conceived people’s attitudes towards information about donors (Rodino et al., 2011) and how demographic characteristics, mental health and disclosure experiences influenced information seeking patterns among donor-conceived people (Macmillan et al., 2021). While these studies come from positivist traditions, several studies other Australian studies following an interpretivist approach have also been conducted with donor-conceived adults. These studies have explored how donor-conceived people frame their motivations for information in ‘statements of reasons’ documents written for donor conception registers (Dempsey et al., 2019; Kelly et al., 2019) and how donor-conceived people negotiate relationships with their infertile social fathers (Cosson et al., 2021). Therefore, there is significant scope to build on and extend previous research on Australian donor-conceived people’s experiences.

From the early 2000s, studies pointed to how the internet could/would impact the ways that donor-conceived people accessed information about their genetic relatives and other aspects of their conception story (Blyth, 2002b). In the following decade, scholars predicted that the internet, coupled with DNA testing and matching technologies, would represent the most popular method for locating donors and donor siblings, including those who may not wish to be found (Hertz & Mattes, 2011; Jadva et al., 2010). Since that time, more donor-conceived people have joined online groups for donor-conceived people (Adams & Lorbach, 2012; Crawshaw et al., 2015; Cushing, 2010) and the rapid uptake of direct-to-consumer DNA testing and, more recently, facial recognition technologies, have provided donor-conceived people with more avenues to search for and identify family members (Crawshaw, 2018; Crawshaw et al., 2016; Darroch & Smith, 2021; Frith, Blyth, Crawshaw, & van den Akker, 2018; Harper et al., 2016; Klotz, 2016; Łukasiewicz & Allan, 2022). Indeed, research has
emphasised how “online social engagement is central to new intimate family formations” (Andreassen, 2017, p. 362; see also Hertz & Mattes, 2011). Yet, few empirical studies have explored how digital technologies are reconfiguring donor-conceived people’s relational possibilities. One exception that merits attention is Klotz's (2016) article which focused on how DNA testing allows donor-conceived people to assert agency, based on interviews with six participants (see also Crawshaw et al., 2016; Frith, Blyth, Crawshaw, & van den Akker, 2018). As such, there is significant scope for in-depth exploration of how donor-conceived people are using digital technologies such as social media and direct-to-consumer DNA testing to trace their biological family members. Further, more empirical work is needed to understand how, beyond affording new opportunities for familial relationships, these technologies might allow donor-conceived people avenues to negotiate collective identity and community.

While few studies have explored donor-conceived adults’ identities or personal narratives, two studies are worth drawing attention to. The first, by Harrigan and colleagues (2015), took a novel approach to donor-conceived adults’ identity construction by exploring how – through communication – identities are negotiated and maintained. Specifically, the study explored five themes, the first encapsulated as “I am the victim” relating to how donor-conceived people felt “burdened”, “deceived” and “silenced” by donors and parents, fertility specialists, the medical community and legislating bodies, and by social discourses and stereotypes that constrained their identity. Donor-conceived people positioned themselves as “wanted”, given the processes required by their parents to conceive, and also “enigmatic” in relation to their donors’ anonymity, their limited contact with other donor-conceived people, and the intrigue by the general public in relation to their experiences. However, according to the authors, donor-conceived people also understood themselves as storytellers who could captivate others with this aspect of their identity, shape the general public’s understanding of the issue to minimise shame, and create narratives about the imaginary lives of their unknown family members. Finally, due to this aspect of their identity, donor-conceived people viewed themselves as a “process”; as their experience, knowledge and relationships evolved so did their sense of self. From this work we can see how donor-conceived people are active agents, and their identity constructions are dynamic, multifaceted and complex. This research also highlights how for donor-conceived people, identity extends beyond family, to relationships with peers, the general public, institutions and governments.
The second important contribution to understanding donor-conceived adults’ experiences is scholarship by Postan (2016, 2017). Postan (2016) drew on previous empirical work to argue that information about one’s conception can contribute to self-narratives in multiple ways. For example, information about conception and birth informs the ways individuals envisage the starting point of their biographies. Additionally, conception information can influence the ways donor-conceived people understand their relational roles and relationships within broader genetic and social familial networks. This can be experienced as disruptive if it conflicts with long established identity narratives and can jeopardise the coherence of identity narratives, or have explanatory potential in terms of physical and character (dis)alignments with family members. Finally, donor-conceived people may self-label as ‘donor-conceived’ as a consequence of engagement with networks of donor-conceived people and shared informational practices. Postan’s scholarship, then, gestures towards a more holistic approach to understanding of donor-conceived people’s self-narratives, illustrating how individuals may incorporate information to position themselves within their families and peer groups but also to situate themselves within historical, political and legislative contexts. Further research is thus needed to explore what the identity of donor-conceived means in a digital age and how peer interaction might impact the ways donor-conceived people understand themselves.

A small yet valuable body of literature has explored donor-conceived people’s views about donor conception as a practice. Researchers have suggested that donor-conceived people born in the 1970s and 1980s represent some of the strongest proponents in movements to end secrecy and anonymity, and have long been speaking publicly to educate the general public and assisted reproduction providers about their experiences and attitudes (Allan, 2017; Daniels, 2020; Macmillan, 2016; Mahlstedt et al., 2010). In one of the only empirical studies of its kind, Mahlstedt and colleagues (2010) examined donor-conceived people’s attitudes towards their own conception and gamete donation as a practice and found that 60% believed that donor conception should only occur where there is identity release, and that birth certificates should state the donor’s name (Mahlstedt et al., 2010; see also Blyth, 2012b; Kirkman, 2004). Further, two thirds indicated they would not donate gametes and a majority of respondents said they would not conceive using donated gametes, gesturing toward broadly negative attitudes towards the practice (Mahlstedt et al., 2010). However, this research leaves unanswered questions in relation to whether and how donor-conceived people’s attitudes impact their relationships with their parents. Donor-conceived people’s attitudes towards and interactions with the fertility practitioners and clinics responsible for
their conception or the fertility industry more broadly are unclear. Additionally, there is limited evidence around how donor-conceived people advocate for change, interacting with decision-makers, regulatory bodies and governments responsible for ensuring ethical practice in donor conception.

In summary, there is an emerging body of research on donor-conceived people’s experiences. This research has largely focused on familial relationships and offered useful insights disclosure patterns and attitudes towards relationships with donors and donor siblings. There is significant scope to further explore how donor-conceived people position themselves beyond the family, particularly in relation to peers and the State. Building on the above and other work, in this thesis I explore donor-conceived people’s everyday, digital lives across social domains considering what it means to belong as a donor-conceived adult today.

Research aims
This research was deliberately exploratory in nature and pursued three primary aims:

- To describe and analyse Australian donor-conceived adults’ experiences across private and public domains.
- To combine a range of approaches and methods to explore donor-conceived people’s social, linguistic and digital practices.
- To extend theoretical understandings of belonging in relation to family, peers and the State.

As I will discuss in the following chapter, an interdisciplinary, mixed method approach was selected to consider donor-conceived people’s experiences across distinct private and public contexts. Through analysis of social, linguistic and digital practices, I sought to explore the processes, events and artefacts that contribute to donor-conceived people’s sense of belonging. Specifically, I consider how donor-conceived people individually and collectively position themselves in relation to their families, peers and the State and how understanding, visibility and recognition in these distinct contexts might contribute to a sense of belonging. Below, I offer a discussion of the literature on belonging most useful for considering donor-conceived adults experiences.

Conceptual framing
In exploring donor-conceived people’s lived experience, I drew on a range of theoretical frameworks, with the concept of belonging offering an overarching lens. Specifically, a focus
on belonging allows for analysis of experiences across a range of contexts in which individuals strive to be included, accepted and recognised (Kuurne (née Ketokivi) & Vieno, 2021; May, 2011a; Probyn, 1996; Yuval-Davis, 2006). At times and for some, a sense of belonging is taken for granted in everyday life, whereas for others a sense of unbelonging can be a constant struggle as it is more explicitly felt and politicised (Kuurne (née Ketokivi) & Vieno, 2021; May, 2011; Yuval-Davis, 2006). Robust evidence indicates that social connectedness and a sense of belonging lead to positive health, wellbeing and longevity outcomes, providing protection from morbidity and mortality (Holt-Lunstad, 2018; Holt-Lunstad et al., 2015; Shor et al., 2013; Theeke, 2010; Van Beek & Patulny, 2022). Yet, how is belonging achieved?

One approach to thinking about belonging is to consider social inclusion, that is, a group’s participation and representation within organisations and institutions, such as the media, politics, business, government and education (Arvanitakis et al., 2020; Australian Social Inclusion Board, 2012; Robinson et al., 2013; Rogers & Ashforth, 2017; Soutphommasane et al., 2018; Tienda, 2013). However, a sense of belonging is also fostered through close personal relationships with family and friends which are characterised by intimacy, care and love (Kramer, 2011; McCarthy, 2012; Newman et al., 2020; Policarpo, 2019; Roseneil & Budgeon, 2004; Smart, 2007; Weston, 1997). Therefore, taking a holistic approach to donor-conceived people’s experiences via the lens of belonging involves identifying the realms in which being donor-conceived is relevant or meaningful, and considering the distinct levels at which donor-conceived identities are negotiated.

The concept of belonging has received increased attention across the social sciences over the last two decades (see Allen, 2020; Antonsich, 2010; Lähdesmäki et al., 2016). Despite the ubiquity of the concept, some scholars have argued that belonging has been “vaguely defined and ill-theorized” (Antonsich, 2010, p. 644). Yuval-Davis’ (2006) comprehensive analytical frameworks for examining belonging is divided into three levels: social location (distinct and intersecting aspects of an individual’s identity), identifications and emotional attachments (emotional investments in groupings and collectivities), and ethical and political values (positioning within the State as full and legitimate citizens with rights and responsibilities). Another more grounded approach to belonging, by May (2011, 2013), underscores how belonging is multidimensional, specifically how it occurs in relation to not only people, but ideas, places, events, material objects, habits and processes. May’s focus on the everyday, including the mundane and ordinary, illuminates how social realities are always becoming,
dynamic and fluid (May, 2011). Further, according to May, belonging occurs across official and unofficial social domains in relational, material and cultural contexts. These insights invited an attunement to the agentic, processual and political aspects of belonging.

In addition to the frameworks above developed by sociologists concerned with exploring people’s experiences and practices in relation to broader cultural, structural and historical contexts (Woodman & Threadgold, 2021), my approach to belonging was also influenced by work from social semiotics. Social semiotics is a functional model which views language as a meaning-making system and resource for negotiating social relations (Halliday, 1978). This model also accounts for how context shapes texts; that is, how all aspects of the situation, including the statuses, roles and relationships between interactants, shape the language produced by an individual (Halliday, 1985; Malinowski, 1923). Since the turn of the century, in the field of social semiotics, increased attention has been paid to interpersonal meaning; that is, how people negotiate social relations through language (Logi & Zappavigna, 2022; Martin & White, 2005). Specifically, through the expression of shared feelings, principles and preferences, individuals forge belonging (Martin, 2004). Work by Stenglin (2004) was concerned with “ways of building togetherness, inclusiveness and affiliation” which explored how individuals rally around ‘bonding icons’, or symbols of communal ideals (Martin & Stenglin, 2006, p. 216). Later, Knight (2010) developed a model of affiliation in relation to research on conversational humour, which proposed social bonds as the social semiotic unit for building identities and communities. Researchers have both refined and expanded this work on affiliation to explore a range of contexts and ‘ambient’ environments in which individuals may not necessarily be engaged in dialogic communication yet still commune around shared values (Zappavigna, 2011, 2014; Zappavigna & Martin, 2018). Affiliation, therefore, provides a framework for understanding the social and dynamic aspects of how individual and communal identity is negotiated, and may offer valuable insights into how, for donor-conceived people, a sense of belonging might be achieved through everyday language practices.

In addition to scholarship from sociology and social semiotics, the third discipline I was influenced by was media studies. Media scholars foreground how individuals live in, with, and through digital technologies, as they initiate and maintain intimate relationships and seek visibility and recognition (Andreassen et al., 2017; Kember & Zylinska, 2012). In media studies, belonging has largely been considered through the lens of digital intimacies or mediated intimacies (Andreassen et al., 2017; Dobson et al., 2018), building on work on
intimate publics (Berlant, 1998, 2008). For example, extending Berlant’s (2008) argument that intimacy is “a promise of belonging” (p. ix), Andreassen (2018) has argued that “intimacy is relational; it is both the experience of belonging and connection and the practices that surround, lead to and negotiate belonging and connectedness” (p. 362). As such, considering the digital practices that individuals engage in, is critical to understanding intimacy, connection and belonging in a digital age. Moreover, for communities like donor-conceived people, who are largely strictly connected by digital technologies, attention to these mediating processes is essential. As has been argued by Andreassen (2022), donor families are entangled in media technologies to such a degree that media and reproductive technologies are inextricable. Therefore, in this thesis, I draw from media studies to consider how donor-conceived people’s social worlds and associated intimacies, connections and affects are mediated by digital technologies.

The conceptual framing of belonging, then, anchored my thinking and allowed me to consider the distinct levels at which donor-conceived adults related to a range of actors, entities and institutions. Moreover, the concept of belonging lent itself to studying both the mundane and the momentous, including interactions characterised by equality or power asymmetries. Finally, given belonging has been conceptualised in various ways across disciplines, I found it provided an elastic and productive lens to guide the study, with the recognition that other theory and concepts could be drawn upon to support analyses in different chapters.

**Thesis outline**

This thesis contains nine chapters. Chapters 1, 2 and 9 comprise independent chapters which situate the project as a coherent, scholarly body of work. Chapters 3-8 contain publications, including two book chapters (Chapters 3 and 8), and four articles in peer reviewed journals (Chapters 4, 5, 6, 7). Each of the chapters includes a brief literature review, methods, results and discussion on a different aspect of the study. For this thesis, each publication is introduced with a prelude which explains how it is linked to the overall thesis. Chapters 3 and 6 offer a more methodological focus and Chapters 4, 5, 7, and 8 present primary data from the research. While I am the primary author of all of the work included in this thesis, in Chapters 3 and 8, I use first-person singular pronouns to indicate sole author writing, and in Chapters 4, 5, 6, and 7, I use first-person plural pronouns to acknowledge co-authorship with my supervisors and collaborators. Publications are reproduced here in the format required by the journal/publisher to which they were submitted, and as such, there are some
inconsistencies in style and language and some unavoidable repetition between chapters. An overview of the thesis chapters is illustrated in Figure 1.

*Figure 1: Overview of thesis chapters*

Chapter 1 has sketched the background and context of this doctoral study on Australian donor-conceived adults’ experiences.

**Chapter 2** outlines the interdisciplinary, mixed-method approach taken in this thesis, and provides an overview of the ethical considerations, research design and methods.

**Chapter 3** provides a methodological account of how I position myself as a donor-conceived person, activist and researcher. With the aim of ‘doing reflexivity’, I offer three vignettes capturing moments of becoming and belonging in order to consider how donor-conceived people are seeking to belong across a range of domains including through activism and research. This chapter was written during the data collection phase in 2020 and published 24/06/22.

In **Chapter 4**, I turned to analysing the Hansard of the 2010 Australian Senate Committee Inquiry into Donor Conception in Australia to consider donor-conceived people’s participation in public hearings. Building on Chapter 3, I explore donor-conceived people’s transitions from lived experience to lived expertise. I take a social semiotic approach to examine how donor-conceived people position themselves in relation to other witnesses in this specific institutional context. One of the most challenging chapters to complete, the analysis and writing for this chapter were undertaken in iterative stages throughout the project. The article was submitted 29/07/2022 and is currently under review.
Chapter 5 considers one of the more private contexts in which donor-conceived peers interact: a Facebook meme group. Incorporating both reflexive thematic analysis of semi-structured interview data and a social semiotic analysis of meme texts, I conceptualise memes as bonding icons: semiotic artefacts which foreground shared feelings and invite alignment around a collective identity. This article was submitted 04/05/21 and published 06/12/21.

Turning to another media environment, Chapter 6 explores the hashtag #donorconceived on TikTok. Within this hashtag, content from donor-conceived and LGBTQ+ people (prospective recipient parents) coalesces, making visible the distinct positions and priorities of each group in their plights for increased visibility, recognition and belonging. In response to these tensions, Chapter 6 offers a method for analysing a reflexive encounter between two researchers in order to generate situated insights into a polarising topic. The article forms part of a special issue ‘Cultures of TikTok in the Asia Pacific’ and was submitted 01/08/21 and published 25/01/22.

Chapter 7 explores three key forms of information that can contribute to donor-conceived people’s sense of (un)belonging: genetic knowledge from direct-to-consumer DNA testing, familial narratives and official medical records. Analysis in this chapter weaves together survey data – including free-text responses – and semi-structured interview data to explore how donor-conceived people interpret and incorporate distinct (and sometimes conflicting) forms of identity information. This article was submitted 23/11/21 and published 08/06/22.

The final data-driven chapter, Chapter 8, explores donor-conceived people’s experiences living with anonymity and absence. Taking up the concept of ‘haunting’ and combining vignettes and semi-structured interview data, I explore how anonymity and absence reshape flows between past, present and future, altering personhood and relationality. This chapter was submitted 26/10/21, accepted 01/04/2022 and will be published in an edited collection in 2023.

Chapter 9 is the final chapter of the thesis and combines the discussion and conclusion. In this concluding chapter, I look across the findings from the different analysis chapters and discuss the study’s key empirical, theoretical and methodological contributions. I also propose a series of policy and practice implications derived from these insights and offer conclusions to the thesis.
Legislation

Assisted Reproductive Technology Act 2007 (NSW)

Assisted Reproductive Treatment Act 1988 (SA)

Assisted Reproductive Treatment Act 2008 (VIC)

Assisted Reproductive Treatment Amendment Act 2016 (VIC)

Assisted Reproductive Treatment Further Amendment Act 2014 (VIC)

Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021 (SA)

Human Reproductive Technology Act 1991 (WA)

References


Andreassen, R. (2022). From the families we choose to the families we find online: Media technology and queer family making. Feminist Theory, 146470012110595. https://doi.org/10.1177/14647001211059517


Chapter 1: Introduction


https://doi.org/10.1163/15718189820494067

https://doi.org/10.1080/1464727022000199102


https://doi.org/10.1093/lawfam/ebs006


https://doi.org/10.1016/j.rbmo.2018.11.033

https://doi.org/10.1093/humrep/deab198


Chapter 1: Introduction


https://doi.org/10.1016/j.socscimed.2007.08.029


https://doi.org/10.1093/oxfordjournals.humrep.a138290


Chapter 1: Introduction


Chapter 1: Introduction


Chapter 1: Introduction


the University of New South Wales, Sydney.


NHMRC. (2004). *NHMRC Ethical Guidelines for Assisted Reproductive Technology*.


https://doi.org/10.1111/chso.12158

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https://doi.org/10.1007/s11673-015-9690-0


https://doi.org/10.1111/ajo.13175


CHAPTER 2 - Methodology

This chapter describes the methodological choices and rationale underpinning this doctoral study. First, I outline the interdisciplinary approach taken which spans sociology, media studies and social semiotics, and explain how this approach is aligned with a mixed method research design. Next, I explain the ethical approach taken (developed further in Chapter 3) and describe the research methods and data collection procedures. Specific details about analysis techniques are contained in the methods section of each respective data chapter (Chapters 4-8).

Interdisciplinary approach

This doctoral thesis sought to explore Australian donor-conceived adults experiences using a range of approaches and methods from distinct disciplines to generate rich and robust findings. Specifically, I drew theoretically and methodologically from the academic disciplines of sociology, social semiotics and media studies. This approach was supported by supervision from three supervisors whose expertise span cultural studies, sociology, media studies and social semiotics.

Scholars have long oriented their research in relation to disciplines, categories that function to organise and regulate knowledge (Shumway & Messer-Davidow, 1991). However, over the last few decades, interdisciplinary approaches have become increasingly prevalent in the social sciences as well as in research focused on health-related topics (Austin et al., 2008; Hesse-Biber, 2016; Leahey et al., 2017). Interdisciplinarity has been defined as “a process that combines knowledge from one or more disciplines and occurs when researchers collaborate with the goal of synthesizing new knowledge” (Hesse-Biber, 2016, p. 650). Many interdisciplinary teams follow a problem-oriented approach whereby interdisciplinarity offers greater explanatory power to understand complex and multifaceted topics which in turn drive novel theoretical developments (Bindler et al., 2012; Martin, 2011; Maton et al., 2016; Van Leeuwen, 2005). Van Leeuwen (2005) describes this style of approach as an integrationist interdisciplinary model that views each discipline as equally valuable and legitimate, each with its own strengths and limitations in studying social phenomenon (see also Bernstein, 2003; Mason, 2006; Maton et al., 2016). It has also been suggested that exposure to different knowledge practices and ways of conducting research invites reflexivity, since researchers are forced to articulate and justify the paradigm from which they are working and to explain their selection of methods (Woodward, 2016). Researchers have also explored the challenges
Chapter 3: Doing reflexivity in research on donor conception (published book chapter)

associated with interdisciplinary research, such as increased labour involved in communicating, coordinating and reaching consensus, given the underpinning epistemological and theoretical assumptions can often differ across teams (Bindler et al., 2012; Leahey et al., 2017; Litsou & Byron, 2020). As such, interdisciplinary research requires “discursive technology”, a shared common language which can facilitate communication about the project and the specific problem under investigation (Martin, 2011, p. 37; Van Leeuwen, 2005). In the context of a doctoral project – in which one is positioned as an apprentice learning the skills and knowledge required to conduct high quality research – interdisciplinarity typically occurs through dialogue with peers and supervisors and also involves “‘talk[ing] to oneself’, as it were, in the tongue of each theory” (Maton et al., 2016, p. 155).

Due to the complex and dynamic nature of donor-conceived people’s lived experience, an interdisciplinary, mixed method approach was adopted to meet the aims of the research. As suggested by Mason (2006):

Given the multi-dimensionality of social experience, we would do well, up against this challenge, to be interested in and to draw upon different theoretically informed approaches to conceptualizing context, rather than insisting upon the primacy of only one world view (p.19)

Indeed, in order to explain our social lives, and transcend either micro or macro scales of lived experience, mixing methods can provide a fruitful approach. Mason (2006) offers three reasons for mixing methods: to stimulate ‘outside the box’ thinking, to invite multidimensional theorisation, and to extend the logic of qualitative explanation (Mason, 2006). Mason (2006) promotes developing a ‘palette of methods’, governed by the research questions in an iterative and creative process. However, as methods are mixed, tensions between the distinct findings can emerge. Throughout this study, the research team returned to the question of how the different disciplinary lenses complemented one another, as well as facilitated ‘creative tensions’ (Mason, 2006). In mixing methods, I did not seek to triangulate data, rather I sought to integrate, consolidate and mesh distinct findings “to produce a fuller or more valid or more robust picture” (Mason, 2006, p. 20). Building on Mason’s scholarship, Woodward (2016) argues for dialogue between methods that aim to unsettle research assumptions and practices. Here, dialogue functions as a tool to articulate tensions
between approaches. Insights from the aforementioned scholars influenced the way methods were integrated and tensions were explored through processes of dialogue.

**Ethical approach**

*Quality, positionality and reflexivity*

The mixed methods approach adopted in this thesis was underpinned by an interpretivist epistemological stance that recognises that knowledges are always constructions that are produced and reproduced in specific social and cultural contexts, and shaped by the encounter with the researcher, who contributes to a form of co-construction of the knowledge produced through the research encounter (Braun & Clarke, 2013). Analytical quality – according to this position – is “the product of deep and prolonged data immersion, thoughtfulness and reflection, something that is active and generative” (Braun & Clarke, 2019, p.591).

Accordingly, this thesis was guided by a number of principles – namely positionality and reflexivity – key to ensuring quality from an interpretivist position.

In qualitative research, researchers are encouraged to reflect on their positionality as part of ethics in practice (Berger, 2015; Bradbury-Jones, 2007; Guillemin & Gillam, 2004; Taylor, 2011). As well as recognising one’s personal characteristics or social locations, ‘doing reflexivity’ involves cultivating meaningful practices and processes for ongoing consideration of how the researcher influences the knowledge created (Crenshaw, 1991; Fox & Allan, 2014; Guillemin & Gillam, 2004; Kohl & McCutcheon, 2015; Townsend & Cushion, 2020; Yuval-Davis, 2006). While reflexivity is often avoided in quantitative social research, researchers have emphasised the benefits of processes of reflexivity in the quantitative paradigm (Ryan & Golden, 2006).

As discussed in Chapter 1, this doctoral study was shaped by my positionality as a donor-conceived ‘insider’. However, my donor-conceived identity also evolved with and through this research, including through qualitatively and quantitatively driven components. To capture these dynamics, throughout this thesis, vignettes of personal experience are included as a stylistic device in an effort to create a reflexive skeleton to underpin the movement through the various perspectives, methods and insights I explore. Chapter 3 expands on questions of positionality and reflexivity in more detail, exploring processes of becoming.
Advisory panel

At the commencement of the project an advisory panel was constituted to provide expert advice at key points during the study, to meet the research aims, and provide useful outcomes for policy, practice and research in the area of donor conception. The panel consisted of two tiers of membership, reflecting different forms of expertise on this topic:

Tier 1: people with lived experience of being donor-conceived in the Australian context
Tier 2: people with professional expertise regarding the legal, clinical or social aspects of donor conception

Where members had both lived experience and professional expertise, as several did, they contributed via Tier 1. The advisory panel was engaged throughout the study with more concentrated, formal feedback during the creation of the survey instrument. During data collection, analysis and dissemination, members were engaged individually via email or social media.

Ethics approval

Ethics approval for all aspects of the study was primarily sought through the UNSW Sydney Ethics Committees. Methods 1 and 2 were approved by UNSW HREC (HC190998), with 1 and 2 endorsed by ACON (AIDS Council of NSW) 2020/05 and Thorne Harbour Health Community Research Endorsement Panel (THH/CREP 20-008). Method 3 was approved by UNSW HREA (HC190974). Several ethics amendments were requested over the course of the research to incorporate modest changes in design and due to the Covid-19 pandemic.

Methods and data

As described above, a mixed method approach which permitted exploration of donor-conceived people’s experiences from a number of vantage points was selected for this study. Careful consideration was given to the context in which the data were collected. For example, data gathered in an interview with a researcher, talking to senators, or from behind a mobile device at home can reveal complimentary or conflicting insights. The data included in this thesis were derived in four distinct stages (see Figure 2), which are each described briefly below. As previously noted, specific details about data analysis are described in the methods section of each respective data-focused chapter.
Hansard analysis
The first stage of the study considered Hansard from the public hearing of the 2010 Australian Senate Committee Inquiry into Donor Conception in Australia. Public hearings represent an important context for understanding how the lived experience of donor-conceived people has come to figure as a form of evidence to inform law reform. The national inquiry in 2010 was the first and only national inquiry into donor conception to date in Australia. It received 162 submissions and chose to hold three public hearings: in Canberra (29 October 2010), Sydney (2 November 2010), and Melbourne (3 November 2010), attended by 33 witnesses. The transcription of the dialogue, generated for the Official Committee Hansard, did not include paralinguistic features (such as body movement, facial expressions, variations in voice quality in terms of pitch or volume), and was accessed via the Australian Parliament website. The dataset was drawn from the Melbourne public hearing, from the session in which donor-conceived witnesses participated.

Online survey
The second stage of the study comprised an online survey which sought to generate a broad set of responses from donor-conceived people from across Australia. The survey was
designed to be descriptive and exploratory rather than seeking to be representative of the broader population of donor-conceived adults. The research team aimed to recruit a minimum of 100 respondents to permit descriptive analyses of the sample characteristics. We considered any information we could collect on Australian donor-conceived people over 16 years old to be relevant and valuable.

The survey was developed across several iterations as I learnt about survey development, gained more knowledge about the history and politics within the donor-conceived community, and received feedback from stakeholders. Initially, the survey instrument consisted of 45 questions and primarily sought to identify the range of services and support initiatives donor-conceived people access. The first version of the survey was sent out for feedback to six donor-conceived people and three experts in social, political and legal aspects of donor conception. After spending several days with a group of donor-conceived advocates in which a number of political dimensions of being donor-conceived became clearer, further questions were added to the survey regarding participants’ views of donor conception as a practice, participation in the design and delivery of services, and participation in advocacy to change legislation or practice. The supervisory team agreed that exploring these dimensions of donor-conceived people’s lived experience was important and fit with the aims of the research.

The second version of the survey, which included 91 questions, was sent out to two experts in clinical aspects of fertility, one legal expert, and three social sciences researchers with specific expertise in donor conception and surrogacy. Next the survey was tested with one donor-conceived person and three individuals with limited knowledge of donor conception to address any issues with clarity of language, formatting and access via a range of devices and browsers. Additionally, we sought feedback on the demographic questions regarding sex, gender and sexuality questions from key stakeholders. We sought specific guidance from the National LGBTI Alliance (now National LGBTIQ+ Health Australia) and Intersex Human Rights Australia to determine whether questions relating to intersex variation were appropriate to include in this survey, and following their advice excluded questions about intersex characteristics.

The online survey sought to recruit a sample of respondents who met the following inclusion criteria:

- Conceived with donor sperm, eggs or embryo;
Respondents could learn about the survey through information in Facebook groups for donor-conceived people, Facebook advertisements, other social media, media articles information from partner organisations or word of mouth referrals. Information about the study directed potential participants to the study website (DCstudy.org) I created which provided general information on the research and inclusion criteria. The online survey was hosted on the UNSW Qualtrics platform. On the study website, participants could select the ‘Click here to do the survey’ button which led them to the Qualtrics platform. At the end of the survey, respondents are asked if they want to enter the lucky draw to win one of five AU$50 gift cards. Data were collected throughout 2020 and following completion of the survey, the data were extracted. A total of 91 respondents completed the online survey (see characteristics of respondents in Table 2).

Table 2: Survey respondent characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N = 91</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex recorded at birth</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>74 (81.3%)</td>
</tr>
<tr>
<td>Male</td>
<td>16 (17.6%)</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>1 (1.1%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>75 (82.4%)</td>
</tr>
<tr>
<td>Men</td>
<td>14 (15.4%)</td>
</tr>
<tr>
<td>Non-binary</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td><strong>Sexuality</strong></td>
<td></td>
</tr>
<tr>
<td>Heterosexual or straight</td>
<td>69 (75.8%)</td>
</tr>
<tr>
<td>Homosexual, gay or lesbian</td>
<td>9 (9.9%)</td>
</tr>
<tr>
<td>Bisexual or pansexual</td>
<td>13 (14.3%)</td>
</tr>
<tr>
<td>Queer</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1 (1.1%)</td>
</tr>
</tbody>
</table>
### Chapter 3: Doing reflexivity in research on donor conception (published book chapter)

<table>
<thead>
<tr>
<th>Aboriginal or Torres Strait Islander Origin</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>91 (100%)</td>
</tr>
<tr>
<td>Yes</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary school – up to Year 10</td>
<td>5 (5.5%)</td>
</tr>
<tr>
<td>Secondary school – up to Year 12</td>
<td>10 (11.0%)</td>
</tr>
<tr>
<td>Technical or trade certificate</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td>College certificate/diploma</td>
<td>11 (12.1%)</td>
</tr>
<tr>
<td>Undergraduate university degree</td>
<td>32 (35.2%)</td>
</tr>
<tr>
<td>Postgraduate university degree</td>
<td>31 (34.1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual parents</td>
<td>72 (79.1%)</td>
</tr>
<tr>
<td>Lesbian mothers</td>
<td>8 (8.8%)</td>
</tr>
<tr>
<td>Single/solo mother</td>
<td>11 (12.1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>State/Territory of conception</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>1 (1.1%)</td>
</tr>
<tr>
<td>NSW</td>
<td>36 (39.6%)</td>
</tr>
<tr>
<td>VIC</td>
<td>25 (27.5%)</td>
</tr>
<tr>
<td>TAS</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td>SA</td>
<td>4 (4.4%)</td>
</tr>
<tr>
<td>WA</td>
<td>9 (9.9%)</td>
</tr>
<tr>
<td>QLD</td>
<td>10 (11.0%)</td>
</tr>
<tr>
<td>Other country</td>
<td>4 (4.4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conception type</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sperm donor-conceived</td>
<td>90 (98.9%)</td>
</tr>
<tr>
<td>Egg donor-conceived</td>
<td>1 (1.1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conception procedure</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Donor insemination/ intrauterine insemination</td>
<td>74 (81.3%)</td>
</tr>
<tr>
<td>IVF cycle</td>
<td>11 (12.1%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>6 (6.6%)</td>
</tr>
</tbody>
</table>
**Context of conception**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical context, such as a fertility clinic, hospital or general practice clinic.</td>
<td>77 (84.6%)</td>
</tr>
<tr>
<td>Community context, such as donor insemination conducted at home.</td>
<td>12 (13.2%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>2 (2.2%)</td>
</tr>
</tbody>
</table>

**Decade of conception**

<table>
<thead>
<tr>
<th>Decade</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1970s</td>
<td>13 (14.3%)</td>
</tr>
<tr>
<td>1980s</td>
<td>46 (50.5%)</td>
</tr>
<tr>
<td>1990s</td>
<td>22 (24.2%)</td>
</tr>
<tr>
<td>2000s</td>
<td>10 (11.0%)</td>
</tr>
</tbody>
</table>

**Age of disclosure**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Always known</td>
<td>21 (23.1%)</td>
</tr>
<tr>
<td>0-10</td>
<td>19 (20.9%)</td>
</tr>
<tr>
<td>11-20</td>
<td>16 (17.6%)</td>
</tr>
<tr>
<td>21-29</td>
<td>12 (13.2%)</td>
</tr>
<tr>
<td>30-39</td>
<td>21 (23.1%)</td>
</tr>
<tr>
<td>40+</td>
<td>2 (2.2%)</td>
</tr>
</tbody>
</table>

**Semi-structured interviews**

Stage three comprised semi-structured interviews aiming to explore donor-conceived people’s views and experiences, with a particular focus on their engagement with, and perspectives on, Facebook groups for donor-conceived people. Informed by interpretive traditions within sociology, through qualitative interviewing I sought to gather a range of rich and situated accounts from donor-conceived people (Braun & Clarke, 2013).

The semi-structured interviews sought to recruit a sample of participants who met the following inclusion criteria:

- Conceived with donor sperm, eggs or embryo;
- Australian resident or citizen, either currently living in Australia or intending to return;
- 18 years old or older; and
- Participated in Facebook groups for donor-conceived people
Prospective participants could register their interest and schedule an interview via email or through a form on the study website. Due to the rise of the Covid-19 pandemic in early 2020, all semi-structured interviews were conducted online via Zoom software or via telephone.

Interviews followed an interview schedule which covered a wide range of topics: conception, disclosure and family, information and services, support and digital technologies. In total, I conducted 28 interviews. Participants ranged in age from 18 to 40 years old, (see Table 3 for participant characteristics). The duration of interviews varied from 45 minutes to three hours. All interview participants received an AUS$30 voucher in appreciation of their time. Audio recordings of the interviews were transcribed by a professional transcriber. All of the transcripts were checked against the original recordings for accuracy and de-identified to ensure that identifying information, such as names, places, and organisational roles were removed. Interviews were imported into NVivo 12 Pro software for coding.

During the interviews, some participants discussed their participation in Facebook meme groups for donor-conceived people and shared memes that they had created or shared. An ethics amendment was sought for retrospective approval to include memes that had been provided in the interview in the analysis. Participants who had discussed memes were also invited to submit memes which they had permission to share via email.

Table 3: Semi-structured interview participant characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N = 28</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>23 (82.1%)</td>
</tr>
<tr>
<td>Men</td>
<td>4 (14.3%)</td>
</tr>
<tr>
<td>Non-binary</td>
<td>1 (3.6%)</td>
</tr>
<tr>
<td><strong>Family type</strong></td>
<td></td>
</tr>
<tr>
<td>Heterosexual parents</td>
<td>25 (89.3%)</td>
</tr>
<tr>
<td>Lesbian mothers</td>
<td>1 (3.6%)</td>
</tr>
<tr>
<td>Single/solo mother</td>
<td>2 (7.1%)</td>
</tr>
<tr>
<td><strong>Conception type</strong></td>
<td></td>
</tr>
<tr>
<td>Sperm donor-conceived</td>
<td>28 (100%)</td>
</tr>
<tr>
<td>Egg donor-conceived</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Age of disclosure</strong></td>
<td></td>
</tr>
</tbody>
</table>
Chapter 3: Doing reflexivity in research on donor conception (published book chapter)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;13</td>
<td>10 (35.7%)</td>
</tr>
<tr>
<td>13-25</td>
<td>9 (32.1%)</td>
</tr>
<tr>
<td>26-39</td>
<td>9 (32.1%)</td>
</tr>
</tbody>
</table>

**Situated Talk**

In Stage 4, I created a method ‘Situated Talk’ in collaboration with my colleague, Dr Clare Southerton, to consider how social media content, such as TikToks, can facilitate a reflexive and sensitive encounter. Details of how this method was used in this study and the resulting findings are described in Chapter 6.
Chapter 3: Doing reflexivity in research on donor conception (published book chapter)

References


CHAPTER 3 - Doing Reflexivity in Research on Donor Conception: Examining Moments of Bonding and Becoming (published book chapter)

**Link to thesis:** Chapter 3 reflects on my lived experience as a donor-conceived person, with a focus on how my positionality as an insider influences my research (aim 1). I draw on vignettes of personal experience which describe three phases of becoming (aim 2). This chapter contributes to understanding donor-conceived adults’ distinct roles and relationships across a range of contexts, and more broadly, demonstrates how these processes of becoming contribute to a sense of belonging (aim 3).

Introduction

Researchers often hold significant personal investments in their fields of study (Taylor, 2011). The reflexive turn in the social sciences has led to greater transparency around knowledge construction processes (Mauthner & Doucet, 2003; 2018). By practicing reflexivity, that is, critical reflection in relation to knowledge construction, researchers can openly monitor the ways in which their subjectivity affects all aspects of the research process (Nathan et al., 2018). As Guillemin and Gillam (2004) argue, in addition to contributing to rigorous research practice, reflexivity forms part of ‘ethics in practice’ (p. 262). In this way, researchers are sensitised to ethical and interpersonal issues that emerge in research on an everyday basis. In donor conception studies, limited attention has been paid to the way researchers situate themselves in relation to research participants or ethical issues that emerge through the research.
Abstract

For qualitative researchers, reflexivity is always an important aspect of ethical practice. In research on donor conception, there is a particular need for greater attention to be paid to the ways in which researchers’ positionality, experiences and attitudes influence the research process and findings. With the aim of ‘doing reflexivity’, in this chapter I explore three phases of becoming: becoming donor-conceived, becoming activist and becoming researcher. In ‘becoming donor-conceived’, I explore how connecting with other donor-conceived people online strongly influenced the way that I understood my own experiences and contributed to a sense of belonging. Next, I describe how through ‘becoming activist’, I became more aware of the political value of donor-conceived people’s voices and the need to privilege donor-conceived people’s perspectives in research. Finally, I explore how I navigate my position as an ‘insider’ in my research including how I manage risk and reciprocity. In doing so, I explore how people with lived experience bring different priorities and approaches to the research process. More broadly, I underscore the need for donor conception researchers to engage with and empower donor-conceived people in order to meaningfully influence policy and practice responses to this complex topic.
Introduction

Researchers often hold significant personal investments in their fields of study (Taylor, 2011). The reflexive turn in the social sciences has led to greater transparency around knowledge construction processes (Mauthner & Doucet, 2003). By practicing reflexivity, that is, critical reflection in relation to knowledge construction, researchers can openly monitor the ways in which their subjectivity affects all aspects of the research process (Nathan et al., 2018). As Guillemin and Gillam (2004) argue, in addition to contributing to rigorous research practice, reflexivity forms part of ‘ethics in practice’ (p. 262). In this way, researchers are sensitised to ethical and interpersonal issues that emerge in research on an everyday basis. In donor conception studies, limited attention has been paid to the way researchers situate themselves in relation to research participants or ethical issues that emerge through the research process; a remarkable oversight given the emotionally and politically sensitive nature of this topic (for an exception see Kirkman & Kirkman, 2002). Yet qualitative researchers in particular may have a unique opportunity to capture the tensions that arise in research on donor conception, particularly in relation to positionality and research practice (see also Shaw et al., 2020). In this chapter, I explore what it means to 'do reflexivity' in my research on donor conception, illuminating a range of ethical and emotional issues that have arisen for me as an insider researcher.

Commencing a PhD focused on donor conception prompted my own personal reflections on my experiences as a donor-conceived person and motivated me to think carefully about my positionality. ‘Positionality’ refers to all of my personal characteristics that influence my access to the field, relationship to participants and research process (Berger, 2015). Some scholars have critiqued static observations of positionality as a “laundry list of identity markers” (Kohl & McCutcheon, 2015, p. 747), and consequently, several frameworks have been developed for ‘doing reflexivity’. Of these frameworks, Guillemin and Gillam’s (2004, p. 262) focus on ‘ethical moments’, defined as ‘the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research’, has offered a tangible method for reflecting on the research process, emotional connections to research and the role of the researcher. Another framework by Fox and Allan (2014) consists of dialogue between the doctoral student researcher and their supervisor. This approach aims to promote ‘reflexive action’ (p. 101) by recalling salient ethical, performative and conceptual moments during the student’s studies that have impacted the student’s identity and influenced the course of the research. The authors describe these instances as moments of becoming and unbecoming,
recognition the unravelling and re-formation that occurs both to the research and, consequently, to the researcher’s identity. These methods for ‘doing reflexivity’ demonstrate that reflexivity is not static nor individual, but rather an ongoing negotiation between actors involved in the research process.

Based at UNSW Sydney, Australia, my research examines Australian donor-conceived people’s experiences, perspectives and support needs. I consider how donor-conceived people’s sense of identity, community and belonging is forged across different contexts. For example, I explore what donor conception means to participants at an individual level, within their own families, as well as what it feels like to belong to a community of donor-conceived people. Specifically, I consider how participation in secret Facebook groups, direct-to-consumer DNA testing platforms or national inquiries impact participants’ experiences. This study integrates sociological, social semiotic and media studies perspectives, considering participants’ interpretations of their experiences as well as analysing the often less conscious language choices they make. The choice to integrate these distinct approaches was made due to the diverse and complex nature of donor-conceived people’s lived experience. As Mason (2006) argues, our social lives and realities are multidimensional, and mixing methods can help to simultaneously transcend both micro and macro domains of lived experience.

In attempting to synthesise these disciplinary methodologies, significant ontological and epistemological challenges arise. For example, social semiotics is concerned with understanding language in context, collecting data from language use in situational contexts (Halliday, 1978). In sociology, the co-construction of the knowledge produced through the research encounter is foregrounded (Braun & Clarke, 2013). I seek to integrate sociological approaches to belonging with a social semiotic approach that views language as a social resource through and within which relationships are enacted.

In this chapter, I describe three consecutive overlapping phases: becoming donor-conceived, becoming activist and becoming researcher. My experience of ‘becoming researcher’ is deeply entangled with my position as a donor-conceived person and activist, as the subjectivities I simultaneously hold are not autonomous; they are always inflected by the other positions. This perspective aligns with an Intersectional approach from scholars such as Crenshaw (1991), Collins (1998) and Few-Demo (2014), who recognise that social identities are constituted by multiple social locations that may overlap in different ways across time and space. Considering my research through the lens of each of these positionalities, and the
resulting tensions between them, provides insight into the particularities of conducting research on donor conception as a donor-conceived person myself. In reflecting on my personal experiences, I hope to stimulate discussion in donor conception studies about how we can continue to do reflexivity in this field of research.

**Becoming Donor-Conceived**

I have a vague memory that I’ve played on repeat thousands of times throughout my life, where my mother and father are sitting at our round dining room table with a stone blue vinyl tablecloth. I think I was 8 or maybe 10. They have something they have to tell me, and I run away, down the corridor to my bedroom. When I think about this now, I don’t really know why I ran away—they’d been preparing me for this conversation my whole life. To their credit, despite the shame that infertility can carry, and their doctor’s advice to deceive me, my parents always wove the narrative about my donor conception into my sense of identity. They told me how difficult it was for them to have a baby and that they were so lucky to have me. That day that I ran away, we ended up having a conversation about the details of my conception, but it didn’t come as a shock to me that I was donor-conceived.

Growing up in a regional town, I didn’t know any donor-conceived people, didn’t really know what being donor-conceived meant, and didn’t think about it too much. Around the time I turned eighteen, I joined a secret Facebook group for Australian donor-conceived people. I began to see donor-conceived people’s stories on a daily basis. Through this contact with other people like me, I began learning about what being donor-conceived meant.

I write my story into my research because it is embedded in a history of secrecy. I believe it is necessary to recognise my position as a donor-conceived peer—the degree to which this situatedness influences my research approach means that obscuring it would be unethical. I now understand that I am part of a network of shared experiences and values, and that my personal biography is part of a broader social and political context that extends beyond my individual and family relationships.

Throughout its history, the practice of donor conception has often been clouded in secrecy, shame and denial, reflecting the complex social, religious and legal contexts that govern reproduction and gamete donation more generally (Crawshaw, 2018; Daniels, 2020; Frith et
al., 2018). In Australia, while legislation varies between states, historically all states have favoured the rights of donors to lifelong anonymity over the rights of donor-conceived people to access identifying information about their donor. Driven by increased social and legal recognition of the rights of the child, law reform over the last two decades has largely sought to improve the rights of donor-conceived people to access information, and to restrict the rights of donors to remain anonymous. While disclosure of donor-conceived status to children is now widely recognised as best practice (Frith et al., 2018), generations of parents of donor-conceived people were advised by clinicians not to tell their children of their donor-conceived status, and to not seek out identifying information about their donors (Adams & Lorbach, 2012). Since the conception of Louise Brown, the first person conceived via in vitro fertilisation in 1978, the fertility industry has grown rapidly. In 2018, over 19,000 babies were born using assisted reproductive technology in Australia and New Zealand, including 406 babies through donor sperm insemination, 761 babies from oocyte or embryo donation and 86 through gestational surrogacies (Newman et al., 2020). While there is no way to definitively determine the number of donor-conceived people in Australia, estimates suggest that there may be between 20,000 and 60,000 persons (Commonwealth of Australia, 2011). Yet, despite the significant number of people born through donor conception, donor-conceived people have been described as a ‘hidden population’ (Hertz & Nelson, 2018).

The subject of donor conception has attracted a remarkably limited range of research. Prior to 2000, no empirical studies had been published on donor-conceived people’s experiences and from 2000 to 2011, 19 articles derived from empirical research on donor conception were published (Blyth et al., 2012). Studies employing quantitative methods to explore the experiences of donor families comprise most of the existing literature (Andreassen, 2017), and a large portion of that research has sourced participants from the US-based donor registry, Donor Sibling Register (see, e.g., Jadva et al., 2010) or UK-based DNA Link registry (see, e.g., Crawshaw & Marshall, 2008).

Existing research has found that the majority of donor-conceived people view any information about their donors as important (Rodino et al., 2011), and most desire contact with their donor (Beeson et al., 2011) and/or donor siblings (Dempsey et al., 2019; Nelson et al., 2013). For those who do achieve contact, most consider it to have been a positive experience (Jadva et al., 2010). It is also worth noting that, since the topic has received more scholarly attention, research has largely focused on parents’ attitudes towards the disclosure of donor-conceived status and towards connecting with other families who have used the
same donor. However, parental views represent only one set of perspectives on donor conception, and these perspectives are likely to have been shaped by social desirability bias, given the parental desire to believe their children are happy, healthy and well supported, no matter the choices their parents made about their conception (see Macmillan, 2016).

Even fewer studies have focused on the experience of Australian donor-conceived people. In 2002, Australian donor-conceived activist Geraldine Hewitt focused her final year high school project on the identity issues experienced by 47 donor-conceived people. In her concluding remarks, she stated that: ‘it is poignant that this study is, to date, the largest international study of the individuals who have been conceived through donor insemination’ (p. 5). Hewitt’s (2002) informal study, conducted in a high school setting, has received a remarkable number of citations, indicating that there is an appetite for donor-conceived voices to be heard and understood. The same year, Eric Blyth (2002b) noted that, to his knowledge, the few studies of donor-conceived adults’ experiences had all been conducted by donor-conceived people. Little has changed since 2002, with donor-conceived scholars still producing much of the research on donor-conceived people’s experiences and perspectives. Donor-conceived scholars have outlined the need for a child-centred perspective (Adams, 2013; Rose, 2009) and discussed the impact of secrecy on their lives (Whipp, 1998). In a similar vein, Macmillan’s (2016) study of 69 Australian donor-conceived adults was the first to consider the psychosocial implications of donor conception, secrecy and anonymity for donor-conceived adults. More recently, Martin Eggen Mogseth (2019) explored the impacts of donor conception on identity and familial relationships, and Damian Adams’ (2021) study was the first to explore the health outcomes of adult donor-conceived people. More recently, other scholars such as Ken Daniels (2020) have recognised the importance of capturing adult donor-conceived people’s experiences and views and noted the unique insights donor-conceived people bring to examining past and present practices, policies and attitudes.

Returning to the vignette above, and the theme of ‘becoming donor-conceived’, I am often asked how I found out I was donor-conceived. However, perhaps a more influential experience, in terms of becoming and belonging, was joining a Facebook group for donor-conceived people and gaining access to a community who shared that aspect of my identity. Among donor-conceived people, there is a strong history of peer-led organisations, as well as online groups, established as safe spaces to discuss experiences and connect with those who may feel isolated from a lack of contact with donor-conceived peers (Adams & Lorbach, 2012). Having peers to connect with and relate to strongly influenced the way that I
understood my own experience of being donor-conceived. This has shaped my belief that we cannot understand donor-conceived identities without also seeking to understand how meaning emerges through donor-conceived communities, recognising that identity is negotiated in interaction with communities of shared values (Knight, 2010).

Since the turn of the century, the internet has had a significant impact on the way donor-conceived people access information about their donor, their donor siblings and other aspects of their conception story (Blyth, 2002a). Internationally, donor-conceived people have been supporting each other since the advent of the Yahoo group ‘People Conceived Via Artificial Insemination’ in 2000. In Australia, the Australian Donor Conception Forum was founded in 2006 (Adams & Lorbach, 2012). Today, social media groups are used by donor-conceived people to access information, seek advice and share their experiences. Personally, being able to access a community of people ‘like me’ has opened up new avenues for me to seek information about my conception story, the meanings I have ascribed to being donor-conceived and the extent and frequency of contact I have with other donor-conceived people. For example, like many donor-conceived people, I would not have thought to explore DNA testing platforms as a mechanism for initiating contact with my genetic family. However, after hearing repeated stories of donor-conceived people finding their donor or donor siblings via DNA matching, I felt that this could be a significant opportunity to gain information about my own conception history, especially after tiresome battles with hospitals, clinics and registers to seek information about my donor. I did not know that 1737 centimorgans equated to a sibling match, but I learned that on a Facebook group. When I matched with my donor sibling, who may not have known that they were donor-conceived, I did not know how to approach them, and so it was incredibly helpful to be able to access advice and guidance from peers who had already managed these challenges.

I continue to be surprised and moved by the considerable time donor-conceived people take to show empathy and kindness to strangers online. I was curious as to what motivated them to provide lengthy, detailed and supportive comments in Facebook groups for donor-conceived people. From a linguistic perspective, I interpret this as a form of affiliation: a model which views social bonds as the social semiotic unit for building identities and communities (Knight, 2010). Eggins and Slade (1997) coined the term ‘orientation to affiliation’ to describe ‘the extent to which we seek to identify with the values and beliefs of those we interact with, especially in perceiving others as insiders or outsiders’ (p. 53). I seek to understand how donor-conceived people negotiate attitudes, and bond around shared values,
a social process that contributes to a sense of belonging. While online support groups for donor-conceived people have received little scholarly attention, my personal experience has stimulated my interest in the way online groups influence donor-conceived people’s sense of belonging. Indeed, in addition to supporting my process of understanding my own story, these online communities also accelerated another transition for me, this time to ‘becoming activist’.
Chapter 3: Doing reflexivity in research on donor conception (published book chapter)

Becoming Activist

I have never been among so many donor-conceived people in real life. We are packed into a tiny room with barely enough space to get out of our chairs in an office building in the city centre of Geneva. Everyone is taking turns to read through the speech they will present at the UN the following day. Many members of the group have spent decades pushing for reform. The room is hot, filled with nerves in preparation for this milestone event. The organisers, Belgian donor-conceived activist Stephanie Raeymaekers, and Australian health law expert and advocate Professor Sonia Allan, have put hours of work into organising this workshop at the 30th Anniversary of the UN Convention on the Rights of the Child (UNCRC). We have paid our way, travelling from all corners of the world to discuss our experiences of donor conception on the world stage for the first time (Allan et al., 2020).

Those who are delivering speeches at the UN the next day are tasked with telling emotive and persuasive personal stories, rehearsing sensitive and painful experiences with the aim of influencing decision-makers. As people rehearse their stories, highlighting the consequences of donor conception, tissues are handed around as they become emotional. Some tell stories of finding out they have dozens of siblings, others of searching for information about biological parents for decades. The most emotional of the stories are of donor-conceived friends, such as Narelle Grech and Alison Davenport, who tragically passed away from conditions for which they were high-risk, information they would have known had they been permitted access to the medical histories of their donors. Legislation across the globe has failed donor-conceived people by neglecting to recognise our right to know our identities and our families. The speeches are connected by the shared vision of “nothing about us, without us”; governments must listen to and act on the voices of people with lived experience. The next day, the presentation is met with a standing ovation, members of the UN and international community moved to tears.

My trip to Geneva emphasised to me that our stories have political value, and that our voices must be given primacy. I became more aware of how I could leverage my experience to help change laws and support the rights of generations of donor-conceived people. I also witnessed how donor-conceived people bonded around shared adversity and the struggle to have their human rights recognised, and participated in the celebration of feeling listened to and creating change. Reflecting on that moment, it is clear to me how activist involvement shifted my priorities and my approach to research. I now believe that researchers in the field of donor conception have a key role to play as allies and advocates, and that they possess the power to centre the narratives of donor-conceived people. Ignoring donor-conceived people’s
The phrase ‘nothing about us without us’ (Charlton, 2000), coined in the early 1990s by those in the Disability Rights movement, encapsulates the importance of engaging people with lived experience in decision-making about programme and service development, as well as leadership and governance. In the health sector, people with lived experience are increasingly being recognised as experts on issues affecting their own health in the form of ‘consumer participation’, defined as ‘incorporating consumer opinions and perspectives to inform the development and improvement of health-care practice’ (Hall et al., 2018, 708). The beginning of the consumer participation movement was sparked by the reform of the mental health care system in the US in the 1970s (Doyle, 2008), and while the appropriateness of using the term ‘consumer’ in health contexts has been debated (Smith, 2016), the importance of this mode of participation and representation is now widely recognised (World Health Organization, 1978). The large body of scholarship on consumer participation has demonstrated that governments and organisations that act without collaborating with people with lived experience will inevitably have less significance and limited outcomes. For example, Ti et al. (2012) have argued that collaboration between decision makers, service providers and people with lived experience strengthens community voices and results in greater satisfaction and wellbeing. However, in practice, the ability to uphold these standards proves challenging for service providers, as it requires systematic change to include people with lived experience in meaningful ways.

Assisted reproductive technology brings with it considerable scientific and medical complexities, as well as significant social and ethical issues. The social and ethical issues largely stem from balancing the interests of a wide range of stakeholders, including those of intending or recipient parents, clinicians and allied health professionals, fertility clinics and their shareholders, regulators and taxpayers. However, people conceived through assisted reproductive technology are seldom counted among this set of key stakeholders, despite models encouraging a child-centric paradigm (Adams, 2013). Donor-conceived people frequently note that they are the only party who do not consent to this conception arrangement, while being the party most affected by the decision. In the opening of her doctoral thesis, donor-conceived woman Joanna Rose suggested that ‘encouraging social change which goes against powerful interests, is invariably difficult and painful … To my delight, I have found there were people fighting, against the odds, for our rights from before I
was born’ (Rose, 2009, p. viii). Standing against a multi-billion-dollar industry takes significant emotional energy. However, given there are now several generations of people who know they were donor-conceived:

It is paradoxical that those for whom the practice was created in the first place have not been an integral part of academic and practical discussions on secrecy, anonymity, disclosure, and other aspects of its practice that affect their lives in fundamental ways. (Mahlstedt et al., 2010, p. 2236).

Among the literature on donor conception, it is widely recognised that the best strategy for achieving the ‘best interests’ and ‘welfare’ of donor-conceived people is to ask them (Blyth, 1998). As suggested by Rodino et al. (2011), donor-conceived people ‘may be best placed to guide policy makers as to the type of information that should be stored and made available because they have been most affected by the process’ (p. 310). However, limited attention has been paid to the ways in which donor-conceived people are permitted to participate in shaping policy and law regarding assisted reproductive technology based on their lived experience. This raises two questions: are donor-conceived people being included in decision-making, and, if they are, what effect does their participation have on policy and practice?

While few studies have focused on donor-conceived people’s perspectives, it has been noted that the voices of donor-conceived adults are ‘very strong, influential and demanding to be heard’ (Daniels, 2020), and that donor-conceived people are extremely willing to be involved in research (Macmillan, 2016). The feelings of powerlessness which donor-conceived people may experience in relation to their genetic histories may be reinforced when they are excluded from research that affects them. Meaningful inclusion of people with lived experience in research can take many forms, from participatory research (such as Fisher & Robinson, 2010) to advisory committees (see Porter et al., 2006). Scholars such as Schneider (2012) have noted that there is a continuum of approaches to inclusion, from control, collaboration, contribution and consultation (p. 156). In the field of donor conception studies, there is need for a greater focus on what it means to do research with and for donor-conceived people.

In my research, I decided to privilege donor-conceived people’s perspectives by focusing exclusively on their experiences rather than ‘balancing’ their voices with those of donors, recipient parents and clinicians. I was also interested in donor-conceived people’s opinions
on the practice of donor conception itself, to provide context for what it is they need from and bring to online support communities. Consequently, I sought to gather donor-conceived people’s views about payment or reimbursement for gametes, limits on the number of children born from the same donor, disclosure about donor conception (including on birth certificates) and importation or travel to access gametes. In doing so, I sought to deliberately recognise donor-conceived people as experts on the issue. I also wanted to examine whether donor-conceived people felt they were being included in decision-making and development of programmes and services, and whether they had been involved in their design and delivery. Finally, I opted to include donor-conceived people in the governance of the research. In the design phase of my study, I established an advisory panel to provide expert advice on the study, which included people who have lived experience of being donor-conceived in an Australian context. Involving donor-conceived people in a research approach promotes community ownership and facilitates recruitment, which is especially valuable for empirical study with ‘hard-to-reach’ groups.

The decision to focus on donor-conceived people’s perspectives is itself political. The right to know one’s genetic origins is a human right (UNICEF, 1989), and this human rights framework is undisputed within my community. However, these perspectives can come into conflict with other rights claims, and there are people in the community who may disagree with donor-conceived people being able to access identifying information. I am acutely aware that, because of my dual positions as donor-conceived person and as activist, I may not be viewed as an objective researcher, and my research may come under additional scrutiny. Every researcher brings their own insights and biases to their research, although for peer researchers those insights and biases are often subject to greater critique. Bringing my lived experience to my research gives it ethical legitimacy, but also opens the research and myself up to opposition. Flood et al. (2013) have argued that activist researchers must protect themselves, firstly from opposition from political opponents who may aim to silence them, as well as from their institutions who may view activism as going beyond the researcher role. I am particularly cognisant of these tensions as I move into my third position of ‘becoming researcher’.
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Becoming Researcher

I’m with a friend on a Friday night in the middle of winter. I open Facebook to have a quick scroll. A post on my feed catches my attention. It’s from one of the Facebook groups for donor-conceived people, describing how the person had just found out they were donor-conceived, as an adult, in the middle of the coronavirus pandemic. I drop a care reaction, feeling for this person who is newly discovering and trying to make sense of this information, and move back to my conversation with my friend. The following week, the person from the Facebook post reaches out to me to do an interview for my study. I recognise the name, and I wonder if it’s too soon to be doing an interview with them, and whether the interview may be distressing. I decide to proceed with the interview because participants often tell me that they find participating in the research therapeutic, an opportunity to chat with someone who understands.

As I am scrolling through Facebook, I often stumble upon snippets of information relevant to my research, meaning that I may know things about a participant before we meet. I feel unsettled knowing part of a participant’s story before the interview encounter, because they have disclosed that information to me as a peer, not as a researcher.

Despite my discomfort, by agreeing to do the interview, I was also able to check that they were doing okay and provide them with resources. Following the interview, the participant told me that they enjoyed talking to a fellow donor-conceived person and asked to add me on Facebook to keep in touch. This demonstrates several ethical tensions that have emerged from my new and overlapping positions as peer and researcher. For researchers who investigate their own community, the boundaries between work hours and home hours, research and personal life, can become blurred.

My positionality as a donor-conceived person means that I come at my research as an insider. There is a large body of scholarship in qualitative research focused on positionality in relation to research participants which characterises possible impacts of a researcher’s insider or outsider position, although much of what has been written comes from the areas of field research, ethnography and observation (Dwyer & Buckle, 2009). As suggested by Dwyer and Buckle (2009), being an insider does not inherently make the research better or worse; rather, coming at a research topic from different angles can enrich our understanding. In particular, insider researcher can affect the rapport between the researcher and participants as ‘shared experiences cultivate degrees of intimacy between people’ (Taylor, 2011, p. 10). Some
scholars have critiqued the term ‘insider’ as ‘dichotomised rubrics such as “black/white” or “insider/outsider” are inadequate to capture the complex and multi-faceted experiences of some researchers’ (Song & Parker, 1995, p. 243). Further, subjectivities are not static: in interaction, different aspects of identity become more or less prominent depending on audience and context, thus one is neither entirely insider nor entirely outsider (Hodkinson, 2005). Hodkinson (2005) argues that in particular situations, despite identity differences, participants are consciously united by a key feature or set of features. The identity category ‘donor-conceived’ is one that those conceived via third-party reproduction may or may not identify with, and among those who do identify as donor-conceived, individuals may inhabit a range of social locations. Therefore, remaining cognisant of the divide between the stories of the participants and my own experiences of donor conception is vital. For instance, in insider research with fat women, Howe outlines the importance of not overshadowing participants’ perspectives and experiences with her own stories or generalising the experiences of all fat women (Shaw et al., 2020). Berger (2015) has described this as a ‘constant deliberate effort to maintain the separation between mine and theirs’ (p. 224).

When I started my research, I was nervous about how it might be perceived by my community, and wary of negative perceptions that could impact my personal life. Research by Johnson and colleagues (2018), on online communities for military spouses, explored the risks involved in doing research on one’s own online community, particularly emotional risks, such as social isolation, if the research or researcher is not well perceived by the community. However, my major concerns did not come to fruition, rather the affinities created in the interview context have enhanced my sense of belonging to a community of donor-conceived people. As I was conducting interviews, many participants told me that they trusted me to do a good job with the research because I was a peer, that they were able to better open up as a consequence, or that I ‘got it’. As discussed by Attia and Edge (2017), for many insider researchers, empirical work is built upon pre-existing trust. Then, through the research process, interactions with community members increase, and relationships are strengthened. Increased contact with my peers helped me to become more confident in my identity as a donor-conceived person, and, in turn, I now feel more a part of the Australian donor conception community as I am recognised by them as a peer.

My positions as a researcher and donor-conceived person often collide when the expectations of each role conflict. To make sense of these competing norms between my roles, I use the different disciplinary methodologies I have access to. When I consider the tension between
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peer and researcher from a linguistic perspective, for example, I first consider how social context influences my interviewer role and the interaction patterns I can produce. In social semiotics, types of interaction are understood as genres; every type of interaction has stages, goals and social factors (Martin, 2009). In the genre of a qualitative interview, the goal is to ask questions and elicit information from the participant without leading the participant to give a biased or socially desirable response. Therefore, to conform to the requirements of the researcher role, I consciously employ strategies that minimise the extent to which I align or de-align with the values expressed by the participant. At an interpersonal level, maintaining neutrality is challenging, because as a donor-conceived person I feel compelled to align with the participant as a peer in our interaction. There are several strategies, deemed appropriate within qualitative research, that I use to build connection and rapport at the beginning and end of interviews.

By flagging that I am donor-conceived at the start of interviews and demonstrating knowledge of appropriate word choice and understanding of what is going on in the community, I build trust with participants. Further, I conclude interviews by asking participants if they have any questions for me and I find that participants often use this opportunity to ask about my story and to find ways to connect our experiences. In such instances, I think it is appropriate to draw on the similarities between my own experience and the participant’s in seeking to validate their interpretation. I also use this opportunity to recognise the contributions they have made to the research by sharing their stories with me. Using the final moments of the interview to do this allows me to take off my ‘researcher hat’ and connect peer to peer, while also ensuring that participants feel appreciated. Julie Howe has described the experience of a participant reaching out to hug her following an interview and the resulting tension between doing what is ‘right’ as a kind human being and ‘proper research conventions’ (Shaw et al., 2020, p. 282). Like Howe, I believe that through building reciprocal relationships with participants, we strengthen the quality of our data and permit an emotional connection.

The literature on insider research has often focused on participants’ wellbeing, and the emotional toll that insider research can have on the researcher has been explored less (see Nelson, 2020). During this research I have been mindful of assessing how I am feeling given that the topic is so personal. While it is recognised that interviews can be cathartic or therapeutic for participants (Shaw et al., 2020), less has been written about how the researcher may also benefit from the interaction. I have found meeting donor-conceived
people and hearing their stories to be affirming. Reflecting on their data collection, Nelson (2020) has suggested that:

Through hearing the diversity of stories and experiences of people who were like me/not like me, I saw a variety of opportunities, experiences and feelings that I had never had the time to consider in such depth before (p. 13).

Like Nelson, I feel a very deep and personal connection to my interview participants, despite the diverse range of stories and experiences. Nelson (2020) has described the euphoria they experienced from connecting with their peers in the interview context and a resulting sense of contentment with their identity from interacting with others who shared their experience of being queer. Similarly, I believe that exposure to a range of detailed stories from donor-conceived people has normalised my donor-conceived identity. In a similar vein, Mogseth (2019) has argued that:

Of course, no one had told me, or even insinuated, that I keep my conception a secret, but, then again, no one had told me not to. During my fieldwork, by sharing my experience, and by listening to my interlocutors, the topic of my donor conception lost its inexplicit taboo, and with this loss: a veil of displaced shame dissipated (p. 115).

Listening to others’ stories has also led me to reflect more carefully about the circumstances of my own conception and the ongoing unknowns within that story. Despite the agency and authority that doing research can bring, I am completely powerless over the information I have about my donor, donor 257. I am denied information about my medical and biological history, which I believe is central to the truth about who I am. I continue to wonder if I will be able to find donor 257 before he dies, or whether he will pop up on a DNA testing platform tomorrow. This powerlessness is simultaneously heartbreaking, infuriating and mobilising. The consolation is that I am fortunate to have access to a community of people who know what it feels like to deal with systems which deny us access to information about our own identities and histories. My peers empathise with this struggle and reinforce that I am not alone. On the internet, there is a group of people who are ‘like me,’ and together we create a space where we belong. I hope that in the future we have more control over the narrative of who we are and what is important to us. Our stories deserve to be told.

Conclusion
‘Doing reflexivity’ is an ongoing process of considering how my personal attitudes, experiences and motivations affect the decisions I make in my research. This involves
exploring how I approach research differently as an insider, as well as contemplating what I need to change or compromise to take on the additional role of researcher. Overall, the opportunity to do research with my peers is a privilege, and I carry the weight of their stories and the responsibility to represent their voices. In this chapter I have reflected on three phases of becoming: becoming donor-conceived, becoming activist and becoming researcher. My trajectory from person with lived experience to researcher reflects a broader intervention in research that recognises that different conclusions are reached by people with lived experience who are embedded in the communities in which they study. People with lived experience bring different priorities and ways of thinking and build lived experience into the ownership of the research process. This coincides with a social shift away from the secrecy and silence of the past, and more than 30 years since the Convention of the Rights of the Child was adopted, there is a strong and solid movement to recognise the rights and best interests of the child and donor-conceived adult that they grow up to be. Major challenges arise in a constantly shifting field where the technologies, industry and legislation are evolving as the people created by the technologies are growing up. This is compounded by the rapid increase in people accessing assisted reproductive technology worldwide, the rapid uptake of DNA testing technologies and proliferation of social media platforms. Despite these challenges, legal and policy responses must recognise and build upon donor-conceived people’s knowledge, strength and determination. While the role of donor-conceived people is still emerging in research contexts, there is a clear path forward: it is time for researchers to practice meaningful engagement and listen to the voices of donor-conceived people.

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CHAPTER 4 - From lived experience to lived expertise: How donor-conceived witnesses claim and sustain epistemic authority (submitted article)

Link to thesis: In Chapter 4, I document donor-conceived adults’ participation in a public hearing of the 2010 Legal and Constitutional Affairs References Committee Inquiry into Past and Present Practices of Donor Conception in Australia (aim 1). Drawing on theory and analytic frameworks from social semiotics, I analyse how donor-conceived people position themselves as an authority on donor conception (aim 2). I argue that, through this process of enacting lived expertise, the donor-conceived witnesses forge a sense of belonging as peers, while also establishing the legitimacy of donor-conceived adults’ participation in law reform contexts (aim 3).
Abstract

Scholars in pragmatics have long been interested in how knowledge is positioned, contested and legitimised. Much recent work in pragmatics has focused on developing more detailed theoretical understandings of epistemic stance-taking and epistemic authority, including in institutional contexts which are typically characterised by knowledge asymmetries and power inequalities. Taking a social semiotic approach, combining analysis using epistemic stance, turn-taking and evidence frameworks, this article examines a public hearing of the 2010 Senate Committee Inquiry into Donor Conception in Australia. Findings reveal four cumulative discursive patterns: donor-conceived witnesses positioned their lived experience as non-negotiable, cast doubt on fertility practitioners’ expertise, layered opinions upon experience and employed recognised knowledges to bolster authority. This article contributes to understanding how authority and community are simultaneously negotiated in interaction turn by turn. More broadly, this article introduces the concept of ‘lived expertise’; that is, authority grounded in experience and sustained through awareness of additional forms of experiential and institutional knowledges. Empirically, this study sheds light on how donor-conceived people – as people with lived experience – expand the subject positions afforded to them in institutional contexts, inviting legitimacy and belonging.

Keywords: epistemics, epistemic positioning, epistemic authority, lived expertise, social semiotics, Australia
Chapter 4: From lived experience to lived expertise (submitted article)

Introduction

Negotiating knowledge and forms of expertise are key aspects of social life. Much work in pragmatics has focused on developing theoretical understandings of epistemics in social interaction with scholars significantly advancing concepts of epistemic stance, status, primacy, and positioning in recent years (Drew, 2018; Mushin, 2022). Scholars have also paid due attention to how epistemic authority is negotiated within institutional contexts which are characterised by power inequalities and epistemic asymmetries (Drew, 1991; Heritage, 2006). In medical encounters or legal proceedings, for example, particular forms of expertise are valued and evidence is assessed and ranked in line with knowledge hierarchies (Heritage, 2006; Stivers et al., 2011). Further, in these official domains, participant roles are relatively fixed: the institutional representative has the right to ask questions and make decisions, and the patient or witness is expected to cooperate and provide information accordingly (Berry, 2021). However, recent years have seen shifts in traditional power structures in institutional contexts. For example, in medical contexts, clinicians are expected to provide patient-centred care, characterised by shared decision-making between patients and healthcare professionals (Brosnan & Kirby, 2016; Landmark et al., 2015; Mead & Bower, 2000). Similarly, in legal and policy contexts, those in positions of power are increasingly expected to listen to people with lived experience; that is, those who have lived through a specific event or experience such as homelessness or incarceration, or live with a specific identity, disability or health condition (Classen et al., 2021; Gabriel, 2004; valentine et al., 2020). These social shifts not only recognise that individuals who have firsthand experience offer distinct knowledges, but also that people with lived experience should be engaged in decisions that affect their lives (Charlton, 2000; Ti et al., 2012; WHO, 2004). Such developments make visible how epistemics not only relates to access to knowledge, displays of knowledge and degree of certainty, but is also a moral concern regarding who has the right to speak about the topic and claim authority over the knowledge territory (Drew, 1991; Heritage, 2013b; Kamio, 1997; Raymond & Heritage, 2006; Stivers et al., 2011).

One domain ripe for analysis of epistemic authority is the field of donor conception, that is, assisted reproduction using donated eggs and/or sperm to achieve pregnancy. While this practice has existed since the 19th century, doctors promised sperm donors anonymity and encouraged parents to maintain secrecy about donor conception, including by keeping this information from the donor-conceived child (Allan, 2017). As such, until the 21st century donor conception was largely hidden from the public eye and doctors were protected from
public scrutiny and legal accountability (Haimes, 1993). With attitudes evolving over the past three decades, today many people are learning during childhood or later in life that they were conceived with donor gametes (Allan, 2017). Yet when donor-conceived people search for evidence of their conception in medical records, they often find these documents have been incompletely recorded, modified post hoc or destroyed (Dobby, 2010; Haimes, 1993). Due to this complex history, in this field establishing ‘the truth’ is not just about who knows what but also about which actors can be trusted. In legislative reform processes, decision-makers elicit information to establish to extent of the practice and its impacts. In such institutional contexts, different forms of knowledge about donor conception are presented and epistemic authority on the topic is negotiated. Importantly, the people created through this practice – donor conceived people – are able to draw on their lived experience and contest the expertise of recognised authorities. A pragmatic focus on such interactions, through the lens of epistemics, affords rich insight into how authority is claimed or contested in institutional contexts in which power dynamics are rapidly shifting.

Drawing on the Hansard (official transcript) of a public hearing of the 2010 Senate Committee Inquiry into Donor Conception in Australia, this article adopts a social semiotic approach to consider how donor-conceived witnesses position themselves – and negotiate authority – in the unfolding hearing. Specifically, this article contributes to understanding how individuals draw on forms of experiential and institutional knowledge to sustain epistemic authority. More broadly, it develops new understandings of how people with lived experience expand the subject positions afforded to them and gain legitimacy in institutional contexts.

**Background**

*Linguistic approaches to evidentiality and epistemic positioning*

Since the turn of the century, increased attention has been paid to questions of how knowledge is managed in social interactions, with epistemic discourse analysis representing a burgeoning multidisciplinary field (Stivers et al., 2011; van Dijk, 2013). Within linguistics, epistemics has been considered from a range of vantage points, including through concepts such as certainty, reliability and evidentiality (Chafe & Nichols, 1986; Givón, 1982; Pomerantz, 1984). Evidentiality, that is, “how the speaker has come to know what they are claiming” (Hart, 2011, p. 758), has largely been considered in relation to languages in which evidential meaning is marked morphologically and in typological language studies (Chafe & Nichols, 1986; Givón, 1982; Kamio, 1997; Mushin, 2001). Consequently, the ways in which
evidential meanings are construed in English, a language with no morphologised system of evidentiality, has been explored significantly less (Bednarek, 2006). However, in her influential analysis of English language newspapers, Bednarek (2006) demonstrated how epistemological positioning in English encompasses elements such as the basis of one’s knowledge, the certainty of knowledge, the extent and limitations of knowledge, and expectations regarding knowledge. Bednarek (2006) also distinguished between the concepts of ‘source’ which refers to the actor to whom the knowledge can be attributed (e.g. self, other), and ‘basis’, that is, how that knowledge was garnered (e.g., perception, general knowledge, hearsay, unspecified and so on). Researchers have extended this scholarship describing processes of “objectification”, whereby the addresser draws on an independent source as the basis of knowledge, and “subjectification”, which relates to the addresser positioning themselves as the source claiming authority over the knowledge (Hart, 2010). These sourcing choices often depend on “how confident the speaker is that the hearer will ‘take their word’ for the truth of the assertion” (Hart, 2011, p. 759) and levels of (dis)trust between interlocutors (Enfield, 2011). It is clear, then, that individuals carefully negotiate sourcing as they position themselves epistemically. Less clear, however, is how this positioning contributes to the ways in which individuals assert authority.

**Conversation analysis and epistemic authority**

Understandings of how participants negotiate epistemic positions relative to contexts and interlocutors have developed significantly, particularly through research by conversation analysts (Heritage, 2013b; Heritage & Raymond, 2005; Mondada, 2011; Raymond & Heritage, 2006). For example, research has found that individuals typically have authority over their own epistemic territory which covers their “biographical facts”, feelings and experience (Goffman, 1971, p. 39; Heritage, 2011; Kamio, 1997). This basis of knowledge, in which direct experience can be cited and demonstrated has been described as source-based authority (Enfield, 2011). In contrast to source-based authority, status-based authority refers to the claims to knowledge an individual is entitled to make based on their professional, interpersonal or contextual status (Enfield, 2011). Enfield (2011) has argued that generally these two forms of authority are in alignment but points to an example of a comparison between a child’s relationship to a nanny and the child’s relationship with their mother (adapted from Raymond & Heritage, 2006). In the example, the nanny spends more time with the child and therefore gains source-based authority, yet when asked about the child, the mother’s status-based authority overrides the nanny’s due to the normative entitlements and
expectations ascribed to her based on her kinship position (Enfield, 2011; see also Blythe et al., 2022). More recently, scholarship has illuminated how epistemic authority is co-negotiated move by move in interaction (Izadi, 2018; Mondada, 2013). Importantly, this work has demonstrated how the distribution of knowledge can be challenged and re-negotiated within an encounter. Yet there is further scope to examine how context influences the roles and power dynamics between interlocutors, and consider the stances being negotiated in these interactions.

**Towards a social semiotic approach to epistemics: Negotiating solidarity and power**

Building on and complementing the above approaches to epistemics, this article takes a social semiotic approach. Social semiotics is functional model which provides analytical frameworks for examining meaning in context (Halliday & Matthiessen, 2004). Within social semiotics, language simultaneously enacts three metafunctions: ideational (construing experience), textual (organising information), and interpersonal (negotiating relationships) (Halliday & Matthiessen, 2004). As such, as knowledge is negotiated through language, these three types of meaning are in interplay. Considering knowledge from a social semiotic perspective involves examining how individuals position themselves through epistemic stances, that is, through the co-selection of ideational and interpersonal meaning in ideation-attitude couplings (Martin, 2000; Zappavigna et al., 2008). Importantly, ideation-attitude couplings construe social bonds, the social units by which interlocutors align and co-identify in communities (Knight, 2010; Martin, 2010). As such, through epistemic stances individuals position themselves in relation to others, in alignments and disalignments.

Beyond stance, epistemic positioning also occurs via turn-taking. The exchange structure model is used to examine the regulation of discourse, that is, how turns are managed and controlled in talk (Berry, 1981, 2021). This approach illuminates who has the “ultimate authority over the validity of the information exchanged” in an interaction (Zappavigna & Martin, 2018, p. 132). The turns (and roles) adopted or assigned in dialogue are often underpinned by master identities (e.g., gender, age, class, ethnicity, dis/ability, profession, etc.), determined outside the interactional context (Berry, 2021; Knight, 2010). However, exchange structure analysis permits annotation of how authority is negotiated dynamically, turn by turn. As such, in combination the exchange structure and ideation-attitude coupling models provide insights into how – in displaying or contesting knowledge – more broadly interlocutors are negotiating solidarity (intimacy and distance) and power (equality and inequality) (Poynton, 1991). This article explores how community and authority are
negotiated in a specific institutional context by considering how witnesses position themselves and their knowledges turn by turn.

**Method**

**Dataset and public hearing context**

The naturally occurring data analysed in this study comes from the Hansard of a public hearing of the 2010 Senate Committee Inquiry into Donor Conception in Australia (hereafter referred to as ‘the Inquiry’). The 2010 Inquiry is the only national level inquiry in which donor conception has been explored in Australia to date. The Inquiry was held to “assist the Australian Government in extending its understanding of the changing experience of many Australian families” (Government response 2011, p.1). The Inquiry received 156 submissions and public hearings were held across three cities with 33 witnesses. This article focuses on one session of the Melbourne public hearing held on November 2010, which took place between 11.40am and 12.42pm between committee members Senators Barnett (Chair), Crossin and Pratt, and five donor-conceived witnesses: Damian Adams, Lauren Burns, Myfanwy Cummerford, Kimberley Springfield, and Michael Williams (referred to in the analysis by surname as per Hansard convention) (Parliament of Australia, 2010). For the purpose of Official Committee Hansard verbal interactions were transcribed, constituting approximately 10,000 words or 20 pages. Although Hansard is publicly accessible, ethics approval was secured from [University Ethics Committee anonymised for peer review] for analysis.

Public hearings are conducted to gather a variety of views from people with relevant knowledge (understood as either experience or expertise) (Parliament of Australia, 2021). As a macrogenre, public hearings tend to consist of four phases: 1) an opening/framing 2) opening statements delivered by witnesses, 3) questioning from committee members, and 4) closing (see Figure 3). The institutional context shapes the roles of participants which are unequal (as opposed to equal) in POWER and distant (as opposed to intimate) in relation to DISTANCE. For example, the role of the chair and committee members’ is to offer a propositional base for controlling the parameters of the public hearing, to regulate the experiential content and elicit knowledge from witnesses. The role of a witness is to give evidence in accordance with the propositional base set up by the chair and committee members.
Analytical approach and frameworks

In this study, a bottom-up, data-driven approach was taken. First a “soft eyes” analysis was undertaken; in other words, familiarisation with the data occurred through multiple read-throughs followed by identification and isolation of segments for detailed analysis (Baskin, 2015). Stretches of text in which epistemic authority was contested or explicitly negotiated were identified. These stretches of data were analysed using three frameworks, explained below. In social semiotics SMALL CAPS are used for names of systems of meaning.

The first framework, Appraisal (Martin & White, 2005), is a social semiotic framework for analysing attitudinal meaning. A key system of meaning within Appraisal is the system of ATTITUDE, which is modelled as three regions of meaning: AFFECT (emotion), JUDGEMENT (ethics or morality), and APPRECIATION (aesthetics/value). Attitudes can positive or negative in polarity and be inscribed (explicit) or invoked (implicit). However, attitudes are ascribed to things, processes and people (ideation), and such patternings are analysed according to ideation-attitude couplings (Martin, 2000; Zappavigna et al., 2008). Couplings are annotated using the notation convention: [ideation / attitude] (following Martin et al., 2013), attitude is shown in bold, and ideation is underlined (see Figure 4).
Turning to the exchange structure framework (Berry, 1981), this model divides dialogue into action or knowledge exchanges: action moves (A#) and knowledge moves (K#). In exchange analysis, interlocutors are annotated as primary knower (K1), that is, the person (discourse role) who already knows information, or secondary knower (K2), that is, the person (discourse role) to whom the information is imparted. Challenge moves (ch) consist of uncooperative moves in regard to discourse roles, in that they prevent exchanges from meeting their intended end (Berry, 2021). Figure 5 contains an example of a knowledge exchange annotated with exchange analysis.
Finally, data were analysed using an evidence framework of source, quantity and basis (see Figure 6). Sources refers to the actor who is attributed for the knowledge; that is, “who is ‘responsible’ for the content of the modified utterance” (Bednarek, 2006, p. 639). Basis relates to “the mode of knowing”; that is, how the actor attained the knowledge, for example, perception, general knowledge, proof, obviousness, unspecified (Bednarek, 2006; Chafe & Nichols, 1986, p. 263). Quantity refers to whether the attribution is towards an individual or collective source/basis.
Table 4 illustrates the annotation undertaken using the three distinct frameworks: ideation-attitude couplings, exchange structure and evidence. Following Han (2015), alignment and disalignment were also annotated.

Table 4: Example of annotation according to ideation-attitude couplings, exchange structure and evidence frameworks

<table>
<thead>
<tr>
<th>Line no.</th>
<th>Speaker</th>
<th>Talk</th>
<th>Knowledge Exchange (K.E.)</th>
<th>Coupling</th>
<th>Evidence</th>
<th>Alignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g.</td>
<td>CHAIR (committee)</td>
<td><strong>Thanks very much, all of you, for being here and for being willing to be part of this Senate inquiry.</strong></td>
<td>K1</td>
<td>[Participation in Senate inquiry / + APPRECIATION valuation]</td>
<td>Addresser singular opinion</td>
<td>Align towards addressees</td>
</tr>
</tbody>
</table>

**Results and discussion**

The analysis of Hansard from the public hearing using ideation-attitude couplings, exchange structure and evidence frameworks revealed how witnesses characterised their own knowledge, positioned themselves in relation to other witnesses, and drew upon additional knowledges to support their positioning. Specifically, analysis revealed four salient discursive patterns: how donor-conceived witnesses positioned lived experience as non-negotiable, how witnesses cast doubt on fertility practitioners’ expertise, how witnesses layered opinions upon experience and how witnesses employed recognised knowledges to bolster authority. The sections below explore these four discursive patterns derived from analysis.

*‘From personal experience’: positioning lived experience as non-negotiable*

Across all of the opening statements, witnesses positioned themselves on the topic of donor conception by revealing their donor-conceived status. For example, Ms Cummerford and Mr Williams, like other witnesses, outlined their age and circumstances of disclosure.

Table 5: Analysis of right to know donor-conceived status bond

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Talk</th>
<th>K.E.</th>
<th>Coupling</th>
<th>Evidence</th>
<th>Alignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Cummerford (DCP)</td>
<td><em>I found out I was donor conceived at the age of 20, three days after my birthday.</em></td>
<td>K1</td>
<td>[Disclosure by parents as an adult/ - JUDGEMENT social sanction invoked]</td>
<td>Addresser singular experience</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td><em>It was not in the most ideal circumstances—I was told by my mother after my parents had separated.</em></td>
<td>K1</td>
<td>[Disclosure by parents during family separation/ - JUDGEMENT]</td>
<td>Addresser singular experience</td>
<td>Disalignment from parents</td>
</tr>
</tbody>
</table>
I also have a brother, who is my full sibling. At the time that I was told by my mother, she decided not to tell my brother. I discovered when my mother informed me at 21 that I was conceived through donor conception. I too have struggled since that time with my identity.

In Table 5, Ms Cummerford and Mr Williams describe their personal experience (K1; Addresser: internal: singular: experience) of finding out they were donor-conceived as adults via the same coupling: [Disclosure by parents as an adult/ -JUDGEMENT social sanction invoked] (lines 1 and 4). These couplings, like others across the data, contributed to a social bond around the ‘right to know’ one’s donor-conceived status. This bond was characterised by couplings in which the ideational target of disclosure, age of disclosure, and circumstance of disclosure were fused with positive or negative judgement towards parents (e.g. non-disclosure = negative judgement, disclosure as a child = positive judgement, during conflict = negative judgement). The couplings of disclosure and judgement create the basis of the social bond around the ‘right to know’. In other words, the witnesses have similar interpretation of their experiences and ‘the right to know’ is non-contentious among donor-conceived peers.

Another shared social bond enacted among donor-conceived witnesses related to relationships with biological family members such as donors and donor siblings (see Table 6). Ms Burns and Mr Adams personal experiences differ in that Ms Burns reveals how she had made contact with her biological family, while Mr Adams had not. However, both witnesses construe positive judgement towards biological family: [Relationship with biological family/ + JUDGEMENT social esteem invoked] in lines 3 and 6. As such, the two witnesses, like others, demonstrate to the committee their shared position that all donor-conceived people should have the right to know their biological family members. In these formulations, then, the witnesses direct their audience to the basis of their knowledge,
position their interpretation of their experience as uncontentious and unchallengeable, and raise the stakes of any challenges to their representations. As such, witnesses enact source-based authority in this epistemic domain (Enfield, 2011).

Table 6: Analysis of right to know biological family members bond

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Talk</th>
<th>K.E.</th>
<th>Coupling</th>
<th>Evidence</th>
<th>Alignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Burns</td>
<td>My donor replied within days</td>
<td>K1</td>
<td>[Contact with biological family/ + JUDGEMENT social esteem invoked]</td>
<td>Addressee singular experience</td>
<td>Align towards biological family</td>
</tr>
<tr>
<td>(DCP)</td>
<td>and I no longer had to use that impersonal word ‘donor’. My biological father’s name is Ben.</td>
<td>K1</td>
<td>[Impersonal language / - APPRECIATION reaction]</td>
<td>Addressee singular experience</td>
<td>Align towards biological family</td>
</tr>
<tr>
<td>2</td>
<td>Ben and I met for the first time and found we had a lot of surprising similarities and connections.</td>
<td>K1</td>
<td>[Relationship with biological family/ + JUDGEMENT social esteem invoked]</td>
<td>Addressee singular experience</td>
<td>Align towards biological family</td>
</tr>
<tr>
<td>3</td>
<td>I met his three children—my half-siblings—and these new relationships have had a very positive impact on my life.</td>
<td>K1</td>
<td>[Relationship with biological family/ + JUDGEMENT social esteem]</td>
<td>Addressee singular experience</td>
<td>Align towards biological family</td>
</tr>
<tr>
<td>4</td>
<td>He will never be my dad but he is my flesh and blood, my heritage, my mirror, my family.</td>
<td>K1</td>
<td>[Connection to biological family/ + JUDGEMENT social esteem invoked]</td>
<td>Addressee singular experience</td>
<td>Align towards biological family</td>
</tr>
<tr>
<td>5 Adams</td>
<td>I constantly search faces in the crowd for someone who could be my father or for someone who may be my brother or sister.</td>
<td>K1</td>
<td>[Relationship with biological family/ + JUDGEMENT social esteem invoked]</td>
<td>Addressee singular experience</td>
<td>Align towards biological family Alignment towards peer witness</td>
</tr>
<tr>
<td>(DCP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

While these two key social bonds between donor-conceived witnesses, ‘the right to know donor-conceived status’ and ‘the right to biological family members’, are important for orienting and persuading the committee member addressees, social bonds also unite donor-conceived witnesses. Since social bonds are the underlying infrastructure of shared identities (Knight, 2010; Zappavigna, 2014), aligning around shared bonds in this institutional context contributes to and reinforces the donor-conceived identity between witnesses. Moreover, in this setting, donor-conceived witnesses position their identities vis-a-vis other key subject positions in donor conception, such as parents and biological family members and, as we will turn to next, fertility practitioners.
‘You can’t trust fertility practitioners’: casting doubt on traditional expertise

The second section of analysis focuses on how donor-conceived witnesses position their knowledge alongside that of fertility practitioners who represent the biggest opposition attitudinally (Table 7). This positioning commences in the opening statements. For example, Ms Burns highlights how, in contrast to fertility practitioners, donor-conceived people are “the real experts”: [Donor-conceived witnesses / + JUDGEMENT social sanction], line 2. Here, Ms Burns argues that donor-conceived people have epistemic primacy given their lived experience (Stivers et al., 2011). In such moral assertions, the interplay between distinct forms of evidence is visible: between source-based and status-based authority (Enfield, 2011).

Table 7: Donor-conceived witnesses positioning themselves as “the real experts”

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Talk</th>
<th>K.E.</th>
<th>Coupling</th>
<th>Evidence</th>
<th>Alignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Burns (DCP)</td>
<td>I am sure that in the course of this hearing you will be speaking to many professionals involved in assisted reproductive treatment;</td>
<td>K1</td>
<td>[fertility practitioners / - JUDGEMENT social sanction invoked]</td>
<td>Addresser singular opinion</td>
<td>Disalign from fertility practitioners</td>
</tr>
<tr>
<td>2 however, I would like to think that we—the donor conceived people—are the real experts on these issues because they affect our lives every day.</td>
<td>K1</td>
<td>[Donor-conceived witnesses / + JUDGEMENT social sanction]</td>
<td>Addresser singular opinion</td>
<td>Align with donor-conceived witnesses</td>
<td></td>
</tr>
</tbody>
</table>

Following the opening statements, the next phase of the public hearing involves committee members eliciting information from witnesses. In this questioning phase, donor-conceived witnesses further position themselves in opposition to fertility practitioners by undermining the quality and integrity of their practices and evidence. The interaction displayed in Table 8 relates to record keeping practices in donor conception. At the start of the exchange, the committee member points to fertility practitioners’ evidence that had suggested there had been no problems with donor conception record keeping: [record keeping/ + JUDGEMENT social sanction], line 1. This K1 move is met with a challenge move in line 2 from Ms Cummerford who rejects the assertion with “rubbish”, a coupling with opposing polarity [record keeping/ - JUDGEMENT social sanction]. As such, Ms Cummerford disaligns with fertility practitioners and also disaligns from the committee addressee who has drawn on the knowledge.

In line 5, Ms Cummerford offers the following knowledge: “we know that there are records held in people’s garages”, with the coupling: [records are insecure/-judgement]. However,
here the form of evidence is unclear to the addressee and in the following move in line 7 the committee challenges Ms Cummerford’s utterance, asking “How do you know that?” This move has a disaligning function because it questions the confidence of the addressee (Hart, 2011). Following this question, Ms Cummerford specifically points to anecdotal evidence from peers absent from the public hearing and to her awareness of the experiences of her peers, demonstrating that her knowledge extends beyond her own experience. These statements are further reinforced by evidence of her own records being “held in storage somewhere” in lines 8-10. Through this sourcing, the witness reaffirms her position as an authority, a position which is then further reinforced by peer witnesses who are present. More broadly, across lines 2-10, Ms Cummerford builds evidence around the untrustworthiness of fertility practitioners.

Following Ms Cummerford’s comments, Ms Burns and Ms Springfield offer accounts of their experiences of medical records being misplaced and modified: [records are insecure/-JUDGEMENT social sanction] lines 11-13. These accounts, peppered with negative judgement towards the practices of fertility practitioners, sit in contrast with fertility practitioners’ own accounts of past practices. As such, these inconsistencies cast doubt on the credibility of fertility practitioners and the trustworthiness of their knowledges. As such, across excerpts in Tables 7 and 8, we see how donor-conceived witnesses position themselves in opposition to fertility practitioners, actors who have traditionally been viewed as an authority in donor conception. A social bond is reinforced between donor-conceived witnesses around negative attitudes towards the institution of assisted reproduction. Moreover, across these excerpts we start to see how witnesses undermine the authority of other witnesses while positioning themselves as an authority in this epistemic domain.

Table 8: Analysis of excerpt on record keeping practices in donor conception

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Talk</th>
<th>K.E.</th>
<th>Evidence</th>
<th>Coupling</th>
<th>Alignments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 PRATT (committee)</td>
<td>We heard evidence from fertility clinic practitioners that there is no problem with record keeping.</td>
<td>K1</td>
<td>Other collective expertise</td>
<td>[record keeping/ + JUDGEMENT social sanction]</td>
<td>Align towards fertility practitioners</td>
</tr>
<tr>
<td>2 Cummerford (DCP)</td>
<td>Rubbish.</td>
<td>ch</td>
<td>Addresser singular opinion</td>
<td>[record keeping/ - JUDGEMENT social sanction]</td>
<td>Disalign from fertility practitioners Disalign from committee member</td>
</tr>
<tr>
<td>3 PRATT (committee)</td>
<td>I would think there needs to be some</td>
<td>K1</td>
<td>Addresser singular</td>
<td>[preserve records/ + JUDGEMENT]</td>
<td></td>
</tr>
</tbody>
</table>
immediate action to protect what records are out there.

**4**

What would you suggest we should do on that front?

K2 Addresser collective opinion

Align towards donor-conceived witnesses

**5 Cummerford (DCP)**

In the interim, even before a report is tabled, there should be something done to preserve records.

K1 Addresser singular opinion

[preserve records/ + JUDGEMENT social sanction]

**6**

We know that there are records held in people's garages.

K1 Addresser Collective [unclear basis]

[records are insecure/- JUDGEMENT social sanction invoked]

**7 PRATT (committee)**

How do you know that?

ch Addressee [unclear quantity] [unclear basis]

Disalign from donor-conceived witness

**8 Cummerford (DCP)**

Anecdotally, from stories we have been told.

K1 Addresser collective experience

[records are insecure/- JUDGEMENT social sanction invoked]

**9**

People have gone back to doctors.

K1 Addresser collective experience

[records are insecure/- JUDGEMENT social sanction invoked]

**10**

My own records were not even held at the hospital, they were held in storage somewhere.

K1 Addresser singular experience

[records are insecure/- JUDGEMENT social sanction invoked]

**11 Burns (DCP)**

Mine were in the public records office in a permanently closed file just randomly.

K1 Addresser singular experience

[records are insecure/- JUDGEMENT social sanction]

**12**

Even though they will not supposed to be there, that is where they ended up.

K1 Addresser singular experience/ opinion

[records are insecure/- JUDGEMENT social sanction]

**13 Springfield (DCP)**

The non-identifying information that I finally got out of the clinic has actually got the name and address filled in by hand and has got it scrubbed out

K1 Addresser singular experience

[records are insecure/- JUDGEMENT social sanction]

‘Offering expert opinions’: layering opinions upon experience

The next section of our analysis focuses on how donor-conceived witnesses extend beyond their personal experience to offer opinions on donor conception. The excerpt in Table 9
relates to importation of donor gametes in prospective legislation. This domain of knowledge is outside the witnesses’ experience given they were conceived in Australia with gametes donated within Australia. In line 1, the Chair points to an unidentified witness to enquire about the use of imported gametes. Ms Cummerford interjects with a challenge move, suggesting importation of gametes is “inappropriate” via the coupling: [importation of gametes/ - JUDGEMENT social sanction], line 4. Ms Cummerford first orients the addressees towards her position through recounting her own experiences: “it is difficult enough for us to seek out our biological fathers who are Australian”: [access to information about Australian gamete donors/ - JUDGEMENT social sanction], line 7. Next, she extends beyond her experience to argue that issues of access to information are “multiplied” with foreign donors: [access to information about foreign gamete donors /- JUDGEMENT social sanction invoked], line 8. While initially grounded in her own experience, the witness offers a recommendation hypothesising what access to information about foreign gamete donors would entail. This position is not challenged by the committee, thus the witness’ opinion is accepted. This section of the excerpt makes visible the two sides of epistemic authority: by asserting their opinion, the donor-conceived witness claims authority and since the opinion goes uncontested, the authority is upheld.

In the following section, the Chair proceeds to open up the dialogic space to include perspectives from other witnesses in order to determine whether there is agreement on this expert position: “Is that a view across the board?” (K2), line 9. In response to the previous three couplings set out by Ms Cummerford, Ms Springfield states that she “definitely agrees”. Here, the original coupling presented by Ms Cummerford is mirrored in alignment: [importation of gametes/ - JUDGEMENT social sanction], line 10. In line 11, Ms Springfield first draws on her personal experience through a comment on the current lack of regulation: [regulation within fertility industry/ -JUDGEMENT social sanction], followed by a rhetorical question in relation to the added difficulties in regulating imported gametes: “How are we going to regulate that properly?”, line 12. As such, Ms Springfield offers the same second coupling and sourcing combination as Ms Cummerford: [access to information about foreign gamete donors / - JUDGEMENT social sanction invoked] [Addressee singular opinion] line 12. In doing so, Ms Springfield also co-positions herself as an authority against the importation of gametes alongside Ms Cummerford. Next, Ms Burns reproduces the coupling [importation of gametes/ - JUDGEMENT social sanction] in line 13. However, in contrast to the previous witnesses, Ms Burns goes straight to expertise claims via the opinion: “I do not think it fits
into that child-centric paradigm” [Addresser singular opinion]. Like previous opinions from donor-conceived witnesses, this opinion is not challenged and again authority is upheld. Broadly, analysis in Table 9 reveals how lived experience functions as a foundation for layering opinions. Moreover, the positioning of lived experience as uncontroversial is critical to the form and success of authority the witnesses claim and sustain. However, offering opinions is only one aspect of establishing oneself as a legitimate authority on donor conception, the second – bolstering authority through recognised knowledges – is explored in the following section.

Table 9: Analysis of excerpt on importation of gametes in prospective legislation

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Talk</th>
<th>K.E.</th>
<th>Evidence</th>
<th>Coupling</th>
<th>Alignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 CHAIR (committee)</td>
<td>We had evidence on Friday regarding the importation of donor sperm.</td>
<td>K1</td>
<td>Other collective [unclear basis]</td>
<td></td>
<td>Align towards non-specified witness</td>
</tr>
<tr>
<td>2</td>
<td>There was advice to the committee that the majority was coming from overseas and specifically the USA.</td>
<td>K1</td>
<td>Other collective [unclear basis]</td>
<td></td>
<td>Align towards non-specified witness</td>
</tr>
<tr>
<td>3</td>
<td>I am wondering if you have a view on whether it is appropriate or otherwise to —</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td></td>
<td>Align towards donor-conceived witnesses</td>
</tr>
<tr>
<td>4 Cummerford</td>
<td>Inappropriate.</td>
<td>ch</td>
<td>Addresser singular opinion</td>
<td></td>
<td>Disalign from non-specified witness</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>[importation of gametes/ - JUDGEMENT social sanction]</td>
<td></td>
<td>Disalign from committee member</td>
</tr>
<tr>
<td>5 CHAIR (committee)</td>
<td>coming from overseas</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Cummerford</td>
<td>Inappropriate.</td>
<td>ch</td>
<td>Addresser singular opinion</td>
<td></td>
<td>Disalign from non-specified witness</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>[importation of gametes/ - JUDGEMENT social sanction]</td>
<td></td>
<td>Disalign from committee member</td>
</tr>
<tr>
<td>7</td>
<td>It is difficult enough for us to seek out our biological fathers who are Australian.</td>
<td>K1</td>
<td>Addresser singular experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>It is only multiplied.</td>
<td>K1</td>
<td>Addresser singular</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Line</td>
<td>Role/Name</td>
<td>Statement</td>
<td>Addresser</td>
<td>Comment</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>-----------</td>
<td>-----------</td>
<td>-----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>CHAIR (committee)</td>
<td>Is that a view across the board?</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Springfield</td>
<td>I definitely agree.</td>
<td>K1</td>
<td>Addresser singular opinion</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td></td>
<td>Obviously, with regulations and things at the moment, things are not properly regulated as it is with clinics in Australia.</td>
<td>K1</td>
<td>Addresser singular experience</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
<td>How are we going to regulate that properly?</td>
<td>K2</td>
<td>Addresser singular opinion</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Burns</td>
<td>I do not think it fits into that child-centric paradigm.</td>
<td>K1</td>
<td>Addresser singular opinion</td>
<td></td>
</tr>
</tbody>
</table>

‘Across the legislation’: employing recognised knowledges to bolster authority

The final section of analysis considers another strategy used by witnesses: leveraging recognised knowledges (Table 10). Specifically, this excerpt relates to whether or not prospective legislation should allow future gamete donors to donate anonymously. In line 1, Senator Crossin (K2a) invites the witnesses’ stances on anonymous donation via the probe “Can I put this to you…”, followed by an interrogative. The senator then deduces the stance of the witnesses that those unwilling to be identified “should not be allowed to donate”: [anonymous gamete donation/ - JUDGEMENT social sanction], line 3. In line 4, Mr Adams (K1) aligns with the coupling set out by suggesting that he does not agree with anonymous gamete donation [anonymous gamete donation/ - JUDGEMENT social sanction]. Here, given the interaction is related to prospective legislation, Mr Adams’ response is on the basis of opinion [Addresser singular opinion]. Ms Burns in line 5 aligns with and then reinforces the coupling [anonymous gamete donation/ - JUDGEMENT social sanction] before drawing on how such a position is represented in the existing national standards, the NHMRC guidelines (ethical guidelines on the use of assisted reproductive technology in research and practice) [Addresser individual NHMRC guidelines]. Ms Burns also views the position as “a very widely held viewpoint” [Addresser collective public knowledge/consensus], line 7. Again, we
see how the attitudinal alignments between witnesses contribute to social bonds between them, contributing to donor-conceived and authoritative identities. The witnesses have drawn on guidelines and consensus to sustain their opinion and such awareness of traditional forms of knowledge also supports the witnesses positioning as an authority.

In the following section, positioning as an authority is further negotiated. In line 8, Senator Crossin makes a K1 move (suggesting primary knower status), followed by a challenge move stating that the NHMRC guidelines are “not enforceable” [Addresser individual NHMRC guidelines]. As such, the Senator asserts epistemic superiority and disaligns from the witnesses through K1 and challenge moves and by proposing a different coupling [enforceability of guidelines/ -APPRECIATION valuation], line 9. This tension in authority is managed through a move from Ms Burns: “Exactly. You have hit the nail on the head”, in which she aligns with the senator’s position, initiating a social bond between the committee member and witness. Next Ms Cummerford suggests that, beyond non-enforceable guidelines, the stance on anonymity is endorsed in Victorian legislation, line 12. This functions as a one-up in terms of authority, with Ms Cummerford demonstrating her breadth of knowledge and how legislation prohibiting anonymity has been introduced elsewhere. In response, again we see Crossin use a K1 move to affirm the previous statement and then a challenge move “And there are no laws in some states and in the Northern Territory”. However, this authoritative positioning by the committee member is contested in the challenge move in line 15: “we know that”, in an attempt to reposition the donor-conceived witnesses as epistemically superior. In line 17, Senator Crossin returns to a K2 move by clarifying the witnesses’ final position “So you are saying that…” . In doing so, the committee member restoring the witnesses’ epistemic authority. In lines 19-20 Mr Adams and Ms Cummerford affirm with “yes”, reinforcing the coupling: [Victoria’s position on anonymous gamete donation/ + APPRECIATION valuation] which aligns with the initial coupling [anonymous gamete donation/ - JUDGEMENT social sanction], line 2. Such instances in which committee members align towards witnesses by anticipating and verifying the witnesses’ stances contribute to a social bond between interlocutors. Donor-conceived witnesses seek to persuade the committee that their stances align with the broader values of the State and should be enshrined in law. As such, when committee members reconstrue the stances set out by donor-conceived witnesses, they legitimise such values within the institutional context, at the scale of culture.
### Table 10: Analysis of excerpt on anonymity of gamete donors

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Talk</th>
<th>K.E.</th>
<th>Evidence</th>
<th>Coupling</th>
<th>Alignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 CROSSIN</td>
<td>Can I put this to you:</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td></td>
<td>Align towards donor-conceived witnesses</td>
</tr>
<tr>
<td>(committee)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 CROSSIN</td>
<td>if a person wants to donate in this area,</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td>[gamete donation/ + AFFECT inclination]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 CROSSIN</td>
<td>is it your view that, unless they are prepared to have their details released, then they should not be allowed to donate?</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td>[anonymous gamete donation/ - JUDGEMENT social sanction]</td>
<td>Align towards donor-conceived witnesses</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Adams</td>
<td>Yes.</td>
<td>K1</td>
<td>Addresser singular opinion</td>
<td>[anonymous gamete donation/ - JUDGEMENT social sanction]</td>
<td>Align towards committee</td>
</tr>
<tr>
<td>(DCP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Burns</td>
<td>Yes,</td>
<td>K1</td>
<td>Addresser singular opinion</td>
<td>[anonymous gamete donation/ - JUDGEMENT social sanction]</td>
<td>Align towards committee</td>
</tr>
<tr>
<td>(DCP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 CROSSIN</td>
<td>that is covered by the NHMRC guidelines.</td>
<td>K1</td>
<td>Addresser individual NHMRC guidelines</td>
<td>[guidelines/ +APPRECIATION valuation invoked]</td>
<td></td>
</tr>
<tr>
<td>(committee)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 CROSSIN</td>
<td>That is a very widely held viewpoint.</td>
<td>K1</td>
<td>Addresser collective public knowledge/ consensus</td>
<td>[anonymous gamete donation/ - JUDGEMENT social sanction invoked]</td>
<td></td>
</tr>
<tr>
<td>(committee)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 CROSSIN</td>
<td>It is covered by the guidelines.</td>
<td>K1</td>
<td>Addresser individual NHMRC guidelines</td>
<td>[guidelines/ +APPRECIATION valuation invoked]</td>
<td>Align towards donor-conceived witness</td>
</tr>
<tr>
<td>(committee)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 CROSSIN</td>
<td>which are not enforceable.</td>
<td>ch</td>
<td>Addresser individual NHMRC guidelines</td>
<td>[enforceability of guidelines/ - APPRECIATION valuation]</td>
<td>Disalign from donor-conceived witness</td>
</tr>
<tr>
<td>(committee)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Burns</td>
<td>Exactly.</td>
<td>K1</td>
<td>Addresser individual NHMRC guidelines</td>
<td>[enforceability of guidelines/ - APPRECIATION valuation]</td>
<td>Align towards committee</td>
</tr>
<tr>
<td>(DCP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Burns</td>
<td>You have hit the nail on the head.</td>
<td>K1</td>
<td>Addresser individual NHMRC guidelines</td>
<td>[enforceability of guidelines/ - APPRECIATION valuation]</td>
<td>Align towards committee</td>
</tr>
<tr>
<td>(DCP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Cummerford</td>
<td>That is Victoria’s position. It is state law here.</td>
<td>K1</td>
<td>Addresser individual Victorian legislation</td>
<td>[Victoria’s position on anonymous gamete donation/ ]</td>
<td></td>
</tr>
<tr>
<td>(DCP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>CROSSIN (committee)</td>
<td>Yes, that is right.</td>
<td>K1</td>
<td>Addressee individual Victorian legislation [Victoria’s position on anonymous gamete donation/ + APPRECIATION valuation]</td>
<td>Align towards donor-conceived witness</td>
</tr>
<tr>
<td>14</td>
<td></td>
<td>And there are no laws in some states and in the Northern Territory.</td>
<td>ch</td>
<td>Addresser collective legislation [absence of laws/- APPRECIATION valuation invoked]</td>
<td>Disalign from donor-conceived witness</td>
</tr>
<tr>
<td>15</td>
<td>Cummerford (DCP)</td>
<td>We know that.</td>
<td>ch</td>
<td>Addresser collective legislation [absence of laws/- APPRECIATION valuation invoked]</td>
<td>Disalign from committee</td>
</tr>
<tr>
<td>16</td>
<td>CHAIR (committee)</td>
<td>Tasmania is one such state.</td>
<td>K1</td>
<td>Addresser individual Tasmanian legislation [absence of laws/- APPRECIATION valuation invoked]</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>CROSSIN (committee)</td>
<td>So you are saying that</td>
<td>K2</td>
<td>Addressee collective opinion</td>
<td>Align towards donor-conceived witness</td>
</tr>
<tr>
<td>18</td>
<td></td>
<td>the position that the Victorian government holds should be a national position.</td>
<td>K2</td>
<td>Addressee individual Victorian legislation [Victoria’s position on anonymous gamete donation/ + APPRECIATION valuation]</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Adams (DCP)</td>
<td>Yes.</td>
<td>K1</td>
<td>Addresser singular opinion [Victoria’s position on anonymous gamete donation/ + APPRECIATION valuation]</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Cummerford (DCP)</td>
<td>Yes.</td>
<td>K1</td>
<td>Addresser singular opinion [Victoria’s position on anonymous gamete donation/ + APPRECIATION valuation]</td>
<td></td>
</tr>
</tbody>
</table>
Conclusion

This is the first empirical study to consider epistemic positioning and authority in the context of donor conception. Building on scholarship on epistemic positioning and epistemic authority (Bednarek, 2006; Izadi, 2018; Mondada, 2013; Stivers et al., 2011), this article focused on four salient discursive patterns: how witnesses positioned lived experience as non-negotiable, how witnesses cast doubt on traditional expertise, how witnesses layered opinions upon experience, and how witnesses employed recognised knowledges to bolster authority. Importantly, these patterns were accumulative; for example, witnesses’ positioning of their firsthand knowledge as non-negotiable permitted them to assert experience-driven opinions. Similarly, by undermining the expertise of fertility practitioners, witnesses opened up space to position themselves as the “real experts”. Moreover, to support claims to epistemic authority, witnesses drew on a range of knowledges, from their own or peers’ experiences, from legislation and guidelines, or from general consensus. In contrast to previous work which has tended to set up a dichotomy between the “epistemics of experience” and “epistemics of expertise” (Heritage, 2013a, p. 392) or argued that status-based authority outwights source-based authority (Enfield, 2011), this article has demonstrated how individuals simultaneously deploy experience and expertise in their positioning. Indeed, authority is not fixed but rather negotiated as interaction unfolds. As the analysis demonstrated, in some instances displays of authority were contested, however by employing additional forms of knowledge witnesses were able to reassert their authoritative standing. As such, this work aligns with scholarship that has highlighted how epistemic authority is dynamic, it can be displayed, claimed, challenged and reviewed, and in this way it is a “situated accomplishment” (Mondada, 2011, 2013, p. 601).

This article has contributed to understanding and defining the notions of lived experience and lived expertise. The concept of lived experience recognises the knowledges held by individuals with firsthand experience living with a specific identity or living through a particular event (Classen et al., 2021; Gabriel, 2004; valentine et al., 2020). While scholarship has pointed to the notion of lived expertise, it has often been conflated with lived experience (Clifton et al., 2020; Ibáñez-Carrasco et al., 2019; Oliver & Cataldo, 2019). This article has mapped the discursive patterns by which individuals claim and sustain epistemic authority in an institutional context. Individuals enact lived expertise by drawing on experience in combination with other forms of experiential and institutional knowledges. Yet, this positioning – as an authority – is a dual process. The addressee claims authority and is
required to demonstrate sufficient breadth and depth of knowledge to sustain the positioning. Moreover, for the authority to be upheld, the addressee must recognise and confer authority accordingly. Researchers have pointed to how the concept of ‘lived experience’ can function to constrain participation while also delimiting and devaluing the forms of knowledge people lived experience hold (Lancaster et al., 2017; Madden et al., 2021). While particular actors and structural forces no doubt continue to exclude and degrade people with lived experience in many contexts, analysis in this article has illustrated how people with lived experience simultaneously work within and push against institutional structures and interactional processes. In doing so, people with lived experience gradually and strategically expand the subject position afforded to them and, over time, gain legitimacy as actors and knowers. This analysis then, points to the dynamic nature of power asymmetries in contexts like public hearings. Considering the roles and meanings afforded to people with lived experience within institutional macrogenres phylogenetically would provide broader epistemic insights into how who can speak and whose voices matter evolve over time.

A strength of analysis in this article is the three-pronged approach which included annotation of the stances being negotiated in discourse, patterns in turn-taking and forms of evidence drawn upon to sustain positionings. This approach to analysis demonstrated how individuals can assert epistemic authority by adopting a primary knower position or using challenge moves, through alignment in ideation-attitude couplings, or by drawing on a range of evidence that support the epistemic positioning. The three frameworks adopted here thus offer a fruitful toolkit for addressing epistemic questions. Social semiotics offers a robust theoretical model that foregrounds how individuals negotiate relationships and identities (Halliday & Matthiessen, 2004; Knight, 2010). Moreover, analysis in this article revealed how donor-conceived witnesses strengthened their shared identity through alignments in stances towards donor-conceived people’s rights to know donor-conceived status and rights to know biological family. This article reinforces previous work that has suggested that in the negotiation of the boundaries of knowledge territories, identity is of “interactional significance” (Raymond & Heritage, 2006, p. 700; see also Blythe et al., 2022). Beyond collective identities, donor-conceived witnesses also disaligned from parents who disclosed donor-conceived status to them as adults, aligned towards biological relatives by recognising their kinship roles, and disaligned from fertility practitioners who they positioned as untrustworthy. Above all, witnesses sought to persuade committee members to align with their stances by recognising them as equal citizens in law. As such, the analysis not only
resonates with scholarship which has shown how epistemic positioning has relational consequences (Izadi, 2018), but illustrates how individuals simultaneously negotiate a range of social bonds which “cluster as belongings of different orders” (Martin et al., 2013, p. 490; see also Knight, 2010). Through talk, donor-conceived witnesses negotiate everyday social bonds with peer and familial communities as well as social bonds at the scale of culture through interaction with institutional representatives from the fertility industry or the State.
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Dobby, K. (2010). *Submission 33 to Victorian Inquiry into Access by Donor-Conceived People to Information About Donors.*
Chapter 4: From lived experience to lived expertise (submitted article)


Han, J. (2015). ‘#feminism is not a dirty word’: Axiology, ambient affiliation and dialogism in discourses surrounding feminism in microblogging [Honours thesis]. University of Sydney.


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Chapter 4: From lived experience to lived expertise (submitted article)


CHAPTER 5 - More than Humor: Memes as Bonding Icons for Belonging in Donor-Conceived People (published article)

**Link to thesis:** In Chapter 5, I describe donor-conceived adults’ experiences in closed Facebook meme group for donor-conceived people (aim 1). Integrating reflexive thematic analysis of data from semi-structured interviews with social semiotic analysis of meme texts (aim 2), I argue that through creating, sharing and interpreting bespoke meme texts, donor-conceived adults’ negotiate their collective identity, a process which contributed to a sense of belonging (aim 3).

More than Humor: Memes as Bonding Icons for Belonging in Donor-Conceived People

Giselle Newton, Michele Zappavigna, Kerryn Drysdale, and Christy E. Newman

Abstract

Memes are a key feature of participatory digital cultures and have been found to play an important role in collective identity formation. Limited scholarship has explored the role of memes within close communities, where perceived privacy and trust may impact the ways users demarcate the in-group (us) and out-group (them) through humor. This article draws on analysis of semi-structured interviews with Australian donor-conceived people (people conceived with donor sperm or eggs) and a collection of memes they shared. We take an interdisciplinary approach to analysis, combining reflexive thematic analysis informed by interpretive traditions within sociology with an analysis that applies the iconization framework from social semiotics. Our findings explore how donor-conceived people view memes as: texts that “only we get,” that are “light and fun” and that provide a “way to deal with emotions.” We conceptualize memes as bonding icons: semiotic artifacts which foreground shared feelings and invoke alignment around a collective identity. More broadly, we argue that “getting” a meme requires alignment with the values construed, a process which reinforces ties to the community. In doing so, we explore how everyday social and linguistic practices contribute to individuals’ sense of belonging.

Keywords

memes, social media, Facebook, identity, belonging, donor-conceived

Introduction

Meme creation and sharing has become a key feature of participatory digital cultures. The term “meme,” coined before the digital era, describes the cultural transmission of an idea, fashion, or style (Dawkins, 2006). Internet memes are a set of texts with shared characteristics, which are circulated and transformed by users online (Gal et al., 2016; Shifman, 2013). Several factors contribute to meme proliferation online, such as the scope and speed at which content is able to be shared, user-friendly tools which permit remixing of content, and “internet ugly” aesthetic, which promotes simple and low-quality texts (Douglas, 2014; Shifman, 2013).

Some types of memes, such as image macros (memes that combine an image with superimposed text), feature across different social media platforms (Zappavigna, 2020), although a platform’s affordances can also shape patterns of mimesis, for example, scholars have argued that TikTok can be conceptualized as a mimetic text in itself (see Zulili & Zulili, 2020). Memes are social texts in that the actions, behaviors, and norms of social groups are negotiated alongside and through memes (Gal et al., 2016; Knobel & Lankshear, 2007). While many users share memes on their general social media feeds, meme-focused pages and groups, often organized around thematic foci such as a shared interest, experience, or identity, have become popular spaces for niche meme sharing (see Procházka, 2018). Limited scholarship has focused on memetic practices within close communities, such as closed Facebook groups, in which users feel they are interacting with others “like them,” and where collective identity and belonging is created and negotiated (Archer et al., 2021). On Facebook, users are required to be identified (use their real name as per Facebook’s policy) and closed group administrators are able to screen for imposters and restrict access through criteria for membership.

UNSW Sydney, Australia

Corresponding Author:
Giselle Newton, Centre for Social Research in Health, UNSW Sydney.
High St Kensington, Sydney, NSW 2032, Australia.
Email: gnewton@unsw.edu.au

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Abstract
Memes are a key feature of participatory digital cultures and have been found to play an important role in collective identity formation. Limited scholarship has explored the role of memes within closed communities, where perceived privacy and trust may impact the ways users demarcate the in-group (us) and out-group (them) through humour. This article draws on analysis of semi-structured interviews with Australian donor-conceived people (people conceived with donor sperm or eggs) and a collection of memes they shared. We take an interdisciplinary approach to analysis, combining reflexive thematic analysis informed by interpretive traditions within sociology with an analysis that applies the iconisation framework from social semiotics. Our findings explore how donor-conceived people view memes as: texts that “only we get”, that are “light and fun” and that provide “a way to deal with emotions”. We conceptualise memes as bonding icons: semiotic artefacts which foreground shared feelings and invite alignment around a collective identity. More broadly, we argue that “getting” a meme requires alignment with the values construed, a process which reinforces ties to the community. In doing so, we explore how everyday social and linguistic practices contribute to individuals’ sense of belonging.

Keywords: memes, social media, Facebook, identity, belonging, donor-conceived
**Introduction**

Meme creation and sharing has become a key feature of participatory digital cultures. The term “meme,” coined before the digital era, describes the cultural transmission of an idea, fashion, or style (Dawkins, 2006). Internet memes are a set of texts with shared characteristics, which are circulated and transformed by users online (Gal et al., 2016; Shifman, 2013). Several factors contribute to meme proliferation online, such as the scope and speed at which content is able to be shared, user-friendly tools which permit remixing of content, and “internet ugly” aesthetic, which promotes simple and low-quality texts (Douglas, 2014; Shifman, 2013). Some types of memes, such as image macros (memes that combine an image with superimposed text), feature across different social media platforms (Zappavigna, 2020), although a platform’s affordances can also shape patterns of mimesis, for example, scholars have argued that TikTok can be conceptualized as a mimetic text in itself (see Zulli & Zulli, 2020). Memes are social texts in that the actions, behaviors, and norms of social groups are negotiated alongside and through memes (Gal et al., 2016; Knobel & Lankshear, 2007). While many users share memes on their general social media feeds, meme-focused pages and groups, often organized around thematic foci such as a shared interest, experience, or identity, have become popular spaces for niche meme sharing (see Procházka, 2018). Limited scholarship has focused on memetic practices within closed communities, such as closed Facebook groups, in which users feel they are interacting with others “like them,” and where collective identity and belonging is created and negotiated (Archer et al., 2021). On Facebook, users are required to be identified (use their real name as per Facebook’s policy) and closed group administrators are able to screen for inauthentic intruders and restrict access through criteria for membership, filter questions, and security settings (Yeshua-Katz & Hård af Segerstad, 2020). This boundary work within peer-only groups often enhances users’ sense of privacy, safety, and trust and, accordingly, many users experience these closed Facebook groups as “digital safe havens” (Archer et al., 2021; Yeshua-Katz & Hård af Segerstad, 2020). However, it is unclear how this sense of privacy and trust shapes the kinds of humor shared between peers in closed groups.

One example of such peer spaces is a closed Facebook meme group for donor-conceived people; that is, people created through third-party reproduction (with a sperm or egg donor/s). The donor conception meme group, the focus of this article, represents a particularly interesting and timely example for exploring how memes are oriented toward collective identity formation because donor conception has historically been shrouded in secrecy, and as
such, the emergence of the identity of “donor-conceived” is relatively recent. Due to the
shame and stigma associated with gamete donation, up until the late 20th-century clinicians
promised gamete donors’ anonymity, encouraged parents to withhold information about
conception from their child, and failed to keep medical records or kept inaccurate records
(Adams & Lorbach, 2012; Swanson, 2012). While the right to know one’s identity and
maintain direct contact with one’s parents is enshrined in international legislation (see United
many donor-conceived people are still unaware of their conception status and others,
particularly those conceived during the era of anonymity, continue to face barriers to securing
information about their medical and genetic histories and their biological parent/s and
siblings (Allan, 2017). These barriers thus represent a form of disenfranchisement. In the last
decades, there has been a significant shift in social values whereby openness has been
promoted, one consequence of which has been greater visibility around donor conception
(Allan, 2017). In addition, two important technological advancements have enhanced donor-
conceived people’s opportunities to establish connections with kin and peers: the rapid
popularization of affordable direct-to-consumer DNA testing for searching for biological
family members (Adams & Lorbach, 2012; Crawshaw, 2018) and the widespread uptake of
social media including closed spaces for donor-conceived people (Crawshaw et al., 2016;
Darroch & Smith, 2021). While many closed Facebook groups for donor-conceived people
focus specifically on exchanging social and emotional support, others, like the meme group,
are oriented to sharing humor which builds on shared values and experiences. Humor within
such peer groups, where there is a sense of privacy and trust, can serve to unite members in
semiotic terms (Knight, 2010).

Drawing on in-depth interviews with eight Australian donor-conceived meme group members
and a set of donor conception memes as our focus, we explore participants’ perspectives
about closed meme groups and examine the values at stake within the memes themselves.
This study focused on the following research questions: How do memes function to unite
donor-conceived people around shared values? How do everyday practices such as meme
sharing in closed Facebook groups contribute to formation of collective identities and
processes of belonging? We argue that while some users may view meme sharing as a light-
hearted or frivolous activity, over time and through everyday engagement, these texts
contribute to individuals’ affiliation with collective identities and sense of belonging.
Background

Connection, community and storytelling on social media

For members of minority groups, or those disenfranchised from the systems that govern individual rights to recognition and participation, access to social media has offered significant opportunities for connection with peers. Participatory digital technologies have been found to strengthen individuals’ sense of identity and community, particularly through access to more diverse representation and visibility (Craig et al., 2021; Gal et al., 2016; Kirby et al., 2021). On social media, groups which identify as distinct from the mainstream are able to craft self-representations absent in the media, subvert power dynamics, and permit narrative agency and counternarratives (Craig et al., 2021; Williams, 2020). Studies have examined how individuals produce content to be recognized by their peers, as well as searching for stories in which they recognized themselves (Balleys et al., 2020). Indeed, contemporary forms of storytelling are an important device in personal and collective identity formation, particularly for those with minority identities (Gal et al., 2016). In the field of donor conception, Petra Nordqvist (2021) has argued that the dominance of heteronormative reproductive stories that assume genetic ties between parents and children has created a notable absence of social scripts for donor families to talk about donor conception within broader social networks. As such, memes generated by donor-conceived people provide an interesting and timely case study: storytelling through memes provides opportunities to “invent identities for ourselves and others and locate ourselves in these imaged maps” (Plummer, 1995, p. 20), providing a means to counter the secrecy that has long been associated with donor conception and a way to co-create and define a sense of a shared donor-conceived identity.

Facebook Meme Groups and Reinforcing Ties to Community through Humor

In Australia, Facebook remains the most popular social media platform, with many people staying on the platform due to the relational connections it offers through everyday encounters with Facebook friends and groups (Lupton & Southerton, 2021). Of the array of Facebook groups accessed by the approximately 1.8 billion Facebook users (Facebook, 2021), meme groups represent a small but important subset. Akin to other contexts in which humor emerges, meme groups provide an important domain for constructing collective identities. Research has examined how, through humor, participants establish a relational identity, which contributes to a sense of group membership (Boxer & Cortés-Conde, 1997; see also Dynel & Chovanec, 2021; Sinkeviciute, 2019). Humor can offer disenfranchised
groups resources to critique authorities, to cope with painful experiences and to create solidarity with peers (Sandberg & Tutenges, 2019; Williams, 2020). Specifically, joking about an “absent other” has a bonding function, defining and uniting those participating in the humor as the in-group and those who do not or cannot participate as the out-group (Boxer & Cortés-Conde, 1997). Scholars have argued that memes construe solidarity between participants in the form of “I get it”; “I’m part of this”; or “I’m like you,” demarcating those who understand the specific form of humor as part of the “in group” (Knobel & Lankshear, 2008, p. 29). Memes typically incorporate insider jokes, language features and motifs, and references to popular culture, and unpacking memes requires socially shaped digital literacies (Kanai, 2016; Knobel & Lankshear, 2008). Participation in meme cultures requires assimilation of the visual and linguistic practices of a community; the “light bulb moment” of comprehension occurs when the reader, drawing on specific knowledge of the community, is able to align the image and caption within a meme (Kanai, 2016, p. 3; Milner, 2012). In this way, meme groups may offer individuals unique opportunities to reinforce ties to their communities.

**Memes as Bonding Icons: Negotiating Values through Everyday Texts**

Meme creation and sharing involves the constant negotiation of shared values (Procházka, 2018; Zappavigna, 2020). Scholars have argued that values form the core social units through which we establish who we are in relation to others and thus negotiate collective identities moment-to-moment (Knight, 2010). Therefore, in contrast to previous approaches to understanding memes and collective identity (Gal et al., 2016; Shifman, 2013), this article adopts a social semiotic approach oriented toward examining the values construed in memes. Specifically, we draw on work by Stenglin (2008) on the concept of bonding icons to provide a useful analytical approach. Simply put, bonding icons are semiotic artifacts which have accrued shared interpersonal meaning beyond their original experiential meaning. Therefore, bonding icons operate as “emblems or powerfully evocative symbols of social belonging” that have a rallying or privileging function for particular communities (Stenglin, 2004, p. 406). Examples of bonding icons include flags, company logos, or more everyday phenomena such as coffee where individuals rally around the shared positive values which this beverage has accrued such as productivity and conviviality (Zappavigna, 2014). Bonding icons offer a means to construe collective identities: “icons provide the meaning resource for the production and consumption of identity texts, and the texts in turn sustain the icons as socially legitimate ways of talking about identity” (Tann, 2013, p. 380). Therefore, in this
article, we explore how memes operate as bonding icons, and consider how the values expressed within memes relate to the broader communities in which they are (re)produced.

Method

Data collection

Our analysis of donor conception memes forms part of a multi-method study on Australian donor-conceived people’s experiences, perspectives and support needs. Ethics approval was provided by the UNSW Sydney Human Research Ethics Committee (HC190998). This article draws on rich data collected in semi-structured interviews (n = 8) that lasted between 1 and 3 hr, recorded in 2020. Participants who were donor-conceived, over 18 years old, Australian citizens or permanent residents, and members of Facebook groups for donor-conceived people were recruited through donor conception networks, community organizations, and social media. Interviews were audio recorded and then transcribed verbatim, checked for accuracy, and de-identified, and all participants received an AUD $30 voucher. Participants had learned about their donor-conceived status at ages ranging from childhood to their 30s.

The interview schedule employed in our study explored a range of topics including participation in Facebook groups for donor-conceived people. Although we did not anticipate that participants would discuss memes, our approach to data collection foregrounded the co-creation of meaning and as such permitted exploration of memes during the interviews, when the topic was raised by a sub-group of participants. Donor conception memes and participation in an international Facebook meme group for donor-conceived people were discussed as an important outlet for exploring collective identity and rich data were generated. The Facebook meme group described in these data, which had just more than 300 members at time of writing, is a closed group in which potential members are screened to confirm that they are donor-conceived. The group is governed by a rule that stipulates that members must request permission from a meme creator before sharing memes outside the group. Given this rule and the sensitive nature of the topic of donor conception, we sought retrospective ethics approval to include in our analysis the specific memes which were provided to the researcher by participants during interviews. Participants who had discussed memes were also invited to share examples of memes they had spoken about in their interview, as well as others they had permission to share, via email. As with the interview data, we analyzed the memes using inductive qualitative analysis with a focus on identifying patterns of meaning, and, therefore, were not seeking a representative sample.
Data analysis

Following the interdisciplinary approach of the study, we sought to meaningfully analyze two forms of data using two distinct but complementary forms of inductive qualitative analysis. The first analysis, informed by the interpretive traditions within sociology (Charmaz, 2006), focused on the semi-structured interview data, and followed Braun and Clarke’s (2020) method of reflexive thematic analysis. This analytic process commenced during data collection when participants began to speak about the meme group, providing an opportunity to continue exploring the ways in which participants made sense of meme creation and sharing. Using NVivo 12, GN coded the data inductively and themes were developed in an iterative process. GN had been a member of several Facebook groups for donor-conceived people for a number of years prior to the study as a donor-conceived person herself (see also Newton, in press), which informed this approach. In reflexive thematic analysis, the researcher’s subjectivity is viewed as a resource which contributes to the co-production of knowledge between researcher and participants (Braun & Clarke, 2020). All participants were made aware of the researcher’s “insider” status as a donor-conceived person (see Newton & Southerton, 2021), and the manner in which issues of community confidentiality would be managed. This positionality was also viewed as advantageous in an empirical analysis of humor, as scholars have noted the importance of cultural awareness and sensitivity to local contexts (Sandberg & Tutenges, 2019).

The second form of analysis, which sought to explore how memes function as bonding icons, followed a social semiotic approach with a focus on the interpersonal function of language (Halliday, 1978). Memes were analyzed qualitatively applying Tann’s (2013; see also Zappavigna & Martin, 2018) tripartite iconization model (see Figure 7). This framework encompasses: “Communitas” which represents the community or sub-community (following Turner, 1974), “Doxa,” borrowing from Barthes (1977), which encapsulates shared core values, and “Bonding icon,” semiotic artifacts which radiate values for the specific community to commune around (see Stenglin, 2008). This framework was selected because, first, it provides an analytical approach to consider the interpersonal aspects of memes, that is, how individuals (dis)align with values expressed in memes, and second, because it emphasizes understanding meaning-making in its functional context, that is, how the memes were operating in relation to the everyday practices of donor-conceived people. In our analysis below, the values within the bonding icons are annotated using square brackets, with
ideation (the subject or experience being construed) and associated feelings separated by a semicolon, for example, [memes: positive feelings].

Figure 7 demonstrates how the iconization framework with “Communitas” (community), “Doxa” (shared values), and “Bonding icon” (semiotic artifact which radiates values) is applied to a meme. This meme, created and shared within the donor-conceived community, draws on the shared value that medical records should be complete and accurate. The key values being negotiated within the bonding icon relate to feelings toward record-keeping practices and fertility clinics, as depicted in the contrasting images of a pristine and secure fertility clinic compared to the dinosaur stomping on the building where the medical records are kept.

In what follows, we describe the results by combining our reflexive thematic analysis which derived three thematic domains and social semiotic analysis applying the iconization framework. In doing so, we aim to offer two complementary perspectives on the role memes play in construing shared values and collective identity, and contribute to processes of belonging.

**Results**

*A place for us: “only we get it”*

The first theme derived from our analysis explores how meme groups offered participants a private space for connecting with their peers. Memes provided a resource to reflect on the complexities of both forming and protecting peer spaces. As previously mentioned, the rules for the meme group for donor-conceived people state that memes cannot be shared outside
the group without permission from the creator. In general, participants were aware of these rules however, differing views emerged about this rule, given that memes are typically designed to be shared. Some participants believed that this rule went against “the point” of memes or recognized that there may be unauthorized sharing outside the group due to the inability to enforce such rules. This skepticism that the rules would be followed reflected a perceived lack of control for meme creators once they were posted on the internet. For instance, Shane argued that:

Nobody can own a meme. You can try. You can try and say it's your meme. I'm sure it's not gonna help you in court... In the meme wasteland, there are no rules. Once you put something out there, I think at some level you have to let go of it. (Shane)

Others viewed the rule as a means of ensuring that the group was able to function as a safe space. By emphasizing the importance of safety, participants reflected on the value of contexts in which donor-conceived people, as a disenfranchised group, were able to communicate candid feelings and experiences:

You know, memes are broadly used to share something widely and often, you know, with the kind of intent of it going a bit viral and being shared elsewhere... The aim of making this group is more about connection with other donor-conceived people
(Mabel)

Mabel went on to suggest that she viewed the meme group as a space that supported intimate connections between peers:

It's another way of kind of relationship-building, you know. You might share something quite personal with someone as a way of kind of connecting and saying, “Hey, I've had this experience.” And the other person might say, “Yeah, I've had a similar experience,” and it's a nice kind of way of bonding. (Mabel)

Given that the majority of donor-conceived people do not have contact with other donor-conceived people in their daily lives, having a space to share donor conception content was viewed as unique and valuable. Participants noted that the forms of humor in memes shared in the group would only be understood by donor-conceived people and would be lost on other people within their personal networks. For instance:
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It’s nice having a group where you can go “you’ll get why I thought this was so funny.” ... Why would I share that on my main Facebook page? No-one else is going to get it (Athena)

Furthermore, Shane described a meme that captured this sense of a “place for us”:

It’s the meme format of I think like the Greek philosophers walking through the agora and then next to it is a picture of a parent with a toddler, trying to get the toddler to play with the toy. And it’s me talking about being donor-conceived with donor-conceived people versus me talking about being donor-conceived with the recipient parents. And so what that communicates is that there are different levels of understanding of issues around being donor-conceived between donor-conceived people and recipient parents. (Shane)

As Shane explains in the above excerpt, the stance represented in this meme (Figure 8) is that between donor-conceived people (dc people) issues associated with donor conception are able to be discussed with sophistication and depth, whereas conversations with recipient parents (rps; prospective or current parents through donor gamete/s) require the donor-conceived person to simplify the issues or educate the recipient parent. On the left-hand side of the image, two donor-conceived peers are depicted as Greek philosophers walking side by side and looking toward each other as equals. In the image on the right, a donor-conceived person is portrayed as a mother and a recipient parent is portrayed as a toddler. The mother is bent down, looking down at the toddler with one hand on the child’s shoulder and the other showing the toddler an object.
Figure 8: DC peers walking through the agora meme (provided by participant).
Here the shared feelings invited are: [donor-conceived people: positive feelings] and [recipient parents: negative feelings]. To align with the meme, the reader must first recognize the in-group abbreviations “dc” and “rps” as well as align with the notion that peers understand each other, while “outsiders,” such as recipient parents, have a poorer understanding of donor-conceived people’s values (see Figure 9). In Tann’s (2013) terms, this constitutes collectivization, where the producer constructs binary identities: an opposition between “us” and “them.” Therefore, this text functions to highlight the shared understanding between peers and validate their collective identity. Bonding icons draw upon shared values of the community; when a reader aligns with the feelings expressed in the bonding icon, their ties to the community are reinforced. This ongoing process of aligning around values and reinforcing a collective identity creates a sense of belonging for members.

Figure 9: DC peers walking through the agora meme as “bonding icon” in relation to “communitas” and “doxa.”

“Light” and “fun”: meme groups as an escape

For many donor-conceived people interviewed, memes were seen to provide a “light” and “fun” way to make sense of being donor-conceived while also connecting with their peers:

The memes, yeah, it’s a bit like of a more light-hearted thing and a bit of comic relief I guess, which is nice. Nice to have a bit of a laugh. Bit like, “oh yeah, that’s relatable ha ha”. (Leah)

Another participant explained:
They’re [the memes are] pretty light. They’re just a way to lighten the mood, yeah. Very serious subject, so … But that’s what they’re used for: serious things. It’s humour, isn’t it? Humour’s always about the most taboo and difficult-to-talk-about topics of the moment. (Ruth)

While describing memes as “light,” Ruth recognized that humor could often help people to broach a serious subject matter. Participants also spoke directly to the ways in which the donor conception meme group compared with other donor conception groups, which they viewed as contexts in which users could seek advice and tell stories related to more “serious” matters. Several participants made remarks similar to the following:

Some of the groups where you can share your experience or people share that they’ve just found out they’re donor-conceived, or they’re having an issue with their parents or their donor parents, or their siblings, they’re really valuable, but it can be quite heavy. And I think I liked the idea of having this group where it was a bit lighter and it was a bit less formal. People could see a picture and have a bit of a laugh about something that was probably a bit of an in-joke in the donor conception community. (Mabel)

Some participants also described their participation in “triad groups” (see Adams & Lorbach, 2012), that is, groups that included gamete donors, recipient parents and donor-conceived people. Participants spoke about how they contributed significant emotional energy and labor to these triad groups, and therefore meme groups represented a “fun” alternative:

I would say out of the three groups that I’ve been really active in that’s my favourite because it’s very rare for me that donor conception stuff is just light and fun. If I’m engaging on the Internet, I’m doing advocacy or emotional labour, and this is just … Oh my God, isn’t this just ridiculous kind of sharing fun stuff? (Athena)

When discussing the topics that memes most often drew upon, Ruth describe one salient theme:

The constant search for siblings. That one’s constant. Yeah. That one crops up. The never-ending search. And having 50-plus siblings, yeah, that one. (Ruth)

Across the study, participants recognized that the search for donor siblings was often a lengthy process with no determined end point, as people often struggled to access information about the total number of siblings they had. However, participants viewed this topic as
something they could leverage in the donor conception memes they were creating, for example,

*You know, it’s terrible that some people have 300 siblings but you can make a really funny meme about, you know, ‘National Siblings Day’. (Athena)*

In addition to the sensitive and socially controversial issue of large numbers of siblings, participants also described waiting for information on siblings as something that was a shared experience in this social group:

*Like you could just be sitting there one day like floating along, life’s great, and then boom! One [sibling] pops up and it rocks your world… It’s so weird not knowing whether it’s gonna be tomorrow, a month from now, a year from now or heaps of years, or never. (Emily)*

The meme presented in Figure 10 touches on this experience of waiting, and provides an example of how humour is used to tell stories to connect with peers in this context:

![Me: Waiting for new siblings to find me](image_url)

*Figure 10: DC Kermit sad montage compilation meme (meme provided by participant).*

The image macro in Figure 10, referred to as “Kermit sad montage compilation,” features the Muppet’s character Kermit the frog. In the superimposed text which reads: “Me: waiting for new siblings to find me,” the meme producer inserts themself into Kermit’s position via the projection function of the colon in “Me:.” “Getting” this text involves recognizing that Kermit represents a donor-conceived person waiting for their donor siblings. We see the process of iconization occurring: the everyday meaning (the inclusion of an image of Kermit the frog) is backgrounded, while the emotional significance (the feeling of waiting longingly)
is foregrounded. The meme creator draws on shared values, such as the experience of waiting for a donor sibling, to invite communion around shared feelings associated with being donor-conceived, such as longing.

Applying the iconization framework to the Kermit meme in Figure 10, we can see that the meme producer draws on community values such as “the right to identifying information about one’s biological siblings” to create a super charged icon: a bonding icon (see Figure 11). In turn, the bonding icon invites community members to unite around shared feeling of longing. “Getting it” reinforces the viewer’s ties to the community in question, highlighting that they belong within the community. Equally, viewers can reject the values expressed, creating consequences for their perception of their ties to the community.

Participants’ observation that memes were “light” and “fun” was relative in that participants viewed meme creation and sharing as a less serious form of interaction compared with the other online environments for donor-conceived people, which were dominated by text-based communication such as comment threads. In contrast, within the meme group, posts containing memes typically received few (if any) comments and were instead negotiated through likes or “haha” reactions from peers. Therefore, the framing of memes as “light” and “fun” also reflects how memes contain complex textual play within a single multimodal text that could be swiftly negotiated. Furthermore, through incorporation of popular cultural symbols, such as Kermit the frog, memes presented users with an opportunity to creatively depict their experiences of donor conception, in a way that would resonate for others.
However, in the interviews, some participants also recognized that humor often depicted difficult-to-talk-about topics, a subject that will be explored in further detail in the final thematic domain.

**Facing the hard stuff: dealing with emotions through memes**

Participants in the study identified memes as a positive means of dealing with the range of emotions associated with donor conception, and frequently described humor as “healing,” “therapeutic,” or “cathartic.” For example:

> I try to find a way to kind of find the humorous side of things because I think it’s really good therapy. You know, laughing at something can really change the dopamine, serotonin levels in your brain, being able to laugh at something, I think there is true benefit. (Lisa)

> [Those] feelings that are difficult to express. It’s a way to get them out. It feels good. You have a laugh and then you physiologically change, and you feel a bit better. That’s humour. It’s pretty simple. (Ruth)

Lisa and Ruth both highlighted the benefits that humor represented for donor-conceived people. Participants made sense of the benefits of humor using neuroscientific and psychological discourses, ascribing the benefits of humor to physiological changes within the body that improve mood. As such, participants viewed memes as a resource that contributed to their well-being.

In addition, participants talked about how a donor-conceived identity was not well understood within the broader society, and that their sense of self was often impacted by assumptions and silences from other parties such as parents and friends. For example, participants described how the humor shared between donor-conceived people often questioned social expectations regarding the “right way” to be donor-conceived, such as being “grateful” rather than “demanding” or “angry.” Participants described how they valued opportunities to discuss how difficult it is to live with and push back against these expectations. For instance, regarding the meme group, Shane explained that:
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It’s the best one because it’s donor-conceived people talking shit about everyone else, making fun of the things our parents do, the way that society treats us. That’s a really good group because it lets you laugh at it [donor conception] and gives you that catharsis of all this, all this pain [from] being told to be quiet. (Shane)

Through memes, participants could invert inflammatory or triggering comments made by non-donor-conceived people. In doing so, participants could make light of the perceptions of outsiders’ (to the donor-conceived peer group) or “absent others” (Boxer & Cortés-Conde, 1997), such as parents, friends, or recipient parents, and gain control over the framing of what it meant to be donor-conceived. Here we see how memes are used to demarcate the in-group from the out-group. Shane’s comment about “the pain [from] being told to be quiet” is particularly significant, as it communicates the lack of autonomy experienced by many donor-conceived people who wish to discuss the injustices they experience in relation to attempts to secure more information about their genetic relatives and the associated legal and social barriers (see also Newton & Southerton, 2021). Shane went on to provide an example of the way that conversations with family or friends often went:

You’re trying to have this conversation with them, and you get questions like, “Don’t you love your parents?” Or, “Would you rather have not been born?” And so it’s like the trauma bit is wanting to express how the experience of being donor-conceived has impacted on me as an individual. And, when I try and do that, having the broader part of society tell me that I am wrong to feel the way that I do, yeah, that really sucks. And there are a lot of donor-conceived people who I’ve talked to, who share that frustration of not feeling able to talk about their experiences, not feeling heard.

(Shane)

Shane’s point about not being able to speak honestly about one’s experience of being donor-conceived, and particularly the experience of not feeling heard is represented in the meme in Figure 12.
This meme references a specific cultural narrative that views biological ties as less significant than social ties (see Andreassen, 2017). This narrative was first conscripted into the legal and clinical representations of donor conception many decades ago, as a way to justify not disclosing donor conception status and prohibiting donor-conceived people’s access to identifying information about their donors. The narrative has also been employed to bolster the positioning of the non-biological parent (in contexts of two-parent families) as equal (Andreassen, 2017). While some people still downplay the role of genetic information and relationships, over the last decades this narrative has received more criticism, particularly from many donor-conceived people. It is worth noting that a statement such as “all my parents are real” may be socially prohibited in many other contexts, as it may cause conflict, offense, or confusion but is able to be expressed in the closed group due to the perceived privacy and safety. Therefore, a context in which participants could reflect on their shared values in an open and honest—and slightly mocking—manner was valued by participants.

The meme in Figure 12 employs the template “what if I told you...,” in which the lower text acts as the revelation or punch line in the joke, in this case: “all my parents are real.” The protagonist (actor Will Ferrell) looks directly at the viewer and addresses them with the pronoun “you.” The revelation being expressed in this instance of the meme is that biological parents are significant in many donor-conceived people’s lives. In this meme, the addressee, “you,” represents an outsider or “absent other” (Boxer & Cortés-Conde, 1997) to the donor-conceived peer group, yet given the meme is shared within a private peer group, addressing an outsider represents a hypothetical situation.

Figure 12: “All my parents are real” meme (provided by participant).
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The iconography underlying the meme is represented in Figure 13. The shared values being negotiated in this meme relate to the right to relationships with biological parents (and siblings), a core value among many donor-conceived people. Again, we see attitudes charged into the meme, in this case [biological parents: positive feelings], which the viewer, the Facebook meme group member, can either rally around or reject.

![Figure 13: “All my parents are real” meme as “bonding icon” in relation to “communitas” and “doxa.”](image)

Memes, then, offered donor-conceived people an opportunity to connect around shared values. As asserted by Tann (2013, p. 388) “successful retrieval and identification with these icons leads to the renewed communion between author and reader, while unsuccessful ones result in alienation and outrage.” In other words, the process of identifying with the values expressed in donor conception memes, in this example the right to a relationship with biological parents, reinforces members’ sense of belonging to the donor-conceived community. Therefore, a key component of the “therapy” consists of not feeling alone in one’s values and feelings, and instead feeling a sense of connectedness with a collective identity.

**Discussion**

In this article, we contribute an innovative approach to exploring memes, combining reflexive thematic analysis from interviews with social semiotic analysis of memes to explore how memes operate and the impacts they have on the individuals that create and share them. This approach extends Shifman’s (2013) “typology of three memetic dimensions” and Gal and colleagues (2016) research on collective identity to offer a distinct framework for analyzing
memes which specifically attends to the values construed in memes. Indeed, application of the concept of bonding icons (Stenglin, 2008) and iconization framework (Tann, 2013) allows for closer examination of the interplay between memes, the community in which they are (re)produced and their values. As we have explored above, memes created by donor-conceived people draw on shared values, such as the right to information about and relationships with biological relatives, and the value of peer connection. Specifically, we have demonstrated how readers align with the values embedded in memes; “getting” the meme strengthens an individual’s affiliation to the collective identity.

Meme groups represent a rich site of inquiry for social media researchers as memes are complex, layered, identity texts; “a social anchor for the communities that form around them” (Procházka, 2018, p. 78). In this qualitative study, we drew on interviews with a limited number of Australian donor-conceived people and memes shared by them. Despite the relatively modest sample size, participants revealed rich accounts of participation in meme groups. While we do not claim generalizability of our findings, we expect that the indicative themes and conceptual insights are likely to resonate with other contexts. We suggest that future research could explore memes as bonding icons in relation to other interests, identities or experiences where forms of humor are impacted by the perceived privacy of closed groups. Memes could also be used as an elicitation tool in interviews to generate situated insights from participants. Future work could also consider how memes evolve over time, as suggested by Tann (2013) “intertextually, the icon is continually revised by the community in ever new understandings of their identity against the background of other identities” (p. 389).

This study is among the first to examine how donor-conceived people forge communities of connection and support online. Although social scripts within donor families can be limited (Nordqvist, 2021), this article has revealed how, specifically within peer-only contexts, donor-conceived people are able to tell stories about themselves and negotiate what this emerging identity means to them through everyday social and linguistic practices. Our analysis generated three salient themes from the reflexive thematic analysis, each revealing the key affordances of memes, and their utility for managing emotions and disenfranchisement. In the meme group we studied, donor-conceived people were able to constitute a sense of a shared donor-conceived identity that participants felt was not yet understood or recognized broadly by society. While the interviews revealed varied experiences (and extents) of disenfranchisement and vulnerability, participants agreed that the group represented a safe space to express hardship, distress or criticism. In this way, our
analysis complements previous research that has explored humor as a mechanism for coping with adversity, trauma, and conflicting values (see Knight, 2010; Sandberg & Tutenges, 2019; Williams, 2020). Participants expressed how through memes they were able to demarcate between the donor-conceived in-group and non-donor-conceived people out-group, including through humor that depicted the “absent other” as afforded by the closed group context (Archer et al., 2021; Boxer & Cortés-Conde, 1997; Yeshua-Katz & Hård af Segerstad, 2020). Moreover, among our sample of donor-conceived participants, we heard accounts that revealed how donor-conceived people were able to push back against normative or morally laden ways of being. In this way, the creation and exchange of memes offers donor-conceived people opportunities to write their own social scripts and bring their collective identities into being.

While our findings contribute to scholarship on donor conception, they also add to sociological understandings of identity and belonging, the latter concept receiving considerable interest in the social sciences in recent times (see for example May, 2011; Yuval-Davis, 2006). Here, we have sought to contribute to conceptualizations of belonging by unpacking the everyday social and linguistic practices in which collective identities are negotiated and reinforced. As we have explored, identities are made up of complex patterns of values. Memes seek to elicit shared feelings among users, and in doing so, invite users to reinforce their alignments with collective identities. Exploring belonging through the lens of bonding icons, we posit that when a reader identifies and aligns with the values construed in a meme, they recognize that they are the intended audience of the text, and that they belong to that community. Internet memes thus offer productive opportunities for connection and belonging.

**Conclusion**

Closed Facebook groups have emerged as an important site for the mediation of disenfranchised identities, including for those who are donor-conceived. In turn, memes have come to represent various attempts to relate and belong despite, or in response to, the experience of restricted or absent rights, recognition and opportunities for participation in mainstream systems and cultures. In this context, memes, as bonding icons, can cultivate and sustain experiences and feelings of belonging. As such, our analysis of memes, supported by interview accounts from those who create and share them, situates memes as important icons around which donor-conceived people can align. Importantly, the sharing of memes, and participation within closed group contexts, provides privacy and safety for disenfranchised
identities to collect and coalesce. The reinforcing of ties to such collective identities makes visible the significance of memes, for coping, for criticism, and for community.

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CHAPTER 6 - Situated Talk: A method for a reflexive encounter with #donorconceived on TikTok (published article)

**Link to thesis:** Chapter 6 draws on TikToks from #donorconceived to consider how donor-conceived people position themselves and are positioned by LGBTQ+ (prospective) parents (aim 1). Specifically, Chapter 6 describes our method ‘Situated Talk’ designed to facilitate grounded conversations about sensitive topics using TikToks as a prompt (aim 2). In this chapter, I explore tensions between two distinct communities enmeshed in donor conception as well as parallels in experience, and more broadly argue that with topics such as donor conception, which can be sensitive and polarising, finding avenues to meaningfully listening to each other's voices critical (aim 3).

Situated Talk: A method for a reflexive encounter with #donorconceived on TikTok

Giselle Newton 1 and Clare Southerton 2
1Centre for Social Research in Health, UNSW Sydney, Australia
2Vitalities Lab, UNSW Sydney, Australia

Abstract
There is a pressing need to facilitate sensitive conversations between people with differing or opposing views. On video-sharing app TikTok, the diverse experiences of donor-conceived people and recipient parents sit uneasily alongside each other, coalescing in hashtags like #donorconceived. This article describes a method ‘Situated Talk’ which uses TikToks to facilitate a reflexive encounter, drawing on three areas of scholarship: media ethnography and elicitation, researcher reflexivity and duoethnography/collaborative autoethnography. We describe how we, as a donor-conceived adult (Giselle) and a queer woman who would need donor sperm to have a child (Clare), employed TikToks from #donorconceived as prompts to facilitate a sensitive conversation and elicit situated insights. We explore three central insights from applying our method: (1) discomfort as a productive tension; (2) unresolved dilemmas; and (3) discovering parallels in experience. Using TikToks as stimuli, ‘Situated Talk’ contributes an innovative method for generating grounded social media insights.

Keywords
TikTok, donor conception, LGBTQ+, qualitative methods, digital ethnography

* * *

In mid-2020, Clare, who had been researching TikTok, mentioned to Giselle, whose research is focused on donor conception (the use of donor egg/s or sperms to conceive), that she had come across TikToks by donor-conceived people. A short email chain later and we agreed to meet up to discuss. As we began taking a close look at TikToks on #donorconceived, we were intrigued by the way the hashtag brought together communities with very different expectations and needs in an awkward but seemingly unnoticed tension. Initially, Giselle assumed the position of ‘insider’ on donor conception (as a donor-conceived person) and Clare as an ‘outsider’.

Corresponding author:
Giselle Newton, Centre for Social Research in Health, UNSW Sydney, Sydney, NSW 2052, Australia.
Email: g.newton@unsw.edu.au, @newtonatron
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**Introduction**

As TikTok’s popularity has increased, the platform has become part of everyday Internet practices, with content from TikTok spreading across platforms and TikTok content increasingly being discussed in face-to-face interactions. To date, scholars have employed a diverse range of methodological approaches to study the platform such as the app walkthrough method (Kaye et al., 2020; Zulli and Zulli, 2020), netnography (Su et al., 2020) and participant observation and digital ethnography, including experimentation with ‘algorithmic triggers’ (Abidin, 2021). However, given social media content is shared, reshared and is always more-than-digital in the ways it is embedded in non-digital environments (Postill and Pink, 2012), there is significant scope to experiment with methods integrating TikToks into face-to-face encounters. As researchers occupying distinct positionalities in relation to the issue of donor conception, we were interested in developing a method that employed TikToks to prompt a reflexive and situated discussion, aligning with approaches that embrace the embedded, embodied and everyday (Hine, 2015). Indeed, new challenges and opportunities emerge for nuanced and reflexive approaches to research, as the ‘field’, the ‘audience’ and the researcher’s position evolve with our increasingly digital lives (Cavalcante et al., 2017). In this article, we set out the method ‘Situated Talk’ that uses
TikToks as a prompt for facilitating conversations on sensitive topics. Specifically, using TikToks from #donorconceived, we were able to explore issues around who matters within families, parenthood within heteronormative societies and autonomy for donor-conceived people.

The text is structured as follows: first, we provide background on the rise of donor conception content online. Next, we outline three prominent areas of study that our method draws upon and offer the procedure for ‘Situated Talk’. Following this, we describe how we applied the ‘Situated Talk’ method to examine #donorconceived, and explore three central insights. Finally, we highlight how our method contributes an emerging suite of approaches which aim to elicit situated social media insights.

**Discussing donor conception online: From communities of support to awkward tensions**

Broaching sensitive topics can prove difficult including between people who already know each other. The issue of donor conception, that is, the use of gametes from a third party to conceive, often requires sensitive conversations both within donor families, for example, between parents and their children, as well as between members of donor families and wider familial and friendship networks (Nordqvist, 2021). Throughout its history, the practice of donor conception has been shrouded in secrecy due to the stigma associated with infertility and gamete donation (Allan, 2017). However, the last decades have seen a societal shift in values and a ‘turn to openness’ (Nordqvist, 2021). Accordingly, spaces to connect around donor conception have emerged on social media platforms, most notably within private Facebook groups for donor-conceived people, donors and (prospective) recipient parents (those who conceive (d) using donor gametes) (Andreassen, 2018; Darroch and Smith, 2021). A range of studies have explored how LGBTQ+ people have used social media to connect with peers and represent themselves, especially since their identities and families are often not sufficiently visible within heteronormative mainstream media (Byron, 2020; Kirby et al., 2021). Over the last decades, LGBTQ+ users have formed Facebook communities with a specific focus on family and parenting such as ‘rainbow families’, ‘lesbian mothers’, ‘solo mothers’ and ‘gay fathers’ where approaches to ‘alternative’ family formation can be discussed (Andreassen, 2018). The opportunity to form closed communities on social media has benefited donor-conceived people too, providing channels for exchanging information, advice and support (Adams and Lorbach, 2012; Crawshaw et al., 2016; Darroch and Smith, 2021). The possibility to come together online in national and international groups has also
had a significant impact on the way donor-conceived people are able to express and reinforce their collective identities (Newton, in press).

Beyond closed spaces, there is an increasing trend towards sharing publicly oriented content about donor conception. It is unsurprising that users turn to TikTok, a relatively new and evolving platform, which allows users share short videos using charisma and humour to attract visibility, explore aspects of their lives, raise awareness or educate others (Eghtesadi and Florea, 2020; Southerton, 2021; Wang, 2020). Already a rich corpus of scholarship has emerged exploring the affordances, communities and attention economies on the app (see Abidin, 2021; Kaye et al., 2020; Su et al., 2020; Zulli and Zulli, 2020). Structurally, TikTok is oriented around the ‘For You’ page, an algorithmically personalised feed of videos whereby through interaction users gain a more curated experience, as well as via hashtags on the ‘Discover’ page where trending topics are featured. TikTok, then, offers donor-conceived and LGBTQ + people a communicative tool to convey their experiences to the broader public of TikTok users.

Within TikTok hashtags, content from the perspective donor-conceived and LGBTQ + people coalesce, and the distinct positions and priorities of these two groups become visible. For example, user-generated content on donor conception by LGBTQ + people has explored barriers to creating a family via this method, including how donor conception represents a way (sometimes the only way) to achieve parenthood. In contrast, TikToks by donor-conceived people frequently focuses on raising awareness about barriers to securing information about genetic and medical histories and the utility of direct-to-consumer DNA testing as a means of identifying biological parents and siblings. This focus on the importance of relationships with biological family members, emphasised by the donor-conceived community, can sit at odds with the longstanding rejection of biological family within queer kinship practices given the complex history of queer parenting and family-making, in which biological ties have long been downplayed in favour of ‘chosen’ family (Weston, 1997).

Queer scholars have argued that queer life, oriented away from traditional heterosexual life trajectories towards marriage and biological children, finds kinship in the collective and forms its own queer temporalities (Halberstam, 2003). The increasing political orientation towards queer family-making has been critiqued by queer theorists such as Edelman (2004), who argues that that this push for rights to family-making imposes a logic of ‘reproductive futurism’ that preserves dominant heteronormative desire. However, recent decades have
seen a significant shift in the formation of queer families as pathways to biological parenthood are increasingly available for LGBTQ+ people (Power et al., 2010). Andreassen (2018) has explored how, within many queer donor families today, biology continues to be downplayed to protect the position of the non-biological parent, yet in pursuing relationships with donor siblings, the role of biology is reinscribed as significant. Moreover, despite the dominant narrative of familial rejection, recent empirical work has also documented LGBTQ+ people’s experiences of belonging amongst families of origin (Newman et al., 2020). These entanglements, in experiences and expectations around biological, social and queer family, are precisely the productive tensions in which we sought to situate our conversation.

There has been very little – potentially no – research published which deliberately explores the tension between LGBTQ+ and donor-conceived groups, yet such analysis represents a significant opportunity to gain better understandings of distinct experiences of donor conception and improve outcomes for donor families in terms of information sharing and relationship practices. TikTok was specifically selected as the platform for this study based on its organising structure which entangles content from distinct communities in hashtags. TikTok also offers a means to access grounded, first-person accounts of donor conception rather than, for example, texts within the popular culture which represent donor families (which are sparse), or marketing from fertility clinics (Nordqvist, 2021). Further, by centring our own experiences for a reflexive and situated discussion, we align with Mackie and Stevens (2009) who have argued that understandings of global reproductive processes must be grounded in individual, embodied experiences that are inevitably situated within specific sociocultural contexts. In line with this vision, we drew on three areas of scholarship to establish our method: media ethnography and elicitation, researcher reflexivity and duoethnography/collaborative autoethnography, as will be discussed in the following section.

The ‘Situated Talk’ method: Background to approach and specific procedure

In recent years, media scholars have developed several innovative qualitative methods that foreground spatial and temporal dimensions of human-and-media interactions (Møller and Robards, 2019). Digital ethnographic methods such as the media go-along method (Jørgensen, 2016) focused on user’s experience of an app, and the scroll back method (Robards and Lincoln, 2017) which considers users’ digital traces longitudinally, have offered approaches to user-led platform exploration (see also Light et al., 2018). These methods ‘make visible aspects of everyday media that might otherwise pass unnoticed in research focusing on larger-scale media mobility’ (Møller and Robards, 2019, p. 106). In a
similar vein, scholars have also employed elicitation methods that integrate different forms of media into qualitative interviews as a means of prompting reflections and commentary on the content (Croghan et al., 2008; Kaufmann, 2018; Kim, 2006; Li and Ho, 2019). Kaufmann (2018) found that using a mobile device in qualitative elicitation interviews acted to break the tension and was an important point of reference to orient the discussion around participants’ everyday digital practices. Kauffmann’s (2018) method also foregrounds how media is interpreted through an individual’s lens of experience, and as users interpret and respond to videos, they often recall personal memories. In a similar vein, Kim’s (2006) TV talk method allows the researcher to elicit reflections about participants’ everyday lives including about sensitive topics that may otherwise be difficult to broach an interview. While TV talk is oriented towards offering common ground to facilitate discussion, in our study we were explicitely seeking to delve deeply into the tension between our differing positions. Additionally, the specific affordances of TikTok, which constrain amateur content to between 15 and 60 s, allowed us to traverse a broad range of issues related to donor conception from distinct (and opposing) perspectives over the encounter.

In addition to media ethnography and elicitation methods, as we came to analyse donor conception TikToks, we also drew on the concept of reflexivity to navigate our different researcher positionalities. Etherington (2004, pp. 31–32) defines researcher reflexivity as ‘the capacity of the researcher to acknowledge how their own experiences and contexts (which might be fluid and changing) inform the process and outcomes of inquiry’. Scholars have highlighted that reflexivity is a crucial component of conducting ethical research that acknowledges the ways researchers are always implicated in their research (Guillemin and Gillam, 2004; Newton, in press; Pillow, 2003). For example, Pillow (2003) has proposed a ‘reflexivity of discomfort’ that explores: “‘messy” examples, examples that may not always be successful, examples that do not seek a comfortable, transcendent end-point but leave us in the uncomfortable realities of doing engaged qualitative research’ (Pillow, 2003, p. 193).

Another salient approach to reflexivity is the concept of ‘kitchen table reflexivity’ (Kohl and McCutcheon (2015, p. 747) in which researchers create awareness of their positionality through ongoing informal conversations or ‘everyday talk’. This approach was influential to this study because we explicitly sought to conduct situated analysis of #donorconceived, acknowledging our positionalities and their impacts through reflexivity.
Our method also takes inspiration from duoethnography – a method in which two researchers engage in a dialogue focused on a specific topic and draw on their different perspectives to inform a discussion (Sawyer and Norris, 2013). Duoethnographic researchers do not seek to ‘set aside’ their lived experience or identify common ground between the two researchers, though that may occur, rather it is the researchers’ distinct positionalities and differences that are interrogated. Similarly, collaborative autoethnography (Chang et al., 2013), consists of the shared interrogation of personal experiences, facilitating reciprocal probing to deepen the analysis of broader cultural experiences. By design, this method ensures accountability in relation to the research process and product through the involvement of multiple researchers (Chang et al., 2013) and offers catharsis through collaborative efforts to ‘listen to, care for, and represent each other’s voices’ (Hernandez and Ngunjiri, 2013). In this way, in this study, we aimed to understand and centre each other’s voices as a means of understanding donor conception from distinct perspectives.

In taking up duoethnographic and autoethnographic methods, we also sought to be attentive not only to the representational meanings of the TikTok, but also to their sensory and affective qualities. By affect, we refer specifically to the bodily sensations and feelings that are not located within an individual but rather circulate, stick and can bind subjects together (Ahmed, 2004). Existing scholarship on TikTok has emphasised the role of affective atmospheres on the app, especially in relation to how trend-driven the platform is (Southerton, 2021). As Southerton (2021, p. 3252) has argued ‘[w]hen content is shared, it is not merely an expression of a user’s psychological state but an offering toward a collective affective state a viewer of the TikTok may feel, which is constantly shifting within the many broader communities on the platform’ (see also Kirby et al., 2021). Taking seriously the sensory dimensions of TikTok, throughout our situated and reflexive conversation, we draw on our own bodily sensations – especially moments of discomfort and unease – to identify generative lines of inquiry. Indeed, drawing on Ahmed’s work, Chadwick (2021, p.16) argues ‘staying with the discomfort’ can be a generative practice that ‘resists the erasure of differences’.

Having outlined the three areas of scholarship that informed our thinking, we turn now to the specific procedure followed to facilitate a situated and reflexive conversation between two or more participants. Figure 14 offers the procedure for our method ‘Situated Talk’, however, these considerations serve as a guide and can be adapted based on research context and aims. The method is divided into three phases: the design phase (involving reflexivity and
ethnographic observations), the encounter phase (data-gathering through conversation prompted by TikToks) and finally the reflection phase (broader insights are defined and articulated).

Applying 'Situated Talk' to #donorconceived on TikTok

To illustrate the method, here we offer an overview of the project in which we employed ‘Situated Talk’. From the outset of this project, we reflected on our experiences of being donor-conceived and queer and how these experiences are shaped by social, political and legal dynamics within the Asia-Pacific, specifically in the Australian context. While there was a slight distinction in professional status between Giselle and Clare (PhD candidate and postdoctoral fellow), we knew each other through a committee we both participated on in equal roles and our shared positionality as young White childless cisgender women contributed to the free flowing conversation. The hashtag #donorconceived which had attracted 18.9 million views by the time of writing was selected as the hashtag of focus on the basis that it was the most popular hashtag featuring content from both donor-conceived people and recipient parents compared to other hashtags dominated by a single group like
#wearedonorconceived. From August to November, each author conducted ethnographic observations, examining content, form and style of TikToks within the hashtag #donorconceived. Each author recorded their own fieldnotes and used them to inform subsequent conversations between authors, in which we discussed key insights and areas of interest. For example, we noted how though much of the donor-conceived content we encountered on TikTok was created in the United States, reflecting U.S. cultural imperialism in Australia (Bell and Bell, 1996) and in digital spaces more broadly (Yong Jin, 2015), the sample we encountered was shaped and influenced by our location in Australia, English settings and time zone (TikTok, 2020). Despite the limited content from the Asia-Pacific region, we contend that emerging conversations around donor conception on TikTok are an entry point for drawing out more situated and local reflections – engaging ourselves as participants. We also shared our reflections on how the project came about and what we hope to achieve before meeting for the encounter.

For the research encounter, we sat at the ‘kitchen table’ at our workplace and watched TikToks together in November 2020. Kohl and McCutcheon (2015) have discussed the material and metaphorical aspects of the kitchen table, in that it can be both a place of comfort and intimacy, as well as a space for hard conversations. We occupied dual positions as participant and researcher, an approach which ‘challenges the hegemony of objectivity or the artificial distancing of self from one’s research subjects’ (Chang et al., 2013, p. 181). Much like in other social contexts in which friends watch content on the same device, we used a single smartphone for viewing TikTok to feed off each other’s responses and reactions. Given Clare’s engagement with and research on TikTok (fieldnotes from Clare: ‘I’m writing a lot about TikTok right now so I’m on there all the time’), we selected her personal mobile device and TikTok account. This was a somewhat vulnerable act given that, as discussed above, TikToks are organised based on the user’s past browsing, viewing and liking, and using the app in this way to some extent exposed Clare’s prior interactions with TikTok. Given users’ algorithmically personalised feeds on TikTok, we would likely have viewed different content had we accessed TikTok via another device/account. Critically, we were not seeking to gain a ‘clean’ sample free from algorithmic personalisation, given our project is deeply embedded in our personal experience. Just as the feed was personalised by the algorithm, so too was our encounter personalised by what stood out in the moment based on the flow of our conversation – what MacLure (2013: 228) refers to as the ‘wonder’ of data, highlighting the affective entanglement of researcher and the empirical object. The process
was inductive, with sampling designed to span content from a range of content creators, focused on diverse issues and represented using varied TikTok genres. We were not focused on achieving a specific number of ‘TikToks watched’ in the discussion, but rather allowed the conversation to develop. The encounter lasted a duration of 5 hours, a process that left both authors feeling emotionally drained and pondering this personal approach to research for the following days. During the encounter, the authors recorded notes and the conversation was recorded and transcribed verbatim to facilitate reflection on the method.

Following the research encounter, we shared our personal fieldnotes on the encounter via email. Later, we met to reflect on insights generated through applying the ‘Situated Talk’ method and developed this manuscript through immersing ourselves in the transcripts and engaging with relevant literatures. Before we explore the insights derived from the method, it is important to reflect briefly on potential risks, both to researchers and content creators, an issue which we carefully deliberated on throughout our engagement with this method. First, although recounting our experiences required a lot of emotional energy, we approached each other’s stories with care and found that creating space to discuss personal experiences had a positive impact. In terms of risks to content creators, we were sensitive to the potential issues associated with including TikToks in research, given that this content sits on the spectrum between public and private. Risk was mitigated through our focus on the generative aspects of TikToks, that is, the conversation that the TikToks prompted rather than the content of the videos themself. Additionally, we made a conscious choice to exclude any reference of usernames in this article to minimise the ‘searchability’ of the TikToks.

In the following sections we describe how, using TikToks as prompts, we were able to facilitate a sensitive conversation about donor conception. We focus on how this method produced discomfort between researchers, illuminated unresolved dilemmas and highlighted convergences between distinct communities.

**Discomfort as a productive tension: ‘He’s not the dad, he’s the donor’**

We begin by exploring how the proposed method generated discomfort between researchers. Several of the TikToks that we analysed featured queer recipient parents explaining their reasons for opting for donor conception. For example, one salient video featured two recipient parents singing the following jingle, with clapping between each line of the song: ‘Stop calling him the dad, he’s the donor! We’re the parents to our kids and we don’t know who he is. Stop calling him the dad, he’s the
donor!’. The video, with more than 500,000 views and hundreds of likes and comments at the time of viewing, prompted reflection around the role of social and biological parents in a donor-conceived person’s life, as shown in the excerpt from our conversation below:

**Giselle:** Well, it’s very coordinated. They have a very firm stance about the role of the donor in the child’s life. But we don’t really know if the child is even born here.

**Clare:** Yeah, we don’t really know much, or anything about the child. I feel like this video is something I’ve definitely thought about a lot since I saw it the first time, because it really stands out. To me, it’s something I probably would have seen a couple of months ago, and seen as pretty innocuous, I would have been like, ‘I can understand that as a perspective’. And now I have a much better understanding of, I guess, what’s missing in what they’re saying, like you say, where does the perspective of a child come into that? And where does the right of a child to understand their biological parents come into that? And I think, before we started this project, I probably would have just been like, yeah, it is frustrating when you’re like a non-carrying parent and someone refers to the donor, as the other parent, by using the word ‘dad’. But, I think that it’s really easy in these conversations to get caught up in like, how am I being recognised as a parent and not about how’s my child being recognised as a person? How do they get to know themselves?

**Giselle:** Hmm. But also, I wonder, you know, there’s not really a limit on how many parents can actually be involved [in a person’s life], yeah, if you have a dad, you can still have two mums or three mums or five mums. Shouldn’t we hope that a child is loved by multiple people?

**Clare:** I think there’s so much space for a child to have so many relationships that we might think of as being parental. I think there’s a legacy of non-carrying parents being cut out of that… I know, a lot of my friends have had experiences where their family doesn’t recognise the child, and they’re like, ‘Oh, your “friend” had a baby, that’s so nice’, you know, and the lack of familial acceptance of the child really feels incredibly alienating. And so I can’t understand where that comes from. And I have a lot of sympathy for that.

In our conversation, we discussed how queer parents may seek to position themselves as the sole parents of the child and seek to distance themselves from the biological parent/s. This
may be to position each queer parent, both the biological and non-biological parent, as equal or to replicate heteronormative nuclear family structures (Andreassen, 2018; Duggan, 2002; Weston, 1997).

This TikTok, then, which seeks to emphasise the success and validity of the queer family, can be contextualised in broader recent trends of LGBTQ+ media self-representation that emphasise pride over more painful emotions (Sender, 2012). As Sender (2012, p. 221) contends, ‘the opportunities for self-representation afforded to GLBT people in this new media landscape demands that we have no hard feelings; we have moved beyond shame and loss, bitterness and resentment, towards a future orientation of positive self-production’. In our discussion, the unsettling opportunity to see these narratives alongside the experiences of donor-conceived people, which inevitably complicate such neat conceptualisations of the queer nuclear family – drawn together in #donorconceived – hard feelings are not so easily avoided. Giselle’s comment that the creators ‘very firm stance about the role of the donor in the child’s life’ hinted at how they seemingly did not take into consideration the possible consequences that this choice may have for the donor-conceived person. This comment unsettles the representation of ‘no hard feelings’, and opens up space in the discussion for these feelings, with Clare noting the pervasive impact of homophobia and ‘legacy of non-carrying parents being cut out’ that may have contributed to this perspective.

Watching this TikTok prompted Clare to reflect on how she would have identified with the opinions offered by the TikTok creators, even though watching the video was now uncomfortable after hearing Giselle’s perspective as a donor-conceived person. Giselle offered a serious challenge to this perspective – the idea that children can have unlimited parents (both biological and non-biological) – which Clare agreed with, while also offering some explanation of where she felt sympathy for the TikTok creators’ perspective, which Giselle recognised. Indeed, across many of the videos from recipient parents, there was a sense that the creators were either unaware of or disinterested in donor-conceived adults’ perspectives. This was noteworthy because within the same hashtag, donor-conceived people had produced TikToks which spoke directly to their desire to have contact with their donors and donor siblings. This tension and discomfort offered a productive ground to consider why this was occurring within the hashtag and interrogate the tensions between the two perspectives.
In the encounter, we were able to use this TikTok content as a prompt, analysing dimensions of the video and then reflecting on our personal experiences and perspectives where appropriate. The initial focus on the content allowed each person to admit when they did not understand elements of the TikTok. Moreover, we found it easier to demonstrate curiosity, and broach the issues in a way that was not insulting or intrusive through posing questions in relation to the TikTok itself. Indeed, if it were not for the prompt, it is unlikely that we would have been able to delve into the issues in this way due to the lack of awareness of insider assumptions, politics and humour, as ‘outsiders’ of each other’s communities which became visible through the TikToks. In this way, the TikTok content functioned as a vector for uncomfortable conversations by creating a stimulus to blunt or redirect the discomfort.

**Unresolved dilemmas: ‘Can donor conception ever be ethical?’**

The ‘Situated Talk’ method provided us with a framework to discuss and dwell on complex questions without a goal of resolution. This aligned with duoethnographic methods which permit conceptualising these differences and tensions as strengths rather than as problems to be resolved (Sawyer and Norris, 2013). We found that watching TikToks on #donorconceived often led to tangents in the conversation about broader ethical questions associated with donor conception, in which our differing perspectives could gently push against each other. In the following excerpt, we examined a TikTok in which a donor-conceived woman recounted how she found her biological father, which prompted us to speak about whether there is a ‘right way’ to conceive and raise a donor-conceived person. We came together in a discussion of the issue of whether there is a way to allow donor-conceived children to have agency or whether parents’ decisions always influence how donor-conceived people think about their donor-conceived status and identity.

**Clare:** *I can definitely see much more the perspective that donor-conceived communities exist already and have a lot of really great resources, that the recipient parents don’t seem to engage with. But I do wonder if perhaps there’s an element of like, unresolvability about this tension, that recipient parents will always have this anxiety. And yeah, they can kind of be aware of it and work on it but I don’t know if they can necessarily come to a place where they’re like, ‘I’m totally cool about this, and not at all anxious about affirming myself as a parent’. And, you know, I can’t see a future where there isn’t a need for donor conception. And so it seems like two groups that are so entangled with such different priorities.*
Giselle: Yeah. But I often feel like parents want to be spoon fed, like by asking donor-conceived people ‘Oh, if I do it the "right" way, it’s all alright, right?’ And I’m like ‘What is the “right” way? Is there are “right” way?’ And yeah, so tricky. I still don’t really know where I sit with whether I think the practice [of donor conception] should exist. And having that conversation with my own mum is like, like she says to me ‘but then you wouldn’t exist! So how can you not agree with it?’ which is true, but I don’t know that there’s a perfect model [of donor conception in any country]. And lots of donor-conceived people believe that it’s not ethical. I’d like to think that, yeah, there is a ‘right way’ if there are conversations [with the child] around it, and if there is the ability for contact with donors and siblings, and there is a register that holds complete and accurate records. But at the moment, it’s not always regulated in that way. And often there’s not the option to have contact with the donor. And so then if we haven’t been able to get the basics right, maybe it’s better to prohibit it, because in practice, people aren’t doing it the ‘right way’.

Clare: But then would prohibiting it stop people from doing it? So I don’t know.

As the excerpt above explores, often TikToks raised broader ethical questions such as whether people have a right to have a child, what the value of biological relationships is, and whether donor conception can ever be ethical. As Giselle highlighted, many donor-conceived people have experienced first-hand the secrecy and shame associated with donor conception, barriers to accessing information and destruction of records, misconduct by physicians including use of their own sperm, and challenges to achieving contact with donors and donor siblings. These ongoing issues which indicate that donor conception has been practised in unethical ways, have led many donor-conceived people to question whether it can ever be ethical or whether governments, the fertility industry, clinics and parents are willing to see donor conception regulated in a way that ensures the practise is ethical. However, the suggestion that donor conception has been/continues to be practised in unethical ways was a confronting and difficult reality for Clare, who without the practice would be unable to have a child with her partner. Dealing with these complex ethical questions sometimes felt like hitting a brick wall because neither of us had concrete answers. However, it became apparent to us that the aim was not to resolve these tensions but to honour them as part of navigating a sensitive issue like donor conception. Indeed, the TikToks that caused the most discomfort often elicited lengthy, challenging but ultimately rich conversation. This supports Chadwick; (2021, p.8) proposal of discomfort as a sensation that can be generative when we do not
withdraw from it or seek the comfort of resolution but rather stay ‘[r]ooted in bodily and sensory experiences of difficulty, disease and dislocation’. Letting our discomfort with the lack of resolution lie bare, rather than aiming to solve the tension between different groups, was also softened by the ability to reorient back to the TikToks. In summary, we found that this method was well suited to orientating conversations to explore the tensions that arise between different groups and broader ethical questions.

Discovering parallels in experience: ‘The prospect of familial rejection’

Despite our intention to examine difference, we also discovered unexpected convergences between the donor-conceived and queer communities. One TikTok, in particular, prompted this insight which followed the TikTok audio meme ‘put a finger down if you’ in which the narrator swiftly described a chain of events that resulted from being gifted a direct-to-consumer DNA test at the age of 30 years by her mother-in-law. In summary, as a consequence of the DNA test, the person was matched with unknown siblings and family members who were in fact all living in the same community, unbeknownst to any of them. Finally, the narrator described approaching the donor and being harshly rejected. Following this TikTok, we turned our conversation to discuss the risk of familial rejection and the range of feelings associated with a loss or absence of potential familial ties:

Giselle: But the thing is, as an adult going through this, trying to work out what to do, what’s the correct way of like saying, ‘Oh, hi, like, I’m related to you’, it’s so so complicated. And rejection as an adult is something we’re not used to, that kind of familial rejection I guess is not that common. So kind of working out how to navigate like, what it would mean, when someone says like, ‘Fuck off’, that is like 50% genetically related.

Clare: Yeah. It’s really interesting that you say that, I’ve never thought about the interesting parallels with the queer community and family rejection that exists, it’s the same kind of thing, like not wanting to get in touch because you expose yourself to that rejection as an adult. Like, of course, rejection at any time, it’s really hard but rejection as an adult, you’re fully aware of what it means. Like it’s obviously very painful for a child but a child might not fully understand what that’s like, but when you’re an adult, and a family member is like, ‘I don’t want to speak to you ever again’ that’s like, I know what that means. You know, it’s weird that there’s such an
alienation between the donor-conceived community and the queer community, I think, in part, because of almost entirely because of the relationship between queer parents who are recipient parents, but like, yes, queer people go through a very similar process. When you like, ‘come out’, there’s always people who are like, ‘I don’t want anything to do with you anymore’. Even when you think you live in a kind of accepting place.

Giselle: Yeah, and it’s interesting, like, I’ve heard donor-conceived people use the language of ‘coming out’ in relation to telling their friends that they’re donor-conceived. And I guess it’s about this assumption that you’re heterosexual, or in this case, that you’re biologically connected to both of your parents. Yeah. And then having to have a conversation and explicitly state that that’s not true. Yeah, people use that language. And people have said, like, ‘obviously, this is borrowed language’. I don’t know if it’s appropriate for us to use because it’s a very different experience but there are those similarities.

This excerpt explores the parallel experiences between donor-conceived people and queer people in terms of the prospect of family rejection (see Carastathis et al., 2017; Weston, 1997). Another area of convergence related to the experience of ‘coming out’, more commonly used to describe LGBTQ+ people’s experiences (see Newman et al., 2020; Weston, 1997), but also relevant to donor-conceived peoples’ experiences of disclosing to friends or extended family that they were donor-conceived. Exploring these parallels, we were also able to introduce our personal experiences. For example, Giselle shared her experience of matching with biological relatives via direct-to-consumer DNA testing and feeling unsure about how to approach them and Clare related her experience of coming out to her family and its impact on her relationships with her parents and grandparents. These stories are deeply personal, however, we had established an environment of trust between us whereby it was safe to disclose these experiences. This vulnerability and openness was a crucial aspect of the project. Like Kim’s (2006) study using TV talk, we found that by sharing our own personal stories, it was less awkward to ask personal questions as reciprocity was created. Additionally, the fact that we were conscious that our personal stories were indeed relevant and that there was no time limit to exploring these experiences contributed to our willingness to confide in each other. The ‘Situated Talk’ method allowed us to leverage the pre-established trust between us to delve deeper into what it felt like from the other person’s perspective and to have open conversations which revealed convergences.
Conclusion: towards situated social media insights

It is an important task for qualitative researchers to find ways to discuss highly emotive and polarising topics in sensitive ways. We believe that this study is amongst the first to draw on the often unspoken tensions between donor-conceived people and LGBTQ+ (prospective) recipient parents. Here, we have primarily focused on how, through user-generated content such as TikToks, it is possible to facilitate conversations that navigate these fraught oppositions. The study has traced the difficult frictions that can exist between donor-conceived people and LGBTQ+ recipient parents and hopefully provides encouragement that there are ways to meaningfully listen to each other’s voices (Back, 2007; Dreher, 2009; Hernandez and Ngunjiri, 2013).

As we have highlighted in this article, social media offers a stimulus for facilitating nuanced discussion. Moreover, given our media-saturated lives, social media offers an accessible and affordable tool for qualitative research or dialogue more broadly. As researchers, and particularly during a global pandemic, using one’s own experiences as a source of data can be a self-empowering, ethical and useful method (Roy and Uekusa, 2020). There are clear limitations to the generalisability of the findings from a study of this nature, and our intention here has not been to produce data that makes claims about the wider donor-conceived or LGBTQ+ communities. Rather, we suggest our experimental method might offer a starting point to direct future studies exploring both the tensions between these communities and the role social media content might play in facilitating sensitive conversations between them. In this study, we sought to embrace our ‘insider’ knowledges as part of this method (Chang et al., 2013; Sawyer and Norris, 2013). Algorithmic personalisation of social media content can appear a methodological problem to be overcome. Instead, as we have identified, we consider ways researchers can feel empowered to acknowledge and embrace their unique positionalities within digital spaces and the ways in which these positionalities shape research analysis and findings (see also Newton, in press).

In this study, TikTok provided a unique and rich setting for analysis due to the publicly facing user-created content and the consolidation of TikToks from both donor-conceived people and recipient parents via the hashtag affordance. However, we believe that there is significant scope to adapt the method to other social media platforms where sensitive issues emerge. As such, our study aligns with other digital ethnographic approaches which have highlighted individuals’ intimate relationships with and through digital media (Jørgensen, 2016; Robards and Lincoln, 2017). Our method adds to this suite of approaches offering a
means to harness the potential of social media content for facilitating conversation, especially on difficult topics where perspectives may be oppositional. Although this study has focused on a reflexive encounter between two researchers, we argue that there is potential to expand this method to interviews with participants or between members of the general public, for example, if appropriate ethical precautions are taken. Given the large extent to which social media content forms part of everyday social life, and the increasing entanglements between conversations happening in digital spaces and non-digital spaces, it is important that media scholars continue exploring innovative approaches for capturing more-than-digital worlds.

There is a pressing need to examine perspectives that appear at odds and find paths towards understanding. While seeing ‘eye to eye’ on sensitive issues like donor conception may not be a simple nor necessarily desirable objective, it is in the unresolvability of these tensions that rich situated insights emerge. In this article, we have argued that the method ‘Situated Talk’ offers a means to facilitate a sensitive and reflexive encounter. Using TikTok content from hashtag #donorconceived as a prompt was generative, allowing us to draw on our experiences and view discomfort as a productive tension. Our ‘Situated Talk’ method allowed us to contemplate these tensions, without an orientation to resolution, and unearth parallels between the donor-conceived and queer communities.

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Chapter 6: ‘Situated Talk’ Method (published article)

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CHAPTER 7 - Truth, proof, sleuth: Trust in direct-to-consumer DNA testing and other sources of identity information among Australian donor-conceived people (published article)

Link to thesis: In Chapter 7, I document donor-conceived adults’ engagement with direct-to-consumer DNA testing (aim 1). Analysing data from the survey including categorical items and free-text responses along with data from semi-structured interviews (aim 2), I conceptualise genetic narratives from DNA testing in relation to familial narratives and official medical records and argue that (dis)trust shapes the forms of information donor-conceived adults seek out, believe and rely upon for ontological security and belonging (aim 3).

Truth, Proof, Sleuth: Trust in Direct-to-Consumer DNA Testing and Other Sources of Identity Information among Australian Donor-Conceived People

Giselle Newton
UNSW Sydney, Australia

Kerryn Drysdale
UNSW Sydney, Australia

Michele Zappavigna
UNSW Sydney, Australia

Christy E Newman
UNSW Sydney, Australia

Abstract
The digital age is characterised by unprecedented access to technologies to understand our bodies, genetics and family histories. The last decade has seen growing uptake of direct-to-consumer DNA testing, which is (re)shaping individuals’ identity narratives. Drawing on data from a national online survey with Australian donor-conceived people (N = 91) and semi-structured interviews (N = 28), we conceptualise DNA results as a genetic narrative that coexists with other sources of identity information such as familial narratives, medical records and experiential knowledge from peers. Our analysis derived three themes: truth – how DNA results disrupted ontological security and prompted confrontation; proof – how DNA testing was valued and legitimised, especially compared with medical records; and sleuth – how DNA testing was leveraged in agentive practices. In doing so, we explore how processes of (dis)trust shape the forms of identity information individuals seek out, believe and rely upon to position themselves within relational and socio-technical webs.

Corresponding author:
Giselle Newton, Centre for Social Research in Health, UNSW Sydney, unceded territory of the Bedegal people, John Goodsell Building, Sydney, Australia.
Email: g.newton@unsw.edu.au
Chapter 7: Trust in DNA testing (published article)

Abstract

The digital age is characterised by unprecedented access to technologies to understand our bodies, genetics and family histories. The last decade has seen a growing uptake of direct-to-consumer DNA testing which is (re)shaping individuals’ identity narratives. Drawing on data from a national online survey with Australian donor-conceived people (N=91) and semi-structured interviews (N=28), we conceptualise DNA results as a genetic narrative that coexists with other sources of identity information such as familial narratives, medical records, and experiential knowledge from peers. Our analysis derived three themes: truth – how DNA results disrupted ontological security and prompted confrontation; proof – how DNA testing was valued and legitimised, especially compared with medical records; and sleuth – how DNA testing was leveraged in agentive practices. In doing so, we explore how processes of (dis)trust shape the forms of identity information individuals seek out, believe and rely upon to position themselves within relational and sociotechnical webs.

Keywords

DNA; donor conception; identity; family; genetics; trust; truth
Chapter 7: Trust in DNA testing (published article)

Introduction
Few people could have predicted the rise in popularity of direct-to-consumer DNA testing and the associated consequences for those enmeshed in the practice of donor conception. While the threat of DNA testing to donor anonymity has been noted in the media since the mid 2000s (Motluk, 2005), over the last five years autosomal direct-to-consumer DNA testing has become more accessible and affordable, with more than 30 million users worldwide (Kennett et al., 2019). Since 2009, DNA testing companies have introduced features, such as ‘relative finder’ (23andMe, 2009; Larmuseau, 2019), which ‘match’ users according to shared centiMorgans (units of genetic measurement) (Bettinger, 2020). This matching function has offered donor-conceived people, who are often keen to trace their donors and donor siblings, a significant new avenue of investigation (Adams & Lorbach, 2012). Scholars have since declared that these new opportunities to connect to biological relatives mean that “donor anonymity does not exist” (Harper et al., 2016: 1135) and that the concealment of donor conception status is “utopian” (Macpherson, 2019: 1847). This represents an important shift, since throughout its history donor conception has been a largely secretive practice in which the anonymity of gamete donors was protected and disclosure of donor conception status to donor-conceived people discouraged (Swanson, 2012). It is increasingly accepted in academic literature, as well as in national and international legislation, that donor-conceived people have the ‘right to know’ about their donor conception status (Allan, 2017). However, recent studies show that the majority of parents of donor-conceived people are still not disclosing this information to their children (Lassalzede et al., 2017; Tallandini et al., 2016). While some people remain unaware of their donor-conceived status throughout their life course (Klotz, 2016), many find out during periods of familial conflict or bereavement, while others learn this information from donors, or state bodies (Allan, 2017; Macmillan et al., 2021). Critically, and as we will explore below, an increasing number of donor-conceived people are now learning about their conception through DNA testing (see also Klotz, 2016; We Are Donor Conceived, 2020), often upon receiving an unexpected match with a stranger. Few empirical studies have explored donor-conceived people’s engagement with direct-to-consumer DNA testing, yet this cohort’s experiences with DNA testing reveal valuable insights about the social dynamics of power and trust that shape individual and institutional interactions regarding donor conception. In short, DNA testing has offered an alternative pathway to accessing identity information that allows donor-conceived people agency to sidestep medical institutions.
Drawing on reflexive thematic analysis of free-text responses and semi-structured interview data as our primary focus, we explore how DNA test results reflect genetic narratives which sit – often in tension – with other forms of identity information, such as familial narratives, official medical records, and experiential knowledge from peers. We consider how securing genetic narratives can be experienced as disruptive, empowering and/or unifying. In doing so, we foreground the multiple levels at which DNA testing figures in, and impacts upon, donor-conceived people’s social worlds.

**Background**

*When familial and genetic narratives collide*

Across their significant diversity, family is typically constituted through narratives that explore and explain relatedness and connection (Kellas, 2010; Kirkman, 2003). These familial narratives may explicitly outline social and bio-genetic ties through explicitly crafted explanations of the child’s conception or rely upon ‘normative reproductive stories’ (Nordqvist, 2021). Further, narratives are “works in progress”, evolving and expanding over time through iteration and interaction (Harrigan 2010: 36). These forms of interaction and exchange related to familial narratives contribute to a sense of trust between parents and their children and ontological security; that is, a shared sense of reality (Bottero, 2015; Giddens, 1991). Moreover, an absence of information or uncertainty in relation to familial narratives can create a sense of displacement or ‘not belonging’ (Lawler, 2015). This speaks to the enduring social significance of the family, and the work involved in positioning oneself within one’s family.

The last few decades has seen a ‘genealogy craze’ (Barnwell, 2013) in which increasing numbers of people have become invested in developing detailed and accurate family histories to prove cultural authenticity and strengthen social connection and belonging via ‘identity work’ (Barnwell, 2013; Bottero, 2015; Kramer, 2011). In recent years we have also witnessed the rise of digital technologies to measure and track one’s body, bodily functions and genetics (Lupton, 2016). Among these technologies, DNA testing companies offer insights into health, ethnicity and family history (Larmuseau, 2019). Moreover, the genetic knowledge garnered through DNA testing has the potential to reinforce or unexpectedly reshape individuals' sense of identity, both in terms of biological relationships and membership to collective identities (Gibbon & Novas, 2008; Postan, 2016; Rabinow, 1996; Rose, 2009). While information facilitated by DNA testing is often positioned and/or experienced as objective (Lee & Voigt, 2020; Lindee, 2008), DNA testing offers genetic narratives about familial connectedness.
which may prove valuable in familial narratives. Scholarship by Emily Postan (2016) has conceptualised genetic knowledge as a narrative tool that can be incorporated by individuals into their broader identity narrative. Postan (2016) outlines how forms of identity information are instrumental rather than intrinsic that is, they do not reveal “facts” about oneself, rather individuals make decisions about whether and how to incorporate this knowledge. However, it is important to note that these genetic narratives coexist with other forms of identity information individuals uphold, such as familial narratives. For some people these narratives align, while for others, as we explore in this article, they conflict, raising the question: “which account—the genetic or social—is the real one” (Lee & Voigt, 2020: 434).

**The end of reliance on official medical records?**

For donor-conceived people, information about their conception and biological parent/s is sometimes contained within medical records, which are often maintained on registries. However, rights to accessing this information vary between donor-conceived people depending on their place and year of birth. Law reform in many countries has ensured that younger generations of donor-conceived people can access information about their conception and biological parents (see Allan, 2017). Many older donor-conceived people were conceived during an era in which medical records – if kept at all – were often intentionally inaccurate, modified post hoc or destroyed (Dingle, 2021; Hewitt, 2002; Rowland, 1985). During this long history, clinicians also used many arguably unethical practices in donor conception, including sperm mixing to confuse paternity and use of physician sperm without patient consent (Adams & Lorbach, 2012; Dingle, 2021).

Additionally, many medical institutions categorised medical records as belonging to the patient (e.g. the mother), denying donor-conceived people access to information without parental permission (Dingle, 2021). Indeed, scholars have highlighted the extraordinary power and “kinship knowledge-management” regimes of medical institutions and other regulatory bodies involved in the governance of donor conception (Klotz, 2016: 51; see also Crawshaw, 2020). These issues which may cause feelings of frustration, anger and/or powerlessness are frequently discussed among donor-conceived peers who have formed online communities to share their experiences, access support and exchange information (Adams & Lorbach, 2012; Crawshaw et al., 2016; Darroch & Smith, 2021; Harrigan, 2015; Newton & Southerton, 2021; Newton et al., 2022). In this way, these modes of digital sociality offer emancipatory power since practices within the fertility industry can be explored and exposed (Andreassen, 2018). Thus, the emergence of direct-to-consumer DNA
testing, coupled with experiential knowledge from peers, marks a significant shift in the arrangements that sustain a power imbalance between donor-conceived people and very powerful institutions, and may offer donor-conceived people greater control over their medical and genetic histories.

Approaching identity information: the role of (dis)trust

One of the most significant social processes, especially when considering individuals’ understandings of identity, is trust. First established in infancy through the (un)reliability of the caretaker, trust represents a kind of social glue that binds relationships (Giddens, 1991; Luhmann, 1988). Scholars have explored relational, affective and embodied aspects of trust (Fotaki, 2014; Newman et al., 2017) including how individuals’ propensity to believe (mis)information is shaped by the social bonds at stake (Inwood & Zappavigna, 2021). In this article, we adopt the conceptualisation of trust outlined by Khodyakov (2007) which encompasses the notions of thick interpersonal trust (e.g. trust towards family members and close friends), thin interpersonal trust (e.g. trust towards people we do not know well), and institutional trust (e.g. trust towards the government or the health care system). Moreover, Khodyakov’s framework emphasises the social and temporal aspects of trust, arguing that trust is a social process that is developed and maintained over time (see also Möllering, 2013). We find significant utility in this process-oriented and relational approach to trust for examining how donor-conceived people balance distinct forms of identity information from entities of different scales: parents, peers, medical authorities and DNA companies. Indeed, participants’ accounts illuminate the circumstances in which trust can be renegotiated and how select “truths” can be held together. A focus on processes of trust, then, provides a novel vantage point from which to explore individuals’ meaning-making practices as they (re)construct a coherent sense of self, accommodating new, and sometimes conflicting, identity narratives.

Methods

The study

This article is part of a larger mixed method study designed to explore Australian donor-conceived people’s experience, perspectives and support needs. Ethics approval for the study was provided by the UNSW Sydney Human Research Ethics Committee (HC190998). A mixed method approach was adopted, firstly to address the limited existing evidence base on Australian donor-conceived adults’ experiences, and secondly, to allow for ‘different ways of seeing’ in recognition of the complexity and multidimensionality of donor-conceived
people’s experiences and the diverse approaches to understanding those experiences (Mason, 2006). This article draws on two concurrent methods from the study: a national online survey for donor-conceived people (including both quantitative categorical items and qualitative free-text items) and semi-structured interviews. The survey method and interview method represented independent strands conducted concurrently, therefore individuals could take part in one or both methods. Methods were mixed during the analysis stage, as outlined in more detail below.

The survey
The survey sought to describe patterns of experience among Australian donor-conceived adults and included categorical items focused on: demographics and details of donor conception history, support and services, and digital technology use and advocacy. Additionally, a number of qualitative free-text items were included in the survey which allowed respondents to describe their experiences in their own words. Scholars have suggested that free-text items in which large cohorts of respondents can complete their answers anonymously and at their own pace can produce rich and succinct qualitative data sets (Braun et al., 2020; Decorte, 2010). Of the qualitative free-text items included in the survey, the following related to DNA testing: “Please describe your motivations for and (positive or negative) experiences with commercial DNA testing”. Donor-conceived people who were Australian citizens or permanent residents and over sixteen years old were eligible to participate in the survey. Hosted on Qualtrics, the survey required approximately 30 minutes to complete. At the conclusion of the survey, respondents were invited to register their interest to participate in a semi-structured interview if they were over eighteen years old and members of one or more Facebook groups for donor-conceived people.

The semi-structured interviews
Semi-structured interviews covered a range of topics to gather rich, subjective insights on Australian donor-conceived adults’ experiences. Interviews were conducted by GN from April to December 2020 on Zoom video conferencing software. Interviews (N=28) lasted between one and three hours. Although questions relating to DNA testing formed part of the interview schedule, participants often raised their experiences with DNA testing prior to being prompted by the interviewer, reflecting the ubiquity of DNA testing in donor-conceived people’s social worlds. As a donor-conceived person herself, GN had been a member of donor conception Facebook groups for a number of years prior to the study and had also participated in DNA testing in order to connect with biological family members (see
also Newton, in press; Newton & Southerton, 2021). All participants were (made) aware of GN’s ‘insider’ status before or during the interview which supported rapport, trust and confidence towards both the interview and broader study (Andreassen, 2018; Taylor, 2011). Interviews were audio recorded and then transcribed verbatim and de-identified.

**Qualitative analysis**

The methodology for this study is informed by interpretive tradition in sociology (Charmaz, 2006). Following Braun and Clarke’s (2020) approach to reflexive thematic analysis, we took an inductive approach to coding the free-text survey data and interview data. This framework requires reflexive engagement by the researcher, recognising the researcher’s subjectivity as a resource that shapes analysis (Braun & Clarke, 2020). To this end, analysis began as responses to the survey questions were received and as the interviews were unfolding. The analysis was driven by GN who coded the data inductively using NVivo 12 and developed themes in an iterative process. This also included reviewing and refining themes, and engaging with the relevant literatures throughout the writing up process. Below, excerpts are labelled with ‘survey response’ or ‘pseudonym, interview’.

**Results**

In total, 91 donor-conceived people completed the online survey: 14 men, 75 women and 2 non-binary people. Respondents ranged in age from 16 to 49 years old ($M=32.7$, $SD=7.6$). Respondents were conceived in families with opposite-gender parents ($n=72$), single mother ($n=11$), or same-gender mothers ($n=8$), and the majority of respondents were conceived through sperm donation ($n=90$) compared to egg donation ($n=1$). The age respondents learnt they were donor-conceived ranged from “always known” to 42 years old ($M=17.3$, $SD=13.9$). Of the 91 respondents, over two thirds ($n=61$) had participated in direct-to-consumer DNA testing, of whom 12% ($n=11$) reported they learned of their donor-conceived status through this process. Of those who had participated in DNA testing ($n=61$), over 80% ($n=50$) stated that direct-to-consumer DNA testing had been very important or extremely important in providing them with access to information not available through other means. In relation to the interviews, 23 women, four men and one non-binary person took part. Participants ranged in age from 18 to 40 years old, and learnt of their donor-conceived status from early childhood to aged 39. Considering in combination qualitative data gathered from the interviews and from free-text survey responses, which ranged from five words to several paragraphs in length, we derived three key themes from reflexive thematic analysis, which we explore in depth in the following sections.
Uncovering the genetic truth: When DNA testing disrupts ontological security

The first theme encapsulates the experiences of a small group of participants who described how they learnt that they were donor-conceived through direct-to-consumer DNA testing. In these accounts, information revealed through DNA testing clashed with the familial narratives that parent/s and others had relayed to them throughout their lives. As such, DNA results prompted processes of confrontation to verify the “truth” about their conception.

Some participants, prior to receiving their results, viewed DNA testing as a novelty:

*My husband and I thought it would be something fun. I never expected that I would find out I’m donor conceived through it. Not only did my ethnicity come back different to what I was expecting, I also matched with my donor.* [Survey response]

The above response reveals how DNA testing was positioned as something benign and “fun” and individuals were therefore unprepared for the complicated reality presented by the resulting information. Many within this group of participants received immediate matches with close family members, such as donors or donor siblings. Matches of this kind, in which participants shared a significant amount of DNA with a stranger, raised confusion, questions, and shock:

*My results came back that I was a match with a biological father that was not the father I believed to be my own. And that was really shocking to me and it was really shocking that my mother provided the test to me.* [Simone, interview]

Simone explained that her mother was unaware of the ‘matching’ affordances of DNA testing, foregrounding how unexpected the genetic revelation was for both Simone and her mother. As the above remarks reveal, information from DNA testing had the potential to significantly and unexpectedly destabilise familial narratives and the related sense of ontological security. More broadly, these events challenged the thick interpersonal trust between (adult) children and their parents, and raised questions about which forms of information could or should be believed.

In contrast to the above participants, Lindy described an intuitive sense that DNA testing may uncover something:
I saw an ad on TV for a DNA test and don’t 100 per cent know why I decided to do it but it was just something I knew I wanted to do straight away. So sent off for that and it came back with a match to my biological father who was not my dad [Lindy, interview]

Lindy’s inclination that it was “just something I knew I wanted to do straight away” indicates that she had felt a slight sense of displacement or not belonging (see also Hewitt, 2002), which could be (dis)proved through DNA testing. DNA test results demonstrated that there was, indeed, a clash of information between the DNA test and what her parents had led her to believe, and Lindy then sought to unpack what this meant for her identity.

However, not all participants initially believed that the information uncovered through DNA testing was trustworthy. Thomas, for example, concluded that there had to have been a technical mistake or a scam to explain the results:

I get a message from someone [on the DNA testing platform] who said, “Look, we’re 25 per cent DNA match,” you know. “We’re..., I’m your half-sister,” sort of thing. And I was like, “Bullshit. Nah. This is unlikely to be true. Like it’s sort of, they’ve got it wrong.” I mean I felt pretty confident around my sort of family history. [Thomas, interview]

Given the conflict between the information in Thomas’ familial narrative and the DNA results, Thomas attributes the mistake to the latter, protecting his ontological security and his trusted relationships with his parents. However, these events planted doubt and Thomas became determined to establish the exact circumstances of his conception, to get to the bottom of the “genetic truth”. Thomas explained how he then confronted his mother:

“Did you, do you know a Barry Stratton?” ‘Cause that was his name. And she was like, “No.” I said, “Well,” you know, “there’s someone who’s got in contact with me that’s saying this Barry Stratton is my relative, potentially my dad, and he looks like the spitting image of me to the extent that like there need not be any more proof, really. So what’s the story? You know, did you have an affair?” And, as soon as my mum went, “Oh, well...” I was like, “Oh shit,” and I kind of had to sort of sit down. [Thomas, interview]

As we can see across these accounts, DNA testing revealed a clash of information which needed to then be socially validated to determine familial belonging or displacement.

Learning the “true” details of their conception, where the familiar life-world became
unfamiliar (Luhmann, 1988), impacted participants’ feelings of trust in their parents, although there were a range of ways in which these feelings were expressed:

*I get a little frustrated and angry in my reactions whereas I know my sister is still feeling intense hurt and betrayal.* [Simone, interview]

Here we can see how, for Simone and her sister, the “protective cocoon” created in the form of thick interpersonal trust with parents was threatened by the DNA testing results (Giddens, 1991: 3). Disclosure of donor-conceived status as an adult initiated a process of coming to terms with the deliberate omission of information about their conception story in their family. A number of participants described how they made sense of why their parents had not disclosed this information to them before:

*We were created in an era where that [secrecy] was what you did and she trusted doctors who told her, “It’s just like blood donation, it’s no big deal.” And then, by the time she found out it was a big deal, it was too late; she had a kid... So, I wish she’d told me earlier, but I also know that she made the best decision that she could for me.* [Athena, interview]

Participants sought to make sense of their parents’ decisions to use donor conception by locating them within a historical context in which many parents followed doctors’ directions to not disclose donor conception status to their children or others. In many cases, by viewing secrecy or omission of information in this way, participants were able to displace the potential for judgement away from the parents, and as we will see below, this often then shifted onto doctors and medical institutions.

However, not all participants felt comfortable confronting their parents to understand the full story behind their conception:

*So, instead of asking my parents what happened, why this man was suddenly my father, I looked him up in the White Pages [telephone book] and gave him a call, and he explained to me that he was probably a sperm donor.* [Lindy, interview]

While Lindy may not have entirely believed either the genetic narrative or the sperm donor’s account in isolation, the combination of these two pieces of information provided enough evidence for Lindy to accept she was donor-conceived and to begin revising her identity narrative. In this way, trust can be seen to be cumulatively constituted, with the sperm donor’s account strengthening her trust in the genetic narrative provided by the DNA test. This also underscores the social and dynamic nature of identity narratives; individuals cross-
check information based on their trust in the source, interpersonally verifying who they are. While Lindy avoided confronting her parents, she was left to contemplate how, when or whether to inform her parents that she was aware of her donor-conceived status. More broadly, this raised questions about the personal and emotional costs of intervening in long established familial narratives.

**Objective proof: When DNA testing offers hope and empowerment**

The majority of participants in our sample were aware of their donor-conceived status before engaging in DNA testing. The second thematic domain explored here examines the interplay between two distinct forms of identity information for donor-conceived people: medical records and DNA testing results.

Many participants described how, despite extensive efforts to secure records of their conception via formal channels, they had been able to access very limited or no recorded information:

> Everything destroyed, no records etc. No care in any thoughts as to the repercussions of having no information available. [Survey response]

Participants expressed immense frustration and anger in relation to record-keeping practices. More broadly, there were widespread negative attitudes and distrust towards the health facilities in which participants were conceived and towards the authorities responsible for overseeing assisted reproductive technologies. Given how the absence of information available via formal channels had eroded institutional trust, DNA companies offered information at a minimal cost and with limited to no conditions attached. As such, DNA testing often represented a significant source of information and hope:

> It actually offers a lot more than what the government authorities or the clinics can give you. I know there’s a lot of stories of getting the wrong information or being told [by authorities or registries] that the information isn’t there. And I guess those DNA tests, I mean you can’t fake DNA. [Leah, interview]

The temporal aspects of trust are thus revealed, whereby negative experiences with one entity over time can increase openness to exploring other avenues for accessing information. Multiple anecdotes outlining mistakes and malpractice contributed to participants’ distrust in medical records as a legitimate source of information. In contrast, DNA testing was viewed as trustworthy because, in Leah’s terms, “you can’t fake DNA”. Here we see how DNA testing was viewed as reliable and objective; an “undisputed arbiter” (Lee & Voigt, 2020).
Chapter 7: Trust in DNA testing (published article)

Despite participants willingness to engage in DNA testing, many made clear that they did not completely trust DNA testing companies per se, however due to the dearth of alternatives sources of information, DNA testing was their only hope and therefore a necessary “sacrifice”:

Whilst privacy is a concern to me, the utility of testing and potential matching with my siblings outweighed this risk for me personally. [Survey response]

The above excerpt, like many others, reveals how the respondent was acutely aware of what was at stake in submitting their personal data to a private corporation. Yet DNA testing was framed as something donor-conceived people had to do in order to gain proof and in this way, participation in DNA testing was perceived as a necessary “risk”. Participants weighed up privacy risks against information that would contribute to their identity formation, a deliberation in which information that grounded or amplified their self-understanding was considered more important.

Additionally, DNA testing information gained potency as individuals cross-checked medical records against DNA testing information:

The clinic just can’t really be trusted, you know. Just recently I got sent the contact email for someone that wasn’t even related to me and I was like, “I’m so grateful I did the DNA,” because he had said like, you know, “I haven’t matched with anyone on DNA and I’ve had this account, like these two different websites for a few years, are you guys on these websites?” I’m like, “Yeah, we are. If you’re our brother, you would have connected,” [Ellie, interview]

The discrepancies between genetic narratives and medical records provided clear ‘proof’ for many participants that medical authorities were untrustworthy. Participants felt a strong sense of empowerment and personal validation in attaining this ‘proof’ and being able to sidestep the authority of medical institutions who had denied them access to important identity information that they believed they were entitled to:
There was this document stored away in an archive box, down in Births, Deaths and Marriages [Registry], that had all this information about me on it, and I’ve had no right to access that information. It was all in somebody else’s hands and I had to ask sweetly if I wanted information... And being able to spit in a tube, you know, no-one could tell me I couldn’t do it... I think that was really important being able to have that sense of ownership and power over my own story and identity. [Mabel, interview]

Participants described how they resented medical institutions who refused to cooperate or whose staff were engaged in forms of gatekeeping which created delays and unnecessary barriers to information. In contrast to these feelings of desperation, DNA testing was easy and offered a sense of autonomy and possibility in securing access to information.

The advent of direct-to-consumer DNA testing also represented a key turning point for donor-conceived people, a kind of restoring of order or a ‘moment of reckoning’ (Darroch & Smith, 2021: 107), after the long history of institutionalised secrecy and gatekeeping:

Huge step for donor conceived people in reclaiming their rightful information, about direct biological connections, especially since there was no mandatory record keeping in the earlier years and most records have been destroyed by doctors, who probably donated themselves, many times. [Survey response]

Here, DNA testing is represented as marking a new era in which secrecy is no longer feasible and malpractice within the fertility industry is being exposed. Accordingly, information garnered through DNA testing demonstrated to donor-conceived people that their distrust of medical institutions and authorities was well founded. In this way, participants felt that DNA testing gave them the power to determine and document their collective history and identity as donor-conceived people. However, as we explore in the following theme, despite the promise of DNA testing, achieving answers often proved more complex in practice.

The DNA sleuth: When DNA testing affords agentic and strategic practices

The final theme derived from our analysis is focused on how donor-conceived people leveraged direct-to-consumer DNA testing to trace, and in some cases, identify genetic family members.

Participants remarked that, had it not been recommended by peers as an avenue for identity information, they would not have considered, or trusted, DNA testing:
If you’d asked me that question 10 years ago I would have been like, “Hell no! I’m not putting my DNA on there.” [Kirstin, interview]

As this response illustrates, participants were influenced by collective attitudes towards DNA testing as a viable means of accessing information. In this way, DNA testing was legitimised, elevated and recommended within the peer networks in which experiential knowledge was shared. Participants described how they valued and trusted donor-conceived peers:

I like don’t trust them personally like, you know, “Here’s my address. Come to my house, “but... I trust the like credibility of what they say. I trust the like shared experiences. I trust them to like have my best interests [Kylin, interview]

For participants like Kylin, a form of thin interpersonal trust developed between peers online which proved sufficient to encourage participation in DNA testing and to believe the forms of information generated through this source. Upon these layers of thin interpersonal trust, there was also potential for closer peer relationship to develop.

Many participants expressed a belief that identifying family members would be easier:

I guess that’s how [the DNA testing company] advertises it. Like, you know, you’ll get these hints, these leads, and then it’ll all come together [Lisa, interview]

For many, translating technical information about mirror trees and centiMorgans into a feasible strategy for identifying genetic family members was challenging. As such, sleuthing not only required extensive labour but also technical skills. Participants explained how they sought assistance for their sleuthing needs in donor-conceived online communities. Further, some participants directly approached a “DNA search angel” or “DNA sleuth”, that is, a peer who was willing to lend time and expertise to ‘(re)solve’ their case:

With the help of some of the fabulous DNA sleuths on the Facebook group, we were able to find my donor through a first cousin match [Survey response]

Participants gave over their search brief and password details in exchange for sleuthing labour, and in this process bonds between peers were strengthened. In this way, sleuthing can be read as a community practice, one learnt through observing the strategies applied by others and supported by digital platforms in which this exchange of information could easily take place. Further, through this collective sleuthing, a form of thin interpersonal trust could be transformed into thick interpersonal trust based on attributes of similarity (as donor-conceived people) and familiarity (over time) (Khodyakov, 2007).
Although sleuthing was experienced as agentive, participants also experienced being the subject of others’ sleuthing. Given the visibility of matches to all genetic family members, for some participants it became clear that they were not the only ones actively sleuthing. One participant, Leah, described how she had been messaging a “close-ish match” who contacted her donor (of her own accord) which prompted the donor to contact Leah:

*To get that email was like, “Oh my God!” Like it was really surreal and really just out of the blue but really nice that he was, yeah, quite warm in his email and not put out or anything. And it was just kind of relieving as well to know who it was, to have that name like definite.* [Leah, interview]

This example of a third cousin intervening by reaching out to Leah’s donor reveals how sleuthing can be multidirectional on DNA testing services. Beyond the dyad of donor-conceived person and their donor, other family members may be intrigued by family secrets and invested in the accuracy of their own familial narratives.

Importantly, other participants noted that sleuthing could only get them so far in terms of securing the information they needed, and gaining any further information required waiting, sometimes for an unknown amount of time, potentially indefinitely:

*So I guess it’s just a waiting game to see. Like obviously they probably don’t know...  
Like they might never be told or maybe they know and don’t care. It’s a mystery, yeah. So I’m just, I’m just hoping one day they do their DNA and pop up.* [Kelly, interview]

The comment above reveals a state of resignation to active searching. Indeed, many participants experienced a sense of longing and sadness in knowing that they had their genetic family members were out of reach. This points to the limits to practice of sleuthing, with missing information, many unknowns and searches for people who may not be alive (or exist). For some participants this uncertainty felt like a ticking time “bomb”:

*It kind of means that my inbox has turned into a potential bomb. Whenever I open my inbox, I think, “Is today the day Ancestry’s gonna pop up with someone?”* [Simone, interview]

While DNA testing represented a source of hope for many donor-conceived people in that it could reveal genetic family members, there were limits to the sleuthing. In this way, the project of sleuthing was perpetual, never to be complete, given that familial networks held the ongoing potential to expand with new siblings or other genetic family members ‘popping up’
at any time (or potentially never) (see also Blyth, 2012; Newton et al., 2022). As such, donor-conceived people had to be prepared to revise their identity narratives at any time as their familial networks could expand within moments.

Discussion
In this article, we have explored how Australian donor-conceived adults interpret and incorporate distinct forms of identity information. Building on scholarship by Khodyakov (2007), which views trust as a dynamic social process, we have examined how trust in and between different actors and entities influences individual information seeking behaviours and willingness to seek out, believe and rely upon distinct forms of identity information. Specifically, we have sought to demonstrate that individuals do not make decisions about whether to trust an actor or entity in isolation, rather (dis)trust processes are multidimensional and multidirectional. For example, we revealed how donor-conceived people’s willingness to engage in DNA testing as a legitimate source of information was shaped by forms of (dis)trust towards medical institutions and regulatory authorities. In this way, DNA testing and the companies responsible for securing users sensitive data were, for many, viewed as the ‘lesser evil’ given the finite avenues for accessing identity information through formal channels. Our analysis also illustrated the power of thin interpersonal trust between peers in online communities, for normalising DNA testing, for sleuthing labour and for sharing ‘cautionary tales’. Social media, in this way, has transformed donor-conceived people’s capacity to organise, resist anonymity, secrecy and “authoritative regimes of ‘kinship knowledge-management’” (Klotz, 2016: 53; see also Andreassen, 2018; Crawshaw, 2020; Newton et al., 2022). This represents a significant shift, from ongoing feelings of powerlessness to increasing control over genetic and medical histories and to hold clinicians and medical authorities to account for unethical conduct. To date it is unclear whether this reconfiguration of power has influenced institutions’ willingness to listen to and learn from donor-conceived people’s lived experience and act to repair distrust. Regardless, together donor-conceived people have increasing autonomy and opportunities to define what this emerging and evolving identity category means (see also Newton et al., 2022). Indeed, through everyday discourses and practices, such as those related to DNA testing, collective identity and power is forged.

Another key contribution of our analysis is located in our conceptualisation of the ways in which genetic knowledge contributes to individuals’ sense of identity. DNA testing is an identity-oriented tool with a complex and evolving social life (Frith et al., 2018; Lee & Voigt,
This article aligns with scholarship on how genetic information has the potential to (re)shape identity (Gibbon & Novas, 2008; Lee & Voigt, 2020; Postan, 2016; Rabinow, 1996; Rose, 2009) and arguments that suggest “the geneticization of identity has to be located in a more complex field of identity practices” (Novas & Rose, 2000: 491). Our social frameworks for interpreting the “truth” about our bodies, ourselves and our reality are fragile and conditional (Giddens, 1991; Rose, 2009), thus there is great need for reflexivity regarding the “semiotic technologies” employed in reflecting on how we individually and collectively make sense of who we are (Haraway, 1988: 579). Following Postan (2016), we argue that DNA test results have the potential to be significant for identity given our material embodied existence, yet significance depends on how individuals make sense of the information (see also Frith et al., 2018). Individuals have agency to determine how they integrate identity information into their self-narrative, including whether they reject and deny information or adopt and incorporate it. As such, who counts as family is negotiated by individuals, and so DNA testing alone is unable to resolve this question (Lee & Voigt, 2020). In other words: “genes may or may not ‘matter’” (Blyth, 2012: 724). Although genetic information is often perceived to be “objective”, it is always interpreted by an individual based on prior knowledge about their conception and their family. Certainly, for some donor-conceived people, this aspect of their identity is considered unimportant and may remain so throughout their lives (Blyth, 2012), while for others, this information may gain significance gradually, as they mature, or in a specific moment, such as when facing a frightening health issue or with birth of a child. Further, this study makes no attempt to be representative or generalisable, indeed in a terrain where the majority of donor-conceived people are unaware of this facet of their identity, it is impossible to make such claims (Frith et al., 2018; Macmillan et al., 2021).

Scholarship within donor conception studies has begun to identify the range of ways DNA testing is reshaping family and identity for donor-conceived people (Crawshaw, 2018; Frith et al., 2018; Klotz, 2016; Macmillan et al., 2021; Newton et al., 2022). Here, we have contributed to this growing literature by exploring the risks of familial narratives that do not accurately incorporate an individual’s conception story. Simply put, keeping secrets from donor-conceived people is no longer feasible in the age of DNA testing. This article has emphasised the value of understanding how processes of trust influence the complex and dynamic relationships between parents and their donor-conceived (adult) child/ren. Khodyakov (2007: 115) argues that “to create a good or ‘functional’ family, parents try to
establish mutual understanding and build trust with their children”. By focusing on the instances in which familial narratives clash with genetic knowledge, as secured through DNA testing services, we have shown how learning the ‘truth’ as an adult can lead to intense feelings of shock and betrayal which can challenge the forms of thick interpersonal trust that ideally characterise the relationship between a child and their parents (see also Blyth, 2012). This set of insights speaks to novel directions and chains of disclosure (and associated affective experiences therein) which are now ignited by faceless digital platforms, followed by processes of confrontation or verification. In this article, we have highlighted an emerging form of ‘reverse disclosure’ in which an adult child approaches their parents to disclose their donor-conceived status. Our data indicated that, despite the immense shock and displacement that this disclosure may cause, individuals are often oriented to find ways to understand their parents’ historical decisions, rebuild trusting relationships, rewrite familial narratives and (re)secure their sense of belonging. These findings on the dynamicity of familial narratives (see also Harrigan, 2010; Harrigan et al. 2015; Kirkman, 2003), may offer reassurance for those parents of donor-conceived people who continue to uphold secrets today: despite the challenges in forging these difficult conversations later in life and the disruption that the “truth” may cause, families can together (re)write their narratives in ways that incorporate accurate accounts of conception. Our findings also raise a number of questions as well as directions for future research, including how trust is repaired between parent/s and child when information about donor-conceived status is omitted for years (often decades). More broadly, we hope to see future explorations of how omissions of identity information and experiences of deceit contribute to forms of (dis)trust, including with those with whom one has strong ties.

Our sociologically-driven mixed methods analysis reveals how DNA test results often figure as both a meaningful and useful source of identity information for donor-conceived people, particularly throughout attempts to (re)affirm ontological security and grounding within relational and sociotechnical webs. In many respects, DNA testing is the “technology of belonging” articulated by Lee & Voigt (2020: 447), both in relation to familial belonging and belonging among others “like me”. As well as its contribution to the emerging literature around donor-conceived adults’ experiences, this article provides unique insights into the dynamic, relational and collective elements of trust, making visible how social ties shape the forms of information individuals’ regard as valuable and true. In the “posttruth” era, and throughout the Covid-19 pandemic, we have seen the enduring importance of trust for
individuals’ social practices and positionings. It is essential that we continue to pay close attention to the specific socio-historical dynamics which impact upon a community’s trust in both new and old institutions such as family, medicine and DNA testing services.

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References


CHAPTER 8 - On familial haunting: Donor-conceived people’s experiences of living with anonymity and absence (accepted book chapter)

**Link to thesis:** In Chapter 8, I document donor-conceived adults experiences living with secrecy and anonymity (aim 1). I integrate vignettes of personal experience and reflexive thematic analysis of semi-structured interviews, interpreting donor-conceived people’s experiences through the lens of ‘haunting’ (aim 2). I argue that without processes of truth-telling and redress, donor-conceived people will continue to live with the lingering impacts of such past conditions, reinforcing a sense of unbelonging (aim 3).

I’ve always known about the haunting. Yet the outline of my ghost for more than two decades was nebulous; no information to give him shape. Later, a faint sketch of the ghost was formed based on a three-page document, uncovered through four years of negotiation and waiting. At work in front of a bunch of students, I steal a glimpse at my screen to find (his?) cursive writing transported to another era, space, generation. Across the bright blasted photocopier white, hard to make out were the prescribed identity characteristics: “Occupation: security officer/ part-time model. Interests: weights / cycling / running / sailing. Comment on donor personality by interviewer: friendly open manner”. These records “become part of the contest between familiarity and strangeness, between hurting and healing, that the ghost is registering” (Gordon, 2008, p. 103). These scant details, a glimpse of the ghost, and each day since, his contours further inflated by my imagination.

Later, my peers and I learnt that all ghosts can be pinpointed through ‘centiMorgans’, soon experts in measuring via these units of genetic relatedness. I disembark a plane, streams of text flashing across the screen in quick succession, culminating in: “24 Oct 2020 9.11PM: Hi! I’ve solved it”, my ghost almost certainly identified. His mother’s funeral notice states his name alongside those of his two sisters. I examine their profiles as well as those of their children. Like wandering down a dark street looking into to see a family around a fire, the glow of the flames dancing across their faces. This phase, of looking in from the shadows uninvited, makes my stomach churn. I’m invisible to them, am I the ghost? I consider trespassing on private property, knocking on the door and confronting the haunting. No warrant to intrude. The prospect of denial and rejection tugging me away, keeping me out of sight. “Perhaps it’s easier to co-exist with the figure of the ghost?” I wonder. I sit with the haunting.

Introduction

As explored above in my personal account, the concept of ‘haunting’ offers significant utility for interpreting donor-conceived people’s experiences of living with anonymity. By living with anonymity, I mean living with the knowledge that one was conceived using a gamete donor who was promised anonymity. As I explore in this chapter, the culture of anonymity and secrecy in donor conception has produced the conditions for ongoing haunting in the everyday lives of donor-conceived people. Haunting, according to Gordon, is a sociopolitical-
psychological state in which repressed, unresolved or invisible past structures make themselves known and felt in the present (Gordon, 2008; Gordon et al., 2020). A focus on haunting invites us to listen carefully to donor-conceived people’s accounts for experiences pushed to the peripheries, to unsettling, fleeting or illusive occurrences. As I articulate in this chapter, developing the concept of familial haunting, allows us to expand sociological conceptualisations of family by attending to accounts of absence, uncertainty and (unbe)longing.

Cultures of anonymity and secrecy: ghostly fathers

Donor conception has always been characterised by secrecy, omissions, partial knowledge and selective telling in relation to both the use of the practice and disclosure of the identities of gamete donors (Frith, Blyth, Crawshaw, & Akker, 2018). In the nineteenth century, as doctors began experimenting with artificial insemination by donor, the practice was met with suspicion reflecting social attitudes towards masturbation and adultery (Allan, 2017; Swanson, 2012). Since the mid-1940s and for the best part of the remaining decades of the twentieth century, anonymity and secrecy were thought to protect the recipient couple and donor-conceived person from emotional harm and shame (Adams & Lorbach, 2012; Swanson, 2012). Doctors sought to create an illusion that the child was biologically related to the social father via matching techniques in which donors who had similar physical features were selected (Swanson, 2012). Other techniques such as sperm mixing and use of doctor sperm were also used during this period (Adams & Lorbach, 2012; Dingle, 2021; Rowland, 1985). Further, doctors encouraged couples to have sexual intercourse following insemination and to pretend that the insemination had not occurred (Allan, 2017; Swanson, 2012). As such, the issue of male infertility was rarely confronted within the family dynamics, rather it was:

masked by a "ghost father" who was ghostly because he never fully materialized, and was supposed to fade away as soon as conception occurred (Swanson, 2012, p. 612; see also Newsweek, 1934).

Many doctors were also fearful of liability and the “binding” nature of anonymity agreements (Rowland, 1985) and kept inaccurate medical records or later modified or destroyed documentation (Adams & Lorbach, 2012; Dingle, 2021; Hewitt, 2002; Rowland, 1985). While donor conception has also been practiced outside a clinical context, including in the context of queer and solo family arrangements (Dempsey, 2006; Kelly, 2010; Nordqvist, 2011; Power et al., 2010; Riggs, 2008), the era of anonymity continues to impact the lives of
many – arguably most – donor-conceived adults today, restricting access to complete and accurate information about donors and donor siblings.

The last few decades have seen major shifts in social attitudes, professional perspectives, and regulatory frameworks, which support openness in donor conception, underscoring donor-conceived people’s “right to know” (Allan, 2017; Blyth et al., 2012; Nordqvist, 2014). However, in the Australian context, like other parts of the world, legislation is far from uniform and donor-conceived people’s rights to access information about their conception and family are determined by year and jurisdiction of conception. This inconsistency creates tiers of donor-conceived “haves” and “have nots” in terms of formal avenues for accessing information and forging contact with family members.

An alternative route for searching and identifying donors and donor siblings has emerged through direct-to-consumer autosomal DNA testing platforms in which users are matched based on shared centiMorgans (units of genetic measurement). Scholars have argued that these technologies render donor anonymity and concealment of donor-conceived status “utopian” (Macpherson, 2019, p. 1847), with many donor-conceived people learning that they were conceived with donor gametes when they receive a high genetic match with a stranger (Darroch & Smith, 2021; Klotz, 2016; Newton et al., 2022b). For people who are aware of their conception status, DNA testing often offers answers and/or hope for identifying unknown family members (Newton et al., 2022b). However, success largely depends on the individual’s genealogical knowledge, labour, and as I explore below, patience.

A rich field of scholarship has emerged which seeks to describe the experiences of those enmeshed in the practice of donor conception (Blyth et al., 2012). However, much of this research has focused on the perspectives of parents, with less capturing the experiences of donor-conceived people themselves (Jadva, 2021), who are arguably those most affected. Existing research has made it clear that the majority of donor-conceived people view any information about their donors as important (Rodino et al., 2011), and most desire contact with their donor and donor siblings (Beeson et al., 2011; Daniels, 2020; Dempsey et al., 2019; Macmillan et al., 2021). For example, in a study of 69 Australian donor-conceived adults, Caitlin Macmillan and colleagues (2021) found that 88 per cent had been motivated to seek information about their donor and 71 per cent had been motivated to seek contact. Scholars have noted that many donor-conceived people have low expectations for the kind of
relationships that could emerge, potentially as a coping strategy and/or for self-protection from rejection (Freeman et al., 2014; Scheib et al., 2017). Collectively, this scholarship raises interesting questions about how donor-conceived people decide whether to contact their donor and/or donor siblings and their everyday experiences and relationships to unknown family members. This chapter extends previous work by underscoring how framing anonymity as an issue of the past (re)produces ongoing haunting. Anonymity, secrecy, and reform without concomitant processes of widespread truth-telling and equitable redress represent an injustice to those who continue to live with the lingering impacts of such past conditions.

**On Haunting**

In her book *Ghostly Matters* (2008), Avery Gordon expands the scope of the empirical to include subjective experiences which are located at the edges of our consciousness. Gordon proposes an attentiveness to the interrelationship between what she describes as the haunting and the ghost:

> If haunting describes how that which appears to be not there is often a seething presence, acting on and often meddling with taken-for granted realities, the ghost is just the sign, or the empirical evidence if you like, that tells you a haunting is taking place (p.8).

Haunting, as a concept, accounts for the “tangible and tactile as well as ephemeral and imaginary” (Gordon, 2008, p. 201), and the aspects of individuals’ experiences and identities which are “left in the shadows or on the margins” (Smart, 2007, p. 183). Indeed, Gordon’s innovative approach to studying social reality aligns with Carol Smart’s (2007) vision in *Personal Life* in which she articulated the need to “explore those families and relationships which exist in our imaginings and memories, since these are just as real… [to understand] the realms of yearning, desires and inner emotion” (p. 4; see also Nordqvist, 2017).

Gordon explains how haunting is experienced when repressed social violence of the past makes itself known and felt in the present, sometimes explicitly, but often through murky traces or eerie moments. In a similar vein, Ashley Barnwell (2019), drawing on Nixon’s (2011) theory of slow violence, has mapped how, in the context of the family, slow violence can unfold through “shaming, silencing, ostracising, withholding recognition and effectively erasing memories and relationships” (p.1116). Critical, then, is a focus on how suppression, secrecy and silence have enduring impacts on family life and individuals’ sense of familial
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(un)belonging across generations. The concept of haunting allows us to consider how social violence reshapes flows between past, present and future, altering personhood and relationality.

Below, I explore thematic analysis of accounts from donor-conceived people living with anonymity. Divided into three thematic domains, I chart (1) the complexities of living with the inner ghost, (2) how haunting reconfigures the passage of time including through the ongoing waiting and loss, and (3) relationality, ambivalence and the affective pull implicit in attempts to confront the ghost.

Methods

Data collection

The accounts of donor-conceived adults which inform this chapter come from a multi-method study, exploring Australian donor-conceived people’s experiences, conducted between 2019-2022. Ethics approval for the study was provided by the UNSW Sydney Human Research Ethics Committee (HC190998). This chapter draws on data collected in the form of semi-structured interviews (N=28), conducted online between April and December 2020. Donor-conceived people who were Australian citizens or permanent residents, and who were members of Facebook groups for donor-conceived people and over eighteen years old, were eligible to participate in interviews. Interviews lasted between one and three hours and all participants received an AUD $30 voucher for their time. Interviews were audio recorded, transcribed in full, de-identified and all participants were assigned a pseudonym (used in excerpts below).

The sample included 23 women, four men and one non-binary person. Participants were conceived in six jurisdictions of Australia to heterosexual parents (n = 25), lesbian mothers (n = 1), and single mothers (n = 2). Participants ranged in age from 18 to 40 years old, and as such, were conceived during the era of anonymity. Participants reported learning of their donor-conceived status before turning 13 years old (n = 10), between 13 and 25 years old (n = 9), between 26 and 39 years old (n = 9). Participants learnt of their conception from different actors and processes including from a parent/s, grandparent or aunt, in instances of divorce, death, moving or following discussions about fertility; in a letter from a statutory authority; through or following direct-to-consumer DNA testing; or through a hunch or clash in information.
Data analysis

Informed by the interpretive traditions within sociology, the interview data was coded following Braun and Clarke's (2020) approach to reflexive thematic analysis. This framework emphasises the importance of researcher reflexivity given researchers’ subjectivity shapes analysis and findings (Braun & Clarke, 2020), and indeed, all participants were aware of the researcher’s ‘insider’ status, as a donor-conceived person. Smart (2007), like Gordon (2006), has invited us to embrace alternative ways of knowing, shifting our style as well as our content to capture the interplay between researcher and researched via situated and reflexive analysis. To this end, it is important to reflect briefly on how the focus of the paper, living with anonymity, was shaped by my emic perspective (Lambert, 2020). My decision to share my own personal experiences in the form of opening and closing autoethnographic style vignettes, reflects the importance I place on making visible donor-conceived people’s experiences and researcher reflexivity (see Newton, 2022; Newton & Southerton, 2021). Through my subjective engagement, grappling with my own and my peers accounts of haunting, in this chapter I explore what it means to live with anonymity.

Findings

Complex personhood: accommodating the ghost within

Donor-conceived people’s processes of identity (re)formation can be impacted by age of disclosure of conception status, conditions of disclosure and information about and contact with genetic family (Beeson et al., 2011; Frith, Blyth, Crawshaw, & Akker, 2018; Jadva et al., 2010; Macmillan et al., 2021). All participants in this study had been engaged in processes of searching for their donor and/or donor siblings using a variety of methods, such as accessing medical records, enrolment to state registries, media appearances, autosomal direct-to-consumer DNA testing, participation in social media and online forums, among other techniques. The first theme, derived from thematic analysis, encapsulates how participants felt about themselves during the period of living with anonymity.

Some participants described “not feeling like themselves”. For example, Thomas explained the strangeness he felt upon learning he was donor-conceived in his mid-30s:
…a bit perplexed and a bit surreal. You know, that state of when you’ve been in an accident or something and you’re kind of not quite yourself...it’s almost akin to a, a bereavement, a shock, where it’s like you don’t believe that they’re dead or, and it’s like, “That can’t be,” and, “How has that sort of been the case?” And it’s just, it’s hard to take in. (Thomas)

The above account, like others across the interviews, reveals the transformative period of coming to terms with the upheaval of the foundations of one’s personhood. The haunting sets in as Thomas becomes aware that he has misrecognised himself, revealing a form of a complex personhood that must be grappled with. Similarly, Leah spoke of being startled by the new knowledge that she was donor-conceived:

By your mid-twenties, you feel like you’ve got a fair idea, to then like, to be a little bit blindsided by hearing that, especially because, you know, you’ve been told thing all your life... I wonder a lot about, “Well, then who is this other person who has, you know, half of myself comes from?” Yeah. I guess it’s hard to try to integrate that into who you thought you were and, yeah, I don’t know. It just shakes you a bit. (Leah)

Leah recognises the difficulties she experiences in articulating the “seething presence” of the donor within herself (Gordon, 2008, p. 8). In this way, this new way of seeing – the haunting – accessed since participants learned they were donor-conceived, was variously experienced, here as feeling ‘blindsided’ and ‘shaken’.

For Fran, who learnt she was donor-conceived at 31 years old, the ghost took over her face:

I couldn’t really look at myself in the mirror ’cause it kind of felt strange. It was like I’m not actually like half of who I thought I was. So that was really weird to me and I sort of grew up thinking, yeah, like I had my dad’s nose... But the donor must have looked very similar to my dad I guess. Trippy! (Fran)

Here we see how Fran is troubled by the contradiction of her personal narratives of familial resemblance. In this way, everyday encounters with one’s own features were a persisting reminder of the unknown ghost. These dissociative symptoms had implications for how donor-conceived people felt about their bodies and about themselves (Daniels, 2020). Learning of donor-conceived status later in life required unpacking existing personal and relational narratives including those associated with resemblance, where features are read as continuities between past and present. Individuals also became aware of how the medical regime of anonymity sought to mask the donor through matching techniques to the social father, rendering him ghostly.
In contrast to the above accounts of late disclosure, another participant, Brooke, spoke of knowing that she was donor-conceived since early childhood. Brooke’s donor-conceived status began nagging at her after she had children in her 30s, she explained:

*I don’t know, it just came. Like, all of a sudden, I had an overwhelming need to know where I came from, who my biological father was… I remember using that term ‘rollercoaster’ a lot at that time. It was, probably I felt I was ... I remember asking my husband if he thought I was crazy during that period of several months (Brooke)*

Living with anonymity unexpectedly gained prominence for Brooke, after having children (see also Indekeu & Hens, 2019, p.25). The ghost emerged from the peripheries of the donor-conceived conscience to occupy the centre stage; the illusive vision and torment of the ghost seemingly irrational and indicative of craziness. While a break in the intergenerational chain of understanding biological heritage had previously not been significant to Brooke, now with children to consider, the lack of answers became a problem and she sought to resolve this uncertainty (for herself and her descendants).

Participants explained how donor-conceived status figured as a single aspect of individuals’ intersectional identities and many donor-conceived people could, and would, live comfortably with anonymity their whole lives. However, the void in one’s identity occupied by the anonymous donor could gain significance with diagnosis of a medical condition, when entering a new sexual relationship, in experiences of not recognising specific features or traits in their children, or other arbitrary encounters. The haunting could produce a something-to-be-done, a need for resolution or or alleviation through searching for unknown family members. In this way, the donor’s absence carried meaning and consequences; the nothing was something (Scott, 2018). Living with anonymity, then, represents a form of complex personhood characterised by this prevailing absent presence (Gordon, 2008; see also Broom et al., 2021). For donor-conceived people conceived during the era of anonymity, accommodating the ghost within formed part of their identity, sometimes temporarily and sometimes indefinitely, as I discuss in the next section.

**Temporal (re)configurations: anticipation, waiting, loss**

Across the interviews, participants described how knowing they were donor-conceived shaped experiences of temporality. Most participants had broad understandings of family, which included family members who were biologically related as well as family through social ties (see also Newton et al., 2022a). Importantly, participants viewed their ghostly
donor family – unknown biological family members – as part of their family. As such, while these relationships were framed as dormant, they could be activated with changes in circumstances, technologies and regulatory frameworks. The ghost could become known at any time. However, accessing and living these relationships depended on patience and waiting.

Several participants explored the temporal dimensions of searching and waiting, including the lengthy processes of interacting with medical institutions and authorities to secure information. While some participants felt they had agency and that hauntings could be (attempted to be) dealt with, others surrendered to the powerlessness of the “kinship blockage” (Carsten, 2007a, p. 85), recognising that hauntings would continue to figure in their experience of family:

\[\text{It} \text{ can be quite painful, actually, and quite frustrating, and quite annoying, knowing that it’s just all out of our hands; we have to wait for our siblings to do a DNA test.} \]

(Mabel)

In the excerpt above, Mabel articulates the irritation, pain and helplessness she felt in relation to the non-relationships with her siblings. These negative feelings were coupled with a degree of suspense and anticipation towards the prospect that her siblings may participate in direct-to-consumer DNA testing. Across the interviews, it became clear that the culture of anonymity impinged on individuals’ relational and agentive possibilities and for some this caused struggles and feelings of impotence. Participant revealed a normativity to waiting; the everyday haunting must be accepted, though forever mindful that the pace of social life could be accelerated at any time (see also Broom et al., 2018).

Some participants believed they had found all of their family members, yet a glimmer of uncertainty remained that could only be resolved over time:

\[\text{I was lucky. I was [conceived at hospital X] and they kept great records... I’m kind of, you know, five per cent thinking that we’re gonna find out that there’s more [siblings] out there because how much can you actually rely on what’s been kept; you know, records.} \]

(Sharon)

Here Sharon foregrounded her distrust in the medical records (see also Newton et al. 2022b), highlighting how gaining additional siblings was within the realm of possibility. It is perhaps in these circumstances – with the slightest tinge of uncertainty – where the haunting lingers.

Indeed, it is highly unlikely that Sharon will ever be certain about exactly how many siblings
she has, but will instead remain in a state of anticipation, wondering about the reach and boundaries of her family.

Several of the participants underscored how family is fostered over time and through shared experience and practices (Morgan, 2011), and new familial relationships would require a large investment of their time:

*That takes time, yeah. That’s what a relationship is, requires experiences. Shared experiences. You have to show up and do things... I’m open to putting in the time to form those relationships and create them. But there is a big loss there ‘cause you’ve lost that time. So those formative years. You can’t go back and grow up together.*

(Ruth)

For Ruth, the absence of her donor and donor siblings symbolised lost time and as such, if/when a family member emerged, it would be necessary to compensate for time spent out-of-reach. Participants gestured to how meeting after childhood would markedly impact their experiences of siblinghood (see also Jadva et al., 2010). We see how haunting alters social experiences of linear time and life stages (Halberstam, 2005; Pearce, 2018), when “formative years” are experienced atypically during adulthood. Indeed, across the interviews there were indications of altered temporalities via the articulation of a form of ambiguous loss (and related missing and mourning) (Boss, 2007). Unknown family members could not be accounted for and therefore, no resolution or closure could be achieved. In this way, time is frozen with limited means to make sense of (or even articulate) the importance/the affects of non-relationships.

Participants described having a sense that their donor or donor siblings were close, likely living in the same city, yet out-of-reach and unknowable. In this way, the culture of anonymity, and perhaps the doctors who promised such conditions, were responsible for ‘stolen time’ (and associated loss):

*when you do find these donor siblings that, you know, have been there the whole time and that you know you’ve missed out on 35 years of knowing that they even existed, and, you know, you’ve only got a certain amount of time to sit on this earth (Jerome)*

Jerome identified that living with anonymity required grieving the “what-could-have-been” (Gordon, 2008). While some participants invoked the loss of the past, Jerome’s grief was future-facing, recognising time as a finite resource with imminent mortality. In this way,
experiences of haunting reconfigured participants’ experiences of their life courses and while relationships were not materialised, a ghostly presence was felt. As donor-conceived people lived with anonymity, their felt impressions of donors and donor siblings lingered, and so too did an ongoing sense of (unbe)longing and loss. These family members were neither alive nor dead, absent nor present, and could not be mourned during the state of in-between. Thus, the haunting represented unresolved grief (Boss, 2007; Lambert, 2020; Harrigan et al., 2014). More broadly, the sense of loss resulting from disrupted familial memory and continuity, and linear kinship (Carsten, 2007), gave rise to reconfigured temporality within and beyond lifetimes.

Participants described how donor conception also had impacts beyond their generation, haunting the bodies and selves of their children, grandchildren and future generations. For example, Simone expressed how living with anonymity produced guilt around the lack of information she could provide to her children:

One of my greatest fears was: what am I passing down to them? What am I unaware of that I need to share with them? At what stage in their life do they ask someone they’re dating for a DNA test to ensure they’re not related to them? (Simone)

Without a family narrative to tell her children about their biological grandfather, Simone described how living anonymity is intergenerationally experienced; the sense of absence is passed on. As such, the haunting figures as a form of ongoing intergenerational social violence (Barnwell, 2019). While some families were better able to acknowledge, discuss and live with these absences, many people felt compelled to address the void, interrogate the ghost(s) and bring them to life.

Pull towards the unknown: relationality, ambivalence and affective forces

The third thematic domain derived from analysis describes affective forces that pushed and pulled participants towards and away from making contact with their donor and donor siblings.

Participants underscored how non-relationships were highlighted in everyday encounters:
I never knew when things would creep up. You know, it might be watching a movie where there would be, you know, the father unknown or, I don’t know, I can’t even think of any of the movies but there’s always something there, eh? Like that, that triggers. And then, all of a sudden, you know, I’d be days wondering, you know, having deep wonderings. (Henry)

Here, Henry underscores how he is unexpectedly reminded of his donor, leading to periods of heightened awareness of his donor-conceived status and associated lack of information about his donor’s identity or whereabouts. We see here how feelings of (un)belonging emerge in donor-conceived people’s day-to-day lives; the spectre comes in to view as a reminder that one does not know oneself. Living with anonymity involves bracing for the moments that the ghost appears uninvited and finding ways to banish the ghost in such instances.

Some participants described yearning to know their family members, framing this desire as innate:

It’s such a deep longing. It’s a natural kind of, even a, not a conscious feeling; it’s a subconscious thing just to know who your person is, your identity, where you come from. (Fay)

Fay articulated the force compelling her to seek answers about the family history in which she was embedded. We see how anonymity can create a longing to belong. Participants living with anonymity were driven to better understand their identity and put an end to the haunting. Searching, then, offered hope: “horizons of being and becoming” (Eng, 2010, p. 184).

However, other participants expressed how they felt unable or unwilling to search for their donor because they were worried that it may upset their social father:

If I were to meet the donor, I think it might offend my dad. So I don’t want to meet the donor anyway ’cause my dad’s my dad. It doesn’t matter that the donor is my biological father (Fran).

The above remark points to Fran’s concerns about unresolved shame experienced by her social father in relation to infertility, giving rise to the need to protect her father’s masculinity and pride (Cosson et al., 2021). While Fran is not coerced to keep the secret, her relational possibilities are still limited by her fear that her social father will not cope if she seeks out a relationship with her biological father. More broadly, here we see how disharmony and distress is delicately avoided within families (see Smith et al., 2021). For many donor-conceived people, the desire for a relationship with their donors must be carefully negotiated.
through forms of intensive emotional and relational labour to ensure non-biological parents do not feel threatened or replaced by ghostly donors. Searching, then, is not strictly an individual decision but a practice shaped by the attitudes of others within donor-conceived people’s relational, and specifically familial, webs.

For other participants, concerns coalesced around regretting moving from the unknown to the known and regretting that trajectory:

\[ \text{I’m scared to search. It must be maddening to hear, ‘Sorry, the dog ate your records,’ or a differently crushing, being rejected by your donor. I’m not strong enough to face that at the moment. (Shane)} \]

In the above excerpt, Shane underscored the comfort felt within the unknown and their fear of familial rejection. In this sense, by searching for family as an adult, one becomes significantly vulnerable to the prospect of parental disapproval or rejection. Participants described having to construct a particular kind of personal narrative upon forging contact, framing themselves as successful, “well-adjusted”, unthreatening, not needy, not looking for a “father”, and not vying for inheritance. Engaging in searching involved inviting the familial stranger to evaluate their personal intentions, worth and potential to fit within their preestablished family structure. And fears prevailed about “not measuring up” (Freeman et al., 2014, p. 279).

In contrast to the above issue of fear of rejection, participants also discussed the likelihood that they might not like or approve of the person that they found. For example:

\[ \text{I’m always terrified because I think, you know, ‘What if this person is open to meeting and I meet them, and I dislike them?’, you know, ‘or I think they’re awful?, Or they say something terrible?’ Like I don’t know if that’s worse than the bubble of not knowing who they are (Dominique).} \]

Here we can see what has been described as “a sense of the ‘what ifness’” (Carsten, 2007, p. 86), that is, the uncertainty around what kind of person awaits and the vast array of possible outcomes. Like Dominique’s questions above, participants described a range of “what ifs”: What if the person is dead? What if they are a criminal? What if they do not respond? What if they donated thousands of times? What if they are my grandparents’ age? The ambivalence described as part of these questions reflects the overwhelming uncertainty around forging familial relationships as an adult (see also Newton & Southerton, 2021). Like Shane, Dominique describes the comfort of the liminal “bubble”, or the “fantasy” (Freeman et al.,
2014, p. 278), in which the donor lingers neither absent nor present, dead or alive (Lambert, 2020).

In some instances, contact with a donor resulted in unsatisfactory or ambiguous answers. This was the case for Amira who called her donor after receiving no response to a letter sent via registered post:

“He goes, “I’m not exactly sure what you want from me.” And I said to him, “Oh, well, let’s start with a confirmation that you actually were a sperm donor in the 1980s.” He goes, “This is nothing I can confirm or deny.” … and then I asked another question. “It’s nothing I can confirm or deny.” … I said to him, “This just doesn’t sound like it’s gonna be a fruitful conversation. I’m just trying to establish my identity here. I’m 33 years old and I don’t know anything about me.” He’s like, “I’m sorry, I can’t help you” (Amira)

This excerpt reveals Amira’s desperation and disappointment as she confronts the person she believes to be her donor. The pull towards making contact resulted in a sense of increased uncertainty; even direct contact with the presumed donor did not provide adequate evidence for Amira. While the haunting in some ways is alleviated as the ghost takes more shape, the emotional agony is often compounded by negative interactions between the donor-conceived person and the donor. Yet, the significance of the ghost becomes more pertinent as the hopes and desires for relational possibilities do not come to fruition (see also Scheib et al., 2017).

Conclusions

This chapter has revealed donor-conceived people’s profoundly complex, emotional and dynamic experiences of living with anonymity. I have argued that donor-conceived people often experience non-relationships with donor family members as a haunting, an experience in which absence is more significant than presence. I have deployed the concept of haunting to make sense of how anonymity is experienced on a day-to-day basis; how anonymity feels. Through attentiveness to elements of familial connections that participants struggled to articulate, admit or understand, I have demonstrated how absence has a presence, through the figure of the ghostly father or siblings, or through distinct experiences of personhood, temporality and affective pull.

This chapter has conjured experiences of haunting in which familial non-relationships are lived and felt. I align with McCarthy (2012), in emphasising the importance of engagement with the notion of ‘family’, given its dominance in everyday social practices, representations
and language in the English-speaking world. Indeed, it is often through normative assumptions around family that haunting is revealed or produced. It is critical that we continue to explore how individuals’ dynamic positions within social webs, inflect their sense of identity, foregrounding “relational selves” (Mason, 2004, p. 177). Personhood and identity are always shaped by relationships to family, whether positive or negative, absent or present, alive or dead (or across these spectrums). Indeed, sociologists have tended to focus on tangible aspects of social life, neglecting the “no-things”, such as non-relationships, non-identities, invisibilities, absences and void (Scott, 2018). Within the sociology of families and relationships there is significant scope to explore this terrain of non-relationships and their links to (un)belonging. Here, I have attempted to contribute to this vision by exploring experiences of living with anonymity and absence.

As this chapter and previous scholarship has shown, many donor-conceived people view relationships with donors and donor siblings as important (Daniels, 2020; Rodino et al., 2011) and as something that they are entitled to (Allan, 2017; Newton et al., 2022a). Exploring these emerging family forms offers important insights into social meanings ascribed to genetic relatedness and the role of family in individuals’ sense of identity. Normative discourses of resemblance, relatedness and ‘genetic thinking’ are a common feature in everyday life and contribute to individuals’ ability to anchor familial belonging (Dempsey et al., 2019; Indekeu, 2015; Nordqvist, 2017). As I have demonstrated, in instances where genetic origins are unknown, (un)belonging often lingers. Indeed, there is often ambivalence, fears and desires in relation to broaching the unknown, given the (dis)connection and (un)belonging that may be revealed (McCarthy, 2012). More work is needed to further map familial (un)belonging across a range of family forms and social domains, to better understand how belonging as a social phenomenon can be situated, processual and negotiated (Newman et al., 2020).

With regulatory frameworks increasingly privileging donor-conceived people’s rights and needs (Allan, 2017) and the growing uptake of social media and autosomal direct-to-consumer DNA testing (Darroch & Smith, 2021; Frith, Blyth, Crawshaw, & van den Akker, 2018; Klotz, 2016; Newton et al., 2022b), a unique historical moment is unfolding. Donor-conceived people are challenging and reckoning with cultures of anonymity and secrecy, including where states are unwilling to console or acknowledge past wrongdoings. However, while donor-conceived people can maximise experiential knowledge from peers and digital technologies in creating agentive opportunities, there are limits to who can be found and
whether expectations and visions will materialise. Framing anonymity as an issue of the past (re)produces haunting and represents an injustice to those who continue to live with the lingering impacts of such past conditions, including the descendants of donor-conceived people. Acknowledging and remembering past social wrongdoings is widely regarded as a positive approach in terms of collective identity and justice (Misztal, 2003). As such, across law, policy and practice it is essential that the history of donor conception practices is accurately documented, recognising that, while understandings and attitudes of the time were different, by today’s standards and moralities those practices were harmful. Gordon argues that justice is “the social, economic, political and cultural changes required to eliminate the conditions that produce the organized or systemic violence in the first place” (Gordon et al., 2020, p. 341). Therefore, until there is a consistency and equity in the rights of donor-conceived people around the world, and a global commitment to processes of truth-telling and acknowledgement of past wrongdoings, there will be individual and collective, intergenerational haunting.

I have long lived with (coped with) anonymity. Yet I am still caught unprepared, I stutter and stammer when the ghost emerges. As I go about ordinary tasks on autopilot, I am jolted by the slap of the ghost’s hand across my face, the sting of the presence of my donor’s absence:

As shampoo is being massaged into my scalp, my eyelids shut tightly so the suds don’t burn my eyes. “Do both of your parents have your curly hair?” My mind darts, I think of him, “ha ha, no, just my mum”.

As I glance down at the simian crease stamped upon my palm. A fleeting thought of him, a man I am determined has that same topographical map sprawled across his hand.

As they ask “Date of birth?” “any allergies?” “family history of blood clots?” I gulp, smile and shake my head, “I don’t think so”.

Haunting, for me, is part of being donor-conceived; part of living with anonymity.
References


Chapter 8: On familial haunting (accepted book chapter)


CHAPTER 9 – Discussion and Conclusion

This thesis represents a timely investigation into an unprecedented historical moment for donor-conceived people. Today, many donor-conceived people are growing up in families who disclose and discuss donor conception openly, while others are unexpectedly learning of their donor-conceived status later in life. Many donor-conceived people interact with their peers on a daily basis via Facebook groups and trace family members through DNA testing platforms. More donor-conceived people are speaking out publicly about their experiences and rarely does a week go by without more news stories being published which report on DNA discoveries, an extremely large donor sibling group, or a fertility doctor who has been revealed to have inseminated patients using their own sperm. As one example, the latter issue was the focus of a 2022 Netflix documentary Our Father which is narrated from the perspective of US donor-conceived woman Jacoba Ballard and some of her 90+ siblings. This documentary underscores donor-conceived people’s determination to establish and expose ‘the truth’ and achieve justice in the face of powerful institutions, and has brought the topic of donor conception into household conversations across the globe. Elsewhere, donor-conceived people are organising and advocating for policy, laws, and services that align with their best interests within their own jurisdictions and on the international stage at the United Nations. As I write, in Australia, donor-conceived people are forming the first national peak body to support, educate and advocate on behalf of this community. In the last year, two Australian donor-conceived women have published autobiographies: Brave New Humans: The Dirty Reality of Donor Conception (Dingle, 2021) and Triple Helix: My donor-conceived story (Burns, 2022), representing the first two books of this kind. While many challenges remain for donor-conceived people – particularly in relation to ensuring rights are enshrined in law – aided by digital technologies and fuelled by progress and solidarity, change is no doubt more possible today than it ever has been before.

In the initial months of this doctoral project, I systematically and critically engaged with the peer reviewed literature on donor conception for my literature review. Through this process it became clear that limited research had focused on donor-conceived adults’ experiences (Canzi et al., 2019; Daniels, 2020; Jadva, 2021) and among the existing literature, work had largely focused on familial dynamics (Freeman & Golombok, 2012; Golombok, 2018). As such, I identified a disjuncture between how donor-conceived adults were being described in academic scholarship and the ways donor-conceived people understood themselves and their positionings within their families, among peers, and in relation to the State. This thesis has
taken a novel approach, considering donor-conceived people as agents actively responding to and shaping social change. Such an approach to inquiry, driven by situated knowledges gained through my lived experience as a donor-conceived person, offers a novel and significant contribution to the field of donor conception research, policy and practice.

**From lived experience to lived expertise**

Throughout this thesis, I have foregrounded my interpretation of my own experiences alongside my analysis of accounts from other (largely sperm) donor-conceived people in a reflexive and situated approach. Few researchers in the field of donor conception have made clear their positionality, for example as ‘insiders’ or ‘outsiders’, (with the exception of work by Andreassen, 2018; Kirkman & Kirkman 2002), yet reflexivity is widely regarded as a component of ethical practice in qualitative research (Guillemin & Gillam, 2004; Mauthner & Doucet, 2003; Shaw et al., 2019). It is also broadly recognised that research from an emic perspective also leads to distinct findings (Bennett, 2003; Berger, 2015; Taylor, 2011). In Chapter 3, I described three key moments as a donor-conceived person which have shaped this research. For example, I illustrated how joining a Facebook group for donor-conceived people was a major moment in which the ways that I made sense of this identity drastically shifted. I also captured the excitement and empowerment my peers and I felt in coming together to make recommendations to the members of the United Nations and the wider international community at the 30th Anniversary of the Convention on the Rights of the Child. Thirdly, I outlined some of the possibilities, tensions and challenges I have experienced in conducting research with my peers, insights that are relevant to the burgeoning field of peer or ‘insider’ research (Bell et al., 2021; Greene et al., 2009; Hodkinson, 2005).

Since the emergence of the phrase ‘nothing about us without us’ (Charlton, 2000), we have seen increased attention to the involvement of people with lived experience in service provision, research and governance. Today it is untenable to develop policy relevant to a marginalised or disenfranchised group without meaningful consultation and leadership from the community in focus (Askew et al., 2020; Brener et al., 2009; Fisher & Robinson, 2010; Treloar et al., 2011). In donor conception, researchers have argued that the views of those most affected by donor conception should be centred and prioritised in decision-making and service provision (Blyth, 1998; Indekeu & Hens, 2019; Mahlstedt et al., 2010; Rodino et al., 2011). However, in practice these forms of knowledge and expertise are not always valued. Indeed, a core component of this study has been analysing how donor-conceived people draw
on and deliver personal accounts interwoven with knowledge of others’ experiences, legislation and guidelines. I have argued that this layering of experience with other forms of institutional and experiential knowledges constitutes a specific new form of authority and demonstrated how donor-conceived people gain legitimacy when they position themselves through lived expertise. While these findings (outlined in Chapter 4), based on detailed social semiotic analysis of witnesses’ positioning, make a timely contribution to knowledge, they have also shaped the way I personally assert authority on the topic of donor conception, including how I situated myself in public hearings and how my evidence is received, as discussed below.

In 2018, before starting this PhD, my peers encouraged me to make a submission to an upcoming Inquiry into donor conception in Western Australia (the jurisdiction in which my donor provided sperm). I wrote a one-page submission outlining my experience with the hope that I may be able to contribute to reform. Earlier this year, in the final months of my PhD program, bolstered by evidence from the peer reviewed literature including my own findings, I compiled a 31-page submission making recommendations to the Queensland Inquiry into Matters Relating to Donor Conception Information. Over that four-year period, the way I positioned myself in these submissions had transformed significantly, although many of the sentiments expressed in the one-page submission remain the same in the latter version. Of particular note, the recent submission led to an invitation to give evidence at the Queensland public hearing. While a large portion of the total submissions to the inquiry came from my peers, donor-conceived people were a minority among those invited to the public hearing. The voices of donors, recipient parents, privacy commissioners, legal experts, counsellors, and fertility practitioners outweighed those of donor-conceived people. Through their selection of representatives invited to the table, decision-makers made clear the voices that matter on donor conception. However, in response to this ongoing exclusion, donor-conceived people are arming themselves with supplementary knowledge, skills and formal qualifications to be viewed as legitimate stakeholders on donor conception and to drive social change within institutional contexts.

**Belonging in relation to the State, peers, and family**

Since the Inquiry in Western Australia, four years ago, reform in that state has still not occurred. Rumours have indicated that improvements are imminent and will include retrospective access to identifying information about donors in Western Australia, changes which would make my donor identifiable via an official channel. Although donor-conceived
people have gained emancipatory power through leveraging experiential knowledge from peers with genetic narratives from DNA testing (Chapter 7), approaching a donor based on DNA testing represents an unofficial pathway which can be coupled with uncertainty and fear of rejection (Chapter 8). By enshrining the rights of donor-conceived people to identifying information about their genetic family members in law, governments legitimise donor-conceived people’s desire for information and make clear to donors that donor-conceived people’s right to know outweighs their rights to privacy. The law reflects societal values and expectations. For donor-conceived people, recognition by the State is vital to achieving belonging in its fullest sense.

Principles of openness, recognition and justice are the glue of donor-conceived collective identities. Analysis of key values among donor-conceived peers (in Chapters 4 and 5) revealed how values such as the right to know one’s donor-conceived status, the right to have contact with biological family members and the right to accurate information about one’s conception, united donor-conceived people. Openness in donor conception is not about starting from scratch by encouraging intending parents to disclose, rather it requires processes of truth-telling and acknowledgement of past wrongdoings to remedy injustices. Donor-conceived people strive for justice by exposing the unethical practices of fertility practitioners, including with ‘proof’ from DNA testing, via public testimonials online (for example, on TikTok), and in institutional forums (such as the national inquiry) (Chapters 4 and 6). Donor-conceived people push back against pervasive and harmful discourses of “love makes a family” and “being so wanted”, and messages that they should be “grateful” rather than “demanding” or “angry” (Chapters 5 and 6). In doing so, donor-conceived people are paving the way for adequate recognition and visibility of their family forms and experiences. Thus, by viewing donor-conceived people’s experiences in expansive terms, we can see that equal citizenship and belonging to the State matter.

Contemporary positionings in relation to the State are made possible through digital infrastructures that bring donor-conceived individuals together in communities. While previous research pointed to the utility of online spaces for donor-conceived people (Adams & Lorbach, 2012; Crawshaw et al., 2015; Cushing, 2010), scholarship has overlooked the central role digital technologies play in all aspects of donor-conceived sociality. This is the first study to empirically explore the ways in which donor-conceived people use digital platforms to educate, bond, sleuth and strategise. Media scholars have illustrated the benefits of online social support in cases where individuals require support for navigating sensitive (or
secret) health issues as well as specific identities or lived experience (Archer et al., 2021; Craig et al., 2021; Hanckel et al., 2019; Harvey et al., 2007; Hwang et al., 2011; McCosker & Darcy, 2013; Pounds et al., 2018; Pruchniewska, 2019; Yeshua-Katz, 2021). Work in this thesis aligns with this scholarship, demonstrating how participation in closed Facebook groups has provided donor-conceived people with additional opportunities to share their personal experiences with others who may have lived through something similar and, in doing so, allows them access to incomparable social support.

More broadly, this thesis has also contributed to scholarship on collective identity and community in several ways. In Chapter 5, by focusing on donor conception memes as bonding icons, I demonstrated how individuals draw on perceived shared feelings associated with being donor-conceived to invite communion via memes. As a reader interprets a meme and aligns with the values expressed, they recognise themselves as part of the community, reinforcing collective identity and a sense of belonging. In a distinct context, that of a national inquiry, I revealed how donor-conceived witnesses aligned in experiences and stances to jointly position themselves as authoritative figures on donor conception (Chapter 4). Across these two Chapters, attention to how individuals align or disalign with each other linguistically – in each and every clause – offers a fruitful approach to considering collective identity establishment and maintenance (Knight, 2010; Martin & Stenglin, 2006; Zappavigna, 2014). Elsewhere, I argued that interpersonal trust between peers shaped individuals’ attitudes towards familial networks, and the approaches and practices used to identify family members and initiate contact (Chapter 7). Trust towards an actor or entity, as I demonstrated, is multidimensional, temporal and collective in that previous encounters with actors and entities shape which forms of information are sought out, believed and relied upon. As a (digital) community with a shared collective identity, donor-conceived people are not only more connected but also more powerful than ever before (see also Andreassen, 2018). Peer belonging, then, can be viewed as a relational force that offers comfort, security and direction.

While I have begun to examine how digital technologies afford new relationalities and intimacies among donor-conceived peers, there are a number of further avenues that merit exploration. For example, how do donor-conceived people from different generations relate to each other and what does being donor-conceived mean for those growing up in a ‘post-anonymity’ era? How do donor-conceived collective identities develop over time and across digital platforms? And how can peers harness the archival qualities of online interaction to
document their evolving histories? The common idiom expressed among donor-conceived people ‘welcome to the club that nobody really wants to join’ highlights how peership differs from friendship in relation to aspects of choice. While sociologists and social scientists have offered fruitful conceptualisations of friendship (Blatterer, 2014; Byron, 2020; Policarpo, 2019) the concept of peership (that is, a focus on the forms of sociality formed around shared social location and equal social status) has been explored in far less depth and may offer an interesting avenue of inquiry.

The third plane of belonging explored in this thesis is familial belonging. Extending concepts from the sociology of family and personal life on ‘doing family’ and ‘displaying family’ (see Barnwell et al., 2021; Finch, 2007; Morgan, 1996), I explored contemporary practices of familial positioning which can evolve throughout individuals’ life courses as family members are identified, relationships formed, and familial networks expanded. Indeed, familial narratives told within donor families need to be expansive enough to encompass both genetic and social relationships (see Harrigan et al., 2014). More specifically, building on scholarly work on identity and personal narratives (Harrigan et al., 2015; Kirkman, 2003; Postan, 2016, 2017), this thesis has explored how familial and genetic narratives can align or conflict, and the many ways in which individuals make sense and weave together distinct forms of identity information (Chapter 7). Analysis reinforced previous research around how learning of one’s donor-conceived status as an adult can lead to intense feelings of shock and betrayal (Jadva et al., 2009; Lampic et al., 2022; Turner & Coyle, 2000). While learning of one’s conception status as an adult can challenge donor-conceived people’s trust in family members, donor-conceived people sought to repair these relationships and resecure a sense of belonging. Akin to these forms of emotional and relational labour, donor-conceived people also balanced ensuring their non-biological parent did not feel threatened by relationship with their donors, donors did not feel encroached upon, and donor siblings were well positioned to manage learning about a new sibling.

Extending scholarship on familial scripts and mediated family making (Andreassen, 2018; Nordqvist, 2021), I have articulated how donor-conceived people use digital platforms to raise awareness about their familial structures and negotiate the meanings ascribed to social and genetic relationships (Chapter 6). Further, this work illuminated familial tensions, rejection and fears that affect donor-conceive people, which may resonate for other groups experiencing conditional familial harmony and acceptance (as explored in relation to LGBTQ+ prospective parents). Insights also revealed how negative feelings and discomfort
in relation to family could be inverted through humour as part of processes of coping and bonding (Chapter 5). Finally, an alternative focus related to non-relationships, non-information, and nothings can create unresolved traces and imprints: indeed, familial absence can have an enduring presence or haunting (Gordon, 2008; Scott, 2022) (Chapter 8). Familial uncertainty could be managed, but often became significant during transitions in life course, popular culture references or direct questioning from doctors or hairdressers that assumed an individual had access to genetic knowledge.

Broadly, this thesis has documented a range of agentic, affective and normative dimensions of family, paying close attention to the specific linguistic and social practices that bring families into being. As findings have revealed, the meanings donor-conceived people attributed to family evolved over time, especially through interaction with ‘in-group’ peers, information infrastructures and digital technologies. For donor-conceived people in this study, it was important that their specific modes of family were understood and recognised by ‘outsiders’ others such as recipient parents, fertility practitioners, senators and members of the general public. Familial belonging, then, is multidimensional and processual, and can be achieved through micro practices and felt in micro interactions. Further, familial belonging is both inward facing in how family members relate to and feel about each other, and outward facing, in relation to how families are accepted and recognised within broader societies.

There is significant scope for further empirical work to consider familial belonging in the context of donor families. For example, it is worth considering forms of temporality within donor families and transitions from unfamiliarity to familiarity. What processes of selection and critique occur as members of donor families decide to forge and maintain relations? How does importance ascribed to belonging among donor families fluctuate across life stages? How does being part of a family with a large number of donor siblings affect one’s sense of belonging and, indeed, does familial belonging have quantitative limits? As more people are accessing assisted reproductive technologies, including in more diverse family structures, further evidence is needed with respect to how familial belonging is shaped or constrained by these technologies and their associated legislative frameworks. Further, and as I have suggested elsewhere, new knowledge generated from the experiences of donor families are also of relevance to families more broadly, especially non-normative families such a single/solo-parent families, queer families or multicultural families (see also Powell et al., 2016). Donor conception thus raises enduring questions about family and contemporary relational dynamics, for example: what makes a family, and who counts as family? It is
critical that we continue to explore these questions, including as reproductive technologies evolve and social attitudes towards family formation shift. Indeed, despite the significant diversity and difference between families across our societies, many continue to strive to be understood, reflected, represented and legitimised.

Figure 15: Layers of belonging for donor-conceived people

What emerged across the findings of this study was a clear articulation of the distinct domains across which (un)belonging was experienced and felt (Andreassen, 2018; May, 2011b; Yuval-Davis, 2006) (see Figure 15). Drawing on scholarship on collective identities, community and belonging, in this thesis I have sought to capture the motion, movement and - at times - monotony of donor-conceived sociality by exploring relational practices that sustain individuals within relational clusters. Overall, this represents an effort to centre a kind of ‘being-in-process’ (Roseneil & Ketokivi, 2016, p. 154). Roseneil & Ketokivi, (2016) have suggested that:

Any particular family, or ‘individual’, gains its identity and becomes ‘what’ it is in relation to surrounding persons, places, meanings and events. Hence,
rather than being pre-given bounded entities, they are in a state of becoming within a wider set of relational processes (p. 149).

Indeed, within everyday moments and milestones, relational ropes tug beings towards a promise or potentiality of belonging (Berlant, 1998; Probyn, 1996; Yuval-Davis, 2006). In this way, belonging is not ever completed, but rather in constant flux. Belonging is a pluralistic endeavour, hence there are always multiple belongings unfolding and overlapping in any individual’s life.

**Mixing methods to explore the distinct (con)texts of belonging**

This research represents an innovative and creative intervention to research on donor conception. My approach has drawn from and contributed to the academic disciplines of social semiotics, sociology and media studies both theoretically and methodologically. Further, data analysed were generated across myriad social domains in which the experience of being donor-conceived matters. Hence insights reveal how donor-conceived identities are enacted in relation to a range of actors. Importantly, I have argued that an approach spanning disciplines and mixing methods is critical for conceptualising the distinct layers and modalities of belonging. Indeed, belonging is forged and challenged through a range of linguistic, social and digital practices across private and public domains, which required a creative, expansive approach to capture these layers.

Following a social semiotic approach, in which naturally occurring data is examined, I drew on two distinct sets of data generated independent of this research. First, I analysed discourse from a public hearing of the 2010 Senate Committee Inquiry into Donor Conception in Australia. In this context, donor-conceived people interacted with committee members who controlled both the discourse of the hearing and outcomes of the inquiry (Chapter 4). As such, these interactions were characterised by significant distance and unequal status. My analysis demonstrated how donor-conceived people undermined the accounts of fertility practitioners (typically perceived as experts), layered opinions on experience and drew on recognised forms of knowledge to bolster their authority as people with lived expertise. The second social semiotic driven analysis considered meme texts created and shared in a closed Facebook group for donor-conceived peers, a context characterised by a strong sense of privacy, safety, and trust (Chapter 5). As I demonstrated, the context shaped the forms of humour available and acceptable to participants and through interaction in this context, donor-conceived peers negotiated shared values and forged collective identities. Considering
these two chapters in tandem makes visible how belonging is negotiated across distinct social domains and in each and every utterance.

Elsewhere, I considered questions of donor-conceived adults’ sense of (un)belonging using theoretical and analytic frameworks from sociology. Following a sociological approach, in which data is generated for research through methods in which individuals ascribe meaning to their experiences (Blaikie, 2007; Ezzy, 2002), I collected data using a survey instrument (N=91) and interview schedule (N=28). In Chapter 7, I interpreted donor-conceived people’s experiences with DNA testing through the conceptual lens of trust (Khodyakov, 2007). Specifically, I showed how donor-conceived people’s trust in genetic narratives from DNA testing must be understood in relation to familial narratives and medical records, as well as within a broader socio-historical context in which families were encouraged to maintain secrecy and doctors kept inaccurate medical records. In Chapter 8, I drew on the concept of haunting (Gordon, 2008) to interpret interview data. Framing participants’ experiences in this way, I made visible how past structures of secrecy and anonymity affect donor-conceived people’s sense of self, time and family both in the present and into the future. Moreover, I argued that justice in donor conception to prevail requires increased processes and practices of openness and accountability. A sociological approach, then, permitted analysis of the social and historical forces which shaped donor-conceived people’s experiences.

This thesis also contributes to media studies in terms of empirical insights and methodological approach. Building on the range of innovative qualitative methods within media studies over recent years (Jørgensen, 2016; Light et al., 2018; Møller & Robards, 2019; Robards & Lincoln, 2017), the ‘Situated Talk’ method outlined in Chapter 6 offered an approach which integrated TikToks as a prompt for conversation, akin to everyday contexts in which individuals bring social media content to their conversations with friends and family. Empirically, using this method I documented some of the public-facing donor conception narratives emerging on TikTok and described several tensions and parallels between the experiences of the donor-conceived and LGBTQ+ communities. More broadly, this work contributes to understanding how individuals are using platforms like TikTok to raise awareness and educate the public via first-person short videos. Considering social media, then, through both approach and focus, is vital to understanding the myriad ways people of marginalised or disenfranchised identities achieve everyday belongings.
Looking more holistically between and across the chapters, the interplay of distinct theoretical and analytical approaches reveals the “creative tension” at the heart of this research (Mason, 2006, p. 20; see also Bernstein, 1995). One aspect of this tension derives from the distinct ontological and epistemological assumptions underpinning questions about how to access and understand donor-conceived people’s social worlds and collect data accordingly. For example, social semiotics privileges naturalistic data, taking into account that individuals are not always conscious or reflexive about their own language choices. In contrast, sociology focuses on how individuals make sense of their experiences and views individual accounts as constructions of reality. Despite these subtle distinctions, approaches from both disciplines underscore the interplay between an individual experience or text, and the macro social structures and systems of meaning shaping the experience or text. Likewise, both approaches view individuals in relation to particular identities, sub-cultures and broader cultures. Therefore, while the unit of analysis in these approaches varies, together they allowed me to orient donor-conceived people’s experiences and discourses in relation to broader power structures and social groupings within a specific historical moment.

This approach also had some limitations which are important to recognise. First, many people live unaware of the accurate details of their donor conception and so research in the field of donor conception is restricted to those that are aware (Skoog Svanberg et al., 2020). Like the majority of studies with donor-conceived adults (Indekeu et al., 2021), in the sample of survey respondents and interview participants, a large proportion were women and the majority of participants were sperm donor-conceived (one of 91 survey respondents was egg donor-conceived). Participants from heterosexual families made up a high proportion of those who took part in the study, although this reflects the period in which they were conceived, in which the majority of parents forming families via donor conception were heterosexual couples. Constraining eligibility for interviews to people who had used donor conception Facebook groups resulted in limited participation in interviews from people conceived within queer families. This trend also suggests that people conceived in queer families may find support in other ways, for example through supportive relationships with other rainbow families.

In order to weave together the range of approaches and perspectives on this complex subject, the breadth and depth of data collected represented more than could be analysed during the course of a doctoral program. Indeed, working together as an interdisciplinary team, integrating analyses, and identifying suitable outlets for publication required additional
planning and communication. While there is surplus data from the project, the range of data sources and methods was critical in allowing “different ways of seeing” (Mason, 2006, p. 13). Using distinct data sets also permitted me to extend my own methodological expertise. The format selected for this thesis, whereby chapters include publications, allowed me to develop publishing skills. As such, beyond this thesis, there is much scope for additional publications.

**Implications for policy and practice**

Findings from this thesis have important implications for policy and practice. This study contributes to a robust literature demonstrating that disclosure of donor-conceived status during early childhood leads to improved psychosocial outcomes (Golombok, 2021; Ilioi et al., 2017; Jadva et al., 2009; Scheib et al., 2005; Turner & Coyle, 2000; Vanfraussen et al., 2003). Yet parents experience significant barriers to disclosing donor conception status (Lassalzede et al., 2017; Tallandini et al., 2016). There are a number of possible approaches to ensuring early disclosure occurs. For example, counselling with an experienced professional or “Time to Tell” or “Telling and Talking” webinars/workshops can offer opportunities for parents to discuss concerns and improve confidence in their familial narrative (Donor Conception Network, 2022; VARTA, 2021b). These workshops are also of relevance to parents with adult donor-conceived children who have not disclosed. As this thesis has shown, donor-conceived people can discover their status via a range of actors and sources, therefore it is never too late for parents to disclose. While late disclosure can be extremely disruptive and difficult, most donor-conceived people are grateful to have access to an accurate conception story (see also Jadva et al., 2009). As findings here have shown, families can find ways to rewrite their familial narratives in ways that account for social and biological family members.

Another approach to ensuring disclosure occurs is via birth certificates. For example, the state of Victoria introduced a system in 2010 in which the birth certificates of all donor-conceived people contain an addendum which states that there is additional information about their conception available. All donor-conceived people who apply for a birth certificate from Births, Deaths and Marriages from age 18 will find out that they are donor-conceived through this mechanism if they do not already know (VARTA, 2022). However, to date it is unclear how this policy impacts parents’ disclosure decisions. Additionally, it is likely that improved outcomes would result from a system that notified donor-conceived people earlier than 18 years old given that an individuals’ identity develops during childhood and adolescence and disclosure during that period is preferable.
Another system which has been proposed, which mirrors policy in adoption, is to identify a donor-conceived person’s legal parents (those legally and financially responsible) and biological parentage (those who provided gametes) on birth certificates (Allan, 2022; Newton, 2022; see also Department of Health, Ireland, 2020). This could occur on a single birth certificate or via two documents (with the first outlining legal parentage and the second an integrated birth certificate reflecting both legal and biological parentage). The latter option would allow donor-conceived people to choose which certificate they wish to use depending on context.

Findings from this study are also relevant to policy in relation to donor conception registers. The 2010 National Inquiry recommended the establishment of a national donor conception register or that each state and territory establish centralised registers ‘as a matter of priority’ (The Senate Legal and Constitutional Affairs References Committee, 2011). While a state/territory-based approach has been opted for, twelve years on, a number of jurisdictions do not have legislation or a donor conception register (Queensland, Australian Capital Territory, Tasmania, Northern Territory). It is critical that each state and territory in Australia establish independent, digitalised and centralised registers in which donor conception records are preserved and managed. Given the transportation of gametes between states and countries, registers must operate in cooperation with interstate and international bodies. Further, it is essential that communication and collaboration exists between state and international bodies to ensure that ongoing support and information is available to donor-conceived people. These services should also operate with transparency, making statistical information about registers available to the public, for example via an annual report (see for example VARTA, 2021a). Reports should include the number of donors, donor-conceived people, parents of donor-conceived people and descendants of donor-conceived people who have applied for information and been matched.

Insights from this study also reveal the range of formal and informal support and services donor-conceived people may require. For example, the provision of free optional counselling delivered by a qualified and experienced professional is critical for many donor-conceived people, especially in cases of late disclosure. Many donor-conceived people also benefit from websites containing up-to-date information about donor conception with resources, testimonials and FAQs. For many donor-conceived people, websites represent one of the first points of information about donor conception. Detailed information about direct-to-consumer DNA testing and support in navigating testing, for example, from a genealogist, is often
sought out by donor-conceived people, and should be offered in donor conception service provision.

This research has also demonstrated the importance of peer-based support for donor-conceived people. This support is entirely unpaid, which is both an unjust and unsustainable model that often leads to burnout. Policymakers should fund peer-led initiatives including the national peak body and peer support meetings and workshops with paid lived experience facilitators. Formal services should employ people with lived experience or lived expertise, in recognition of the advantages that peer-to-peer service provision offers. In line with consumer participation principles, formal services should include people with lived experience via advisory committees or through quotas on their boards. Services that do not include donor-conceived people in their governance and service design will continue to have limited success.

**Concluding remarks**

This thesis has interrogated the question of what it means to belong for donor-conceived adults today. Drawing from distinct disciplines and creatively mixing methods was central to conceptualising donor-conceived belonging, as it enabled a multi-layered analysis of the range of contexts in which (un)belonging was achieved and contested. By positioning donor-conceived people as active agents who, through their lived expertise, challenge and reconfigure the structures of donor conception, I have broadened the scope of investigation on donor-conceived social worlds. Against a backdrop of immense social, technological and legislative change, I have argued that donor-conceived people negotiate belonging across three planes, in relation to family, peers and the State. Belonging for donor-conceived people is constrained by historical practices, established power structures, pervasive discourses and familial denial. Yet donor-conceived people, together, have increasing opportunities to bond, educate, sleuth and strategise. Indeed, through momentous events, everyday encounters and humorous artefacts donor-conceived people sustain everyday belongings. Today, beyond a fact of conception, ‘donor-conceived’ is an identity, a community, and a movement.
References


*Discourse & Communication, 8*(2), 209–228.

https://doi.org/10.1177/1750481313510816
APPENDIX 1 - Ethics approval, low risk research (Hansard)

30-Jan-2020

Dear Associate Professor Christy Newman,

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Thank you for submitting the above research project to the HREP Executive for ethical review. This project was considered by the HREP Executive at its meeting on 28-Jan-2020.

I am pleased to advise you that the HREP Executive has granted ethical approval of this research project. The following condition(s) must be met before data collection commences:

Conditions of Approval:
N/A

Conditions of Approval - All Projects:

- The Chief Investigator will immediately report anything that might warrant review of ethical approval of the project.
- The Chief Investigator will seek approval from the HREP Executive for any modifications to the protocol or other project documents.
- The Chief Investigator will notify the HREP Executive immediately of any protocol deviation or adverse events or safety events related to the project.
- The Chief Investigator will report to the HREP Executive annually in the specified format and notify the HREP Executive when the project is completed at all sites.
- The Chief Investigator will notify the HREP Executive if the project is discontinued before the expected completion date, with reasons provided.
- The Chief Investigator will notify the HREP Executive of his or her inability to continue as Coordinating Chief Investigator including the name of and contact information for a replacement.
The HREP Executive Terms of Reference, Standard Operating Procedures, membership and standard forms are available from https://research.unsw.edu.au/research-ethics-and-compliance-support-recs.

If you would like any assistance, or further information, please contact the ethics office on:

Kind Regards,

Dr Ted Rohr
Director, Research Ethics Compliance Support (RECS)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007). The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.
APPENDIX 2 - Ethics approval, more than low risk research (online survey and semi-structured interviews)

19-Dec-2019

Dear Associate Professor Christy Newman,

<table>
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Thank you for submitting the above research project to the HREC Executive for ethical review. This project was considered by the HREC Executive at its meeting on 19-Dec-2019.

I am pleased to advise you that the HREC Executive has granted ethical approval of this research project. The following condition(s) must be met before data collection commences:

Conditions of Approval:
(1) A link to the online version of the survey as a modification to the HREC executive once the study website and survey are both ready and coded must be provided to the UNSW HREC and approved before advertising, recruitment or data collection commences.

Conditions of Approval - All Projects:

- The Chief Investigator will immediately report anything that might warrant review of ethical approval of the project.
- The Chief Investigator will seek approval from the HREC Executive for any modifications to the protocol or other project documents.
- The Chief Investigator will notify the HREC Executive immediately of any protocol deviation or adverse events or safety events related to the project.
- The Chief Investigator will report to the HREC Executive annually in the specified format and notify the HREC Executive when the project is completed at all sites.
- The Chief Investigator will notify the HREC Executive if the project is discontinued before the expected completion date, with reasons provided.
- The Chief Investigator will notify the HREC Executive of his or her inability to continue as
Appendix 2: Ethics approval (online survey and semi-structured interviews)

Coordinating Chief Investigator including the name of and contact information for a replacement.

The HREC Executive Terms of Reference, Standard Operating Procedures, membership and standard forms are available from https://research.unsw.edu.au/research-ethics-and-compliance-support-regs.

If you would like any assistance, or further information, please contact the ethics office on:

Prof Sean Emery
HREC Presiding Chairperson

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NH&MRC) National Statement on Ethical Conduct in Human Research (2007). The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.
Appendix 2: Ethics approval (online survey and semi-structured interviews)

09-Mar-2020

Dear Associate Professor Christy Newman,

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<th>Project Title</th>
<th>Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers</th>
</tr>
</thead>
<tbody>
<tr>
<td>HC No</td>
<td>HC190998</td>
</tr>
<tr>
<td>Re</td>
<td>Modification request dated 27.02.2020 seeking approval for the following changes to the project:</td>
</tr>
<tr>
<td></td>
<td>(1) Survey instrument</td>
</tr>
<tr>
<td></td>
<td>(2) Online Survey PISC</td>
</tr>
<tr>
<td></td>
<td>(3) Study Website Text</td>
</tr>
<tr>
<td></td>
<td>(4) Per the conditions of approval for this study, the Qualtrics link which will be available on the study’s webpage is: <a href="https://unsw.au1.qualtrics.com/jfe/form/SV_bQHC2Yiz6SBxZ1H">https://unsw.au1.qualtrics.com/jfe/form/SV_bQHC2Yiz6SBxZ1H</a></td>
</tr>
</tbody>
</table>

The following documentation was submitted with this request:
(1) Appendix A – survey instrument clean (26 Feb)
(2) Appendix A – survey instrument tracked (26 Feb)
(3) Appendix D - study website clean (26 Feb)
(4) Appendix D – study website tracked (26 Feb)
(5) Appendix F - Online Survey PIS clean (26 Feb)
(6) Appendix F – Online Survey PIS tracked (26 Feb)

The modification to this project was approved by the HREC Executive on 05-Mar-2020. The following condition(s) must be met before data collection commences:

Modification conditions of approval:
N/A

The conditions of approval listed within the project’s original approval letter still apply.

The HREC Executive Terms of Reference, Standard Operating Procedures, membership and standard forms are available from https://research.unsw.edu.au/research-ethics-and-compliance-
Appendix 2: Ethics approval (online survey and semi-structured interviews)

support-recs.

If you would like any assistance, or further information, please contact the ethics office on:

Kind Regards,

Associate Professor Kathy Petroumenos
HREC Presiding Chairperson

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NH&MRC) National Statement on Ethical Conduct in Human Research (2007). The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.
Appendix 2: Ethics approval (online survey and semi-structured interviews)

27-Nov-2020

Dear Associate Professor Christy Newman,

<table>
<thead>
<tr>
<th>Project Title</th>
<th>Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers</th>
</tr>
</thead>
<tbody>
<tr>
<td>HC No</td>
<td>HC190998</td>
</tr>
<tr>
<td>Re</td>
<td>Response modification dated 24.11.2020</td>
</tr>
</tbody>
</table>

The modification to this project was approved by the HREC Executive on 26-Nov-2020. The following condition(s) must be met before data collection commences:

**Modification conditions of approval:**
1. Please add a statement that states that if the participant does not want to be re-contacted in this manner, that they advise the research team of this. This is as to provide participants with the option to remove their contact details from further contact if they wish.

The conditions of approval listed within the project’s original approval letter still apply.


If you would like any assistance, or further information, please contact the ethics office on:

Kind Regards,

[Signature]

Associate Professor Kathy Petoumenos

Human Research Ethics Presiding Member
APPENDIX 3 - Endorsement from community organisations

20 May 2020

Giselle Newton
PhD candidate
Centre for Social Research in Health UNSW

By email:

Ref: Community Research Endorsement Panel

Dear Giselle

Re: Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers

Thank you for your application to the Community Research Endorsement Panel for the abovenamed research project, which the Panel has reviewed. I'm writing to advise that the Panel is pleased to endorse this research.

The reference number that applies to this project is THH/CREP 20-008, which can be quoted on any materials being distributed, to convey to the community and others that the project has been before the Panel.

Please accept our apologies for the delay in providing this notification, which has been protracted due to the current situation everyone is facing.

Our Partnerships Manager, John Hall, will be able to assist you further and provide

We wish you well and look forward to being kept informed on progress with this worthwhile project.

Yours sincerely

Cheryl Thompson
Secretariat
29 March 2020

Ms Giselle Newton

Sent by email

RERC Reference Number
2020/05

Dear Ms Newton

I am writing in regard to your recent application to the ACON Research Ethics Review Committee (RERC) titled: Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers.

The Committee moved to provide full ethical support to this application.

The following points of consideration were raised by the Committee for the research team, although don’t affect the approval decision:

- Due to the age of some research participants, the Committee suggest the inclusion of a youth specific telephone support service in the list of support services.

The Committee, and ACON itself, welcome research on this topic and we wish you the very best with this project. Please do not hesitate to be in touch so we may best support you in this work, correspondence addressing the above can be directed to Brandon Bear, Manager, Policy Strategy Research at bbear@acon.org.au

Kind regards,

Brandon Bear
Manager, Policy Strategy Research
1. What is the research study about?
You are invited to take part in this research study because you are a donor-conceived person. The research study aims to explore donor-conceived people’s understandings of identity, community and support in online and offline environments.

2. Who is conducting this research?
The study is being carried out by the following researchers: Associate Professor Christy Newman, Dr Kerryn Drysdale and Ms Giselle Newton (PhD candidate/student researcher), Centre for Social Research in Health, and Dr Michele Zappavigna, School of Arts and Media, UNSW Sydney.

Research Funder: This research is being funded by the Centre for Social Research in Health, supported by the Australian Government Department of Health.

3. Inclusion/Exclusion Criteria
Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:
- You were conceived with the use of donor sperm, egg or embryo
- You are an Australian resident or citizen, either currently living in Australia or intending to return
- You are 16 years old or older

4. Do I have to take part in this research study?
Participation in any research study is voluntary. If you do not want to take part, you do not have to.
If you decide you want to take part in the research study, you will be asked to:
- Read the information carefully (ask questions if necessary);
- Complete the online survey.

5. What does participation in this research require, and are there any risks involved?
If you decide to take part in the research study, we will ask you to complete an online survey. The survey will ask you questions about donor conception including questions on the types of support and services you have accessed. It should take approximately 30 minutes to complete.

Once you have finished the questionnaire you may opt in for the chance to win 1 of 5 pre-paid stored value gift cards of $50 in appreciation of your time. In opting in you will provide a contact email which will not be linked to your survey or any other part of the study. At the closing of the study, the five recipients will be randomly drawn and contacted for further information to receive their gift cards.

If you experience discomfort or feelings of distress while participating in the research and you require support, you can stop participating at any time. You can also tell a member of the research team and they will provide you with assistance or alternatively a list of support services and their contact details are provided below. The student investigator may be an active member of donor-conceived peer support groups and generally within the community.

6. What will happen to information about me?
Submission of the online questionnaire is an indication of your consent. By selecting ‘I agree to participate’ Start survey’ you are providing your permission for the research team to collect and use information about you for the research study.

The research team will store the data collected from you for this research project for:
- A minimum of 7 years after the completion of the research
Appendix 4: Online participant information statement

The information about you will be stored in a:
- Non-identifiable format where your identity will be unknown.

7. How and when will I find out what the results of the research study are?
The research team intend to publish and/or report the results of the research. All information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

8. What if I want to withdraw from the research study?
If you do consent to participate, you may withdraw at any time. You can do this by closing the questionnaire. If you withdraw from the research, we will destroy any information that has already been collected. Once you have submitted the questionnaire however, we will not be able to withdraw your responses as the questionnaire is anonymous.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the UNSW Privacy Management Plan.

What if I have a complaint or any concerns about the research study?
If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

<table>
<thead>
<tr>
<th>Position</th>
<th>Human Research Ethics Coordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td>HC Reference Number</td>
<td>HC190998</td>
</tr>
</tbody>
</table>

9. What should I do if I have further questions about my involvement in the research study?
The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member(s) of the research team:

Research Team Contact

<table>
<thead>
<tr>
<th>Name</th>
<th>Giselle Newton</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position</td>
<td>Student investigator/PhD Candidate</td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
</tbody>
</table>
# Appendix 4: Online participant information statement

## ONLINE PARTICIPANT INFORMATION STATEMENT

**Seeking Someone Like Me: Activities and Intimacies among Donor-Conceived Peers**

Associate Professor Christy Newman, Ms Giselle Newton, Dr Michele Zappavigna, Dr Kirsty Drysdale

### Chief Investigator

<table>
<thead>
<tr>
<th>Name</th>
<th>Associate Professor Christy Newman</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position</td>
<td>Chief Investigator</td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td>[Redacted]</td>
</tr>
</tbody>
</table>

### Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

<table>
<thead>
<tr>
<th>Name/Organisation</th>
<th>Lifeline (free 24-hour phone support or web chat 7-12pm AEST)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web</td>
<td><a href="https://www.lifeline.org.au">https://www.lifeline.org.au</a></td>
</tr>
<tr>
<td>Telephone</td>
<td>13 11 14</td>
</tr>
<tr>
<td>Name/Organisation</td>
<td>Beyond Blue (free 24-hour phone support or web chat 3-12pm AEST)</td>
</tr>
<tr>
<td>Telephone</td>
<td>1300 22 4636</td>
</tr>
<tr>
<td>Name/Organisation</td>
<td>QLife (free LGBTI specific phone support or web chat 3-12pm AEST)</td>
</tr>
<tr>
<td>Web</td>
<td><a href="https://qlife.org.au/">https://qlife.org.au/</a></td>
</tr>
<tr>
<td>Telephone</td>
<td>1800 184 927</td>
</tr>
</tbody>
</table>
APPENDIX 5 - Online survey instrument

Thank you for your interest in participating in this survey exploring Australian donor-conceived people’s understandings of identity, community and support. This survey will take approximately 30 minutes. Please ensure you have enough time to complete all the questions.

First, we need to ask a few questions to determine whether you are eligible to participate in this survey.

Q1. Are you 16 years old or older? (Requires response)

Yes, I am 16 years old or older
No, I am under the age of 16
[No] Sorry, you are not eligible to participate in this study because you are not 16 years old or older. Thank you for considering participating this study.

Q2. Were you conceived through donor conception? (Your parents used donated sperm, eggs or embryo to conceive you.)

Yes, I was donor-conceived
No, I was not donor-conceived
[No] Sorry, you are not eligible to participate in this study because you were not donor-conceived. Thank you for considering participating in this study.

Q3. Are you an Australian resident or citizen, either currently living in Australia or intending to return?

Yes, I am
No, I am not

[No] Sorry, you are not eligible to participate in this study. Thank you for considering participating.

[PIS embedded into the page here]

Q4. By clicking the ‘I agree to participate. Start survey’ option below:

☐ I understand that I am being asked to provide consent to participate in this research study.
☐ I have read the Participant Information Sheet.
☐ I provide my consent for the information collected about me to be used for the purpose of this research.
☐ I understand that I can ask questions and the research team will respond to my questions.
☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members.

The online survey will take approximately 30 minutes to complete.
I agree to participate. Start survey
I do not agree to participate. End survey

[No] Sorry, you are not eligible to participate in this study. Thank you for considering participating.

There is a great deal of diversity among and between donor-conceived people and a range of terminology is used. For the purposes of this survey, the following list of definitions has been compiled to provide clarity around exactly what is meant by specific terms.

Definitions

Donor – a person who provides sperm or egg(s) for use by a person other than their spouse or partner for the purpose of conceiving a child (sometimes referred to as biological father, biological mother, etc.).

Donor insemination/intrauterine insemination – a practice where donor sperm is inserted into the reproductive tract without the use of In Vitro Fertilisation (IVF)

Gamete – a sperm (spermatozoa) or egg (oocyte or ovum)

IVF (In Vitro Fertilisation) cycle – a sequence of procedures where an egg is fertilised by sperm outside of the body and the resulting embryo is transferred into the uterus with the purpose of achieving a pregnancy.

Surrogacy – a practice where an individual agrees to carry a pregnancy for another individual or couple.

Traditional surrogate – an individual who carries a pregnancy and is biologically related to the child they carry

Non-traditional/gestational surrogate – an individual who carries a pregnancy and is not biologically related to the child. The child is conceived through a donated oocyte/embryo or using the intending parents’ eggs/sperm or embryo.

Demographics

Let's begin with some demographic questions.

1. What year were you born?
Drop down menu
Prefer not to answer
2005-1900

2. What was your sex recorded at birth? (i.e., the sex recorded on your original birth certificate)
Male
Female
Something else (please state)
Prefer not to answer

3. How do you describe your gender?
Appendix 5: Online survey instrument

Man/male
Woman/female
Non-binary
I use a different term: please state
Prefer not to answer

4. How do you describe your sexuality? (Select all that apply.)
Heterosexual or straight
Homosexual, gay or lesbian
Bisexual or pansexual
Queer
I use a different term: please state [open text box]
Prefer not to answer

5. What is the highest level of education that you have completed?
Primary school
Secondary school - up to Year 10
Secondary school - up to Year 12
Technical or trade certificate
College certificate/diploma
Undergraduate university degree
Postgraduate university degree
Prefer not to answer

6. Where were you born?
Australia
Overseas: please state which country

7. Are you of Aboriginal or Torres Strait Islander origin?
No
Yes, I am Aboriginal
Yes, I am Torres Strait Islander
Yes, I am both Aboriginal and Torres Strait Islander

8. Where do you currently live?
ACT
NSW
VIC
TAS
SA
WA
NT
QLD
Other country
Prefer not to say
9. Are there any other important aspects of your identity that you would like to mention? (e.g. ethnicity, disability, faith, etc.)?

Text box

**Donor conception history**

*Great! The following questions relate to your conception and the information you have. If you are unsure about any questions, that is fine. You can indicate that you are ‘unsure’ or answer with as much information as you have.*

10. In which state were you conceived? (where the implantation of gametes or embryo took place)

- ACT
- NSW
- VIC
- TAS
- SA
- WA
- NT
- QLD
- Other country: please state
- Unsure

11. To the best of your knowledge, what was your family structure at the time of your conception?

- Single mother
- Single father
- Opposite-sex parents
- Same-sex mothers
- Same-sex fathers
- Unsure
- Other: please state

12. Which donor gametes were used in your conception?

- Donated sperm only
- Donated egg only
- Donated embryo
- Donated sperm and donated egg sourced separately
- Unsure

13. To the best of your knowledge, where did the donor gametes originate from? (Where were the gametes from which you were conceived donated?)

- ACT
- NSW
- VIC
- TAS
- SA
- WA
Appendix 5: Online survey instrument

NT
QLD
Other country: please state
Unsure
Other: please state

14. To the best of your knowledge, what procedures were involved in your conception? (Select all options that apply.)
Donor insemination or intrauterine insemination (i.e. where sperm is inserted without the use of IVF or surrogacy)
IVF cycle (i.e. where an egg is fertilised by sperm outside of the body and the resulting embryo is transferred into the uterus with the aim of achieving a pregnancy)
Surrogacy (i.e. where an individual agrees to carries a pregnancy and bear a child for another individual or couple)
Other: please state
Unsure

15. [for people who said yes to surrogacy] What type of surrogacy was involved?
Traditional surrogacy (i.e. you are biologically related to the surrogate)
Non-traditional/gestational surrogacy (i.e. you are not biologically related to the surrogate)
Other: please state
Unsure

16. In what context were you conceived?
Clinical context, such as a fertility clinic, hospital or general practice (GP) clinic
   Please state the name of the facility, to the best of your knowledge:
   Text Box
Community context, such as donor insemination conducted at home
   Please provide more information on that context, to the best of your knowledge:
   Text Box
Unsure
Other: please state

17. To the best of your knowledge, at the time you were conceived what conditions were in place relating to the recording and release of information about the donor?
Non-identifying information about the donor available; donor identity never to be released (i.e. anonymous donation)
Non-identifying and identifying information about the donor available upon request after the donor-conceived person reaches maturity (e.g. identity release at 16 years or 18 years of age)
Identifying information available from time of conception; known donor (e.g. parent/s knew the donor personally)
Other: please state
Unsure

18. Where were you born?
Appendix 5: Online survey instrument

ACT
NSW
VIC
TAS
SA
WA
NT
QLD
Other country: please state
Unsure

19. What age were you when you found out you were donor-conceived? If unsure, please indicate to the best of your knowledge.
Drop down menu [always known, 1-100]

20. How, or by whom, was your donor-conceived status disclosed to you?
Mother
Father
Parents
My donor
Stepparent
Sibling/s
Friend
Other family member
Medical professional (e.g., doctor, nurse)
Commercial DNA testing service
From a government body such as Registry of Births Deaths and Marriage
Other: please state
Unsure

21. What information do you currently have relating to the donor? Select all that apply:
I have no information
Donor code
Donor name
Non identifying information received prior to/at the time of conception
Non identifying information obtained after conception (e.g., information requested from Registry of Births Deaths Marriages, clinic at which I was conceived, etc)
Medical information
Contact information
Answers to specific questions (e.g., through correspondence)
Other: please state

22. Which options are applicable to you in relation to seeking information about the donor? (select all that apply)
I have never personally sought information about my donor
I have always had information about my donor
I have unsuccessfully attempted to obtain information about my donor
I have successfully obtained some information about my donor
23. Which options are applicable to you in relation to seeking contact with the donor?
   (Select all that apply.)
I am unable to make contact with my donor
I have never personally sought contact with my donor
I have always had contact with my donor
I have successfully made contact with my donor
I have unsuccessfully attempted to make contact with my donor
Somebody else has successfully made contact with my donor (e.g., sibling, parent, etc.)
Somebody else has unsuccessfully attempted to make contact with my donor (e.g., sibling, parent, etc.)

24. How do you refer to the donor? (i.e. what name or label do you use to refer to them?)
   (Please answer both questions if applicable.)
Now: Text box
If this has changed over time, how did you previously refer to the donor? Please state: text box

25. [for people born from a surrogacy] How do you refer to the person who gave birth to you? (i.e. what name or label do you use to refer to them?) (Please answer both questions if applicable.)
Now: Text box
If this has changed over time, how did you previously refer to them? Please state: text box

26. From the information available to you, how many siblings do you know you have?
   (Please state in numerical form)
[Text box] siblings I grew up with but who are not biologically related to me
[Text box] siblings I grew up with and are biologically related to me through one parent but are not related to my donor
[Text box] siblings from the same donor that grew up in the same household as me
[Text box] donor-conceived siblings that did not grow up in the same household as me
[Text box] children raised by my donor [additional question]
[Text box] Other: please state

27. Have you ever had contact with siblings conceived with sperm/eggs from the same donor as you but with whom you did not grow up in the same household?
Yes, I had contact with donor sibling/s while I was growing up
Yes, I made contact with donor sibling/s later in life
No, I know at least one exists, I have no way of making contact, but I would make contact if I could
No, I know at least one exists, I have no way of making contact, but I wouldn’t make contact if I could
Other: please state
Unsure
Appendix 5: Online survey instrument

28. How did you initially make contact with siblings conceived with gametes from the same donor as you?
Through state donor conception registry
Through commercial DNA testing
Other: please state

29. If you had siblings conceived with gametes from the same donor as you, would you be interested in making contact?
Yes, I would be interested in making contact
No, I wouldn’t be interested in making contact
Unsure

30. [if yes to children raised by donor] Have you had contact with any children raised by the donor?
Yes, all of them that I know about
Yes, one/some of my donor's children but not others
No
Prefer not to say

31. Have you ever informed one of your siblings of their donor-conceived status?
Yes
No
Prefer not to say

Information, support and services
The next set of questions relate to information, support and services.

32. Have you had contact with other donor-conceived people? (excluding donor siblings)
Yes [go to next question]
No

33. [If yes] In which environments have you interacted with other donor-conceived people?
Offline (e.g., met in person, meet-ups for donor-conceived people, postal correspondence)
Online (e.g., social media, email)
Both

34. How important is having contact with other donor-conceived people to you?
Extremely important
Very important
Moderately important
Slightly important
Not at all important

35. Have you personally sought out information, support or services specific to donor-conceived people?
Yes
No
Prefer not to say
36. [If no] Are there any specific reasons why you have not sought out information, support or services?

Text box

37. Who in your life have you talked to about the fact that you are donor-conceived?
   (select all that apply)
I have not spoken to anybody about my donor conception
Parent/s
Donor/s
Sibling/s
Other family members
Donor’s family
Partner/Spouse
Friend
Colleague
Other donor-conceived people
Doctor or nurse
Staff from donor conception registry
Staff from fertility clinic, hospital or general practice clinic
Psychologist, psychiatrist, counsellor or therapist
Journalist or media worker
Politician or government representative
Researcher
Advocate
Other: please state

38. [yes answers from previous question display] For each person you have talked to, please indicate how useful you found talking to them.

Extremely useful
Very useful
Moderately useful
Slightly useful
Not at all useful

39. Does the state or territory where you were conceived have a donor registry?
Yes, my information was automatically included in this registry
Yes, I have voluntarily joined the registry
Yes, but I have not joined and do not wish to join
Yes, but I have not joined although I may join in the future
No, but if it did, I would join the registry
No, but if it did, I wouldn’t join the registry
Unsure if there is a registry
Unsure if there is a registry and unsure if I would join the register

40. Have you ever participated in commercial DNA testing (e.g. through Ancestry.com, 23 and Me, My Heritage, Home DNA direct or FamilyTree)?
Yes
41. Which of the following forms of donor conception related information, support and services you have accessed? (Select all that apply)

- Counselling or other forms of mental health support
- State government or authority website aimed at donor-conceived people (eg. VARTA website, WA Health website, NSW Health website)
- Face-to-face meet-ups for donor-conceived people (e.g. network meetings, support groups, etc)
- Guidance on navigating DNA platforms
- Guidance on how to access information relating to conception
- Guidance on making contact with donors, donor siblings or other genetic relatives
- Written history of the laws and practices associated with donor conception in all states of Australia
- Resources such as books, documentaries, films and research on donor conception

Other: please state

42. [People who said yes to face-to-face meetup] How many times have you been to a face-to-face meet-up for donor-conceived people?
- Once
- Irregularly, as needed
- Regularly and continued
- Regularly but ceased

43. Please describe your (positive or negative) experiences in attending face-to-face meet-ups

Text box

44. [if no to face-to-face] If you could access face-to-face meet-ups for donor-conceived people where you currently live, would you access them?
- Yes
- No
- Unsure

45. [People who said yes to websites] Please state which state government or authority website you have accessed and describe your (positive or negative) experience with those websites

Text box

46. Prior to starting this survey, had you ever participated in research on donor conception?
- Yes
- No

47. Which forms of online/social media platforms have you ever used to connect with other donor-conceived people? Tick all that apply
- None, I have never used online media to connect with other donor-conceived people
- Email groups
- Online forums
- Facebook
Appendix 5: Online survey instrument

Facebook messenger
Facebook groups
Twitter
Instagram
Tumblr
Reddit
WhatsApp group
Youtube
Blogs
Other: please state

48. In general, how important do you think it is that donor-conceived people have access to each form of information, support or services?

- Very important
- Important
- Neither important nor unimportant
- Unimportant
- Very unimportant

Donor conception registries
Counselling or other forms of mental health support
State government or authority website aimed at donor-conceived people (e.g., VARTA website, WA Health website, NSW Health website)
Online/social media platforms for donor-conceived people (e.g., email lists, forums, Facebook groups)
Face-to-face meet-ups for donor-conceived people (e.g. network meetings, support groups, etc)
Commercial DNA testing
Guidance on navigating DNA platforms
Guidance on making contact with donors, donor siblings or other genetic relatives
Written history of the laws and practices associated with donor conception in all states of Australia
Resources such as books, documentaries and films on donor conception
Research on donor conception

49. Are there any forms of information, support or services for donor-conceived people that do not currently exist that you think should exist?

Text box

50. Have you ever taken action to change information, services or laws regarding donor conception? Select all that apply

- Never
- Participated in reviews of legislation at a state level
- Participated in the national inquiry into donor conception
- Engaged directly with state registry for donor-conceived people
- Engaged directly with clinic or hospital
- Engaged with politicians
- Engaged with media
- Other: please state
Appendix 5: Online survey instrument

51. [For those who selected at least one option] Please describe your motivations for and (positive or negative) experiences with participating in changing information, services or laws

Attitudes towards current information, support and services available

*In the following questions you will be asked about your opinions. There are no correct answers.*

52. In your opinion, how important are information, support and services on donor conception to donor-conceived people’s health and wellbeing?
- Extremely important
- Very important
- Moderately important
- Slightly important
- Not at all important
- Unsure

53. In your opinion, do state and territory governments currently provide enough information, support, and services for donor-conceived people?
- Yes
- No
- Unsure

54. In your opinion, do donor-conceived people currently have sufficient opportunities to participate in the development of programs and services for donor-conceived people?
- Yes
- No
- Unsure

55. In your opinion, how important is it that donor-conceived people are involved in the design and delivery of policy, programs and services for donor-conceived people?
- Extremely important
- Very important
- Moderately important
- Slightly important
- Not at all important
- Unsure

56. In your opinion, how important is it that online/offline groups for donor-conceived people are facilitated/moderated by donor-conceived people?
- Extremely important
- Very important
- Moderately important
- Slightly important
- Not at all important
- Unsure

57. In your opinion, how important is it that donor-conception registers include optional DNA testing to supplement information or confirm connections?
- Extremely important
Questions on donor conception as a practice

58. In your opinion, how important is it that all donor-conceived people are informed that they were donor-conceived?

Extremely important
Very important
Moderately important
Slightly important
Not at all important
Unsure

59. In your opinion, how important is it that all donor-conceived children are told that they were donor-conceived as early as possible?

Extremely important
Very important
Moderately important
Slightly important
Not at all important
Unsure

60. In your opinion, how important is it that donor-conceived status is recorded on an addendum (additional material added at the end) of birth certificates?

Extremely important
Very important
Moderately important
Slightly important
Not at all important
Unsure

61. In your opinion, what should the limit be on the number of people who can be conceived from gametes sourced from the same donor?

[Drop down box none-100] children

62. In your opinion, how important is it that there are limits on how many children a single donor can produce?

Extremely important
Very important
Moderately important
Slightly important
Not at all important
Unsure
63. In your opinion, how acceptable is it to provide a financial payment in exchange for donor gametes, such as donor sperm, donor eggs, or embryos?
Totally acceptable
Acceptable
Neither acceptable nor unacceptable
Unacceptable
Totally unacceptable
Unsure

64. In your opinion, how acceptable is it to provide financial reimbursement to donors for the reasonable, verifiable, out-of-pocket expenses they incurred in providing gametes?
Totally acceptable
Acceptable
Neither acceptable nor unacceptable
Unacceptable
Totally unacceptable
Unsure

65. In your opinion, how acceptable is it to import donor gametes from outside Australia?
Totally acceptable
Acceptable
Neither acceptable nor unacceptable
Unacceptable
Totally unacceptable
Unsure

66. In your opinion, how acceptable is it to travel overseas with the intention of conceiving through the use of donor gametes which have been acquired abroad?
Totally acceptable
Acceptable
Neither acceptable nor unacceptable
Unacceptable
Totally unacceptable
Unsure

DNA specific questions (for people who said they had DNA tested)

Now, please answer a few questions relating to your experiences with commercial DNA testing.

67. Which companies have you undertaken DNA testing with and/or transferred DNA data to? (Tick all that apply)
Ancestry.com
23 and Me
My Heritage
FamilyTree
Home DNA direct
Other: please state
Unsure
68. Was your main motivation for participating in DNA testing to find out more information associated with the donor?
Yes
No
Unsure

69. Which, if any, genetic relatives have you ‘matched’ with through commercial DNA testing? (Select all that apply.)
My donor
My donor sibling
Donor’s children
Donor’s siblings
Donor’s parents
Genetic relatives who are not connected to the donor
None of the above
Other: please state

70. How important has commercial DNA testing been in providing you with access to information about yourself not available through other means?
Extremely important
Very important
Moderately important
Slightly important
Not at all important
Unsure

71. Did you consider any privacy risks before engaging in commercial DNA testing?
Yes
No

72. How concerned are you about the way commercial DNA companies may use or share your personal data?
Extremely concerned
Very concerned
Moderately concerned
Slightly concerned
Not at all concerned
Unsure

73. Please describe your motivations for and (positive or negative) experiences with commercial DNA testing
Text box

Facebook group specific questions (for people who said they had used FB groups)
You're nearly finished! Please answer a few questions on your experiences with Facebook groups for donor-conceived people.
74. Have you ever held an administrator/moderator role in a Facebook group for donor-conceived people?

Yes
No

75. In Facebook group/s for donor-conceived people, how often do you read other people’s posts?
Multiple times per day
Daily
A few times per week
Weekly
Monthly
When I need something specific
Never
Other: please state

76. In Facebook group/s for donor-conceived people, how often do you react to other people’s posts with likes/other reactions?
Multiple times per day
Daily
A few times per week
Weekly
Monthly
Never
Other: please state

77. In Facebook group/s for donor-conceived people, how often do you comment on other people’s posts?
Multiple times per day
Daily
A few times per week
Weekly
Monthly
Never
Other: please state

78. In Facebook group/s for donor-conceived people, how often do you post things yourself?
Multiple times per day
Daily
A few times per week
Weekly
Monthly
When I need something specific
Never
Other: please state

In the following questions state how much you agree or disagree with the statements.

79. “Facebook groups for donor-conceived people are safe spaces to discuss experiences relating to donor conception”
Appendix 5: Online survey instrument

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

80. “People in Facebook groups for donor-conceived people take my experiences seriously”
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

81. “The other donor-conceived members of Facebook groups for donor-conceived people care about me”
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

82. “I feel supported in Facebook groups for donor-conceived people”
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

83. “I take other donor-conceived people’s experiences seriously”
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

84. “I provide support to other donor-conceived people in Facebook groups for donor-conceived people”
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

85. Please describe your (positive or negative) experiences of participating in a Facebook group for donor-conceived people.

Text box

Closing
You've reached the final set of questions.

86. Where did you find out about this study? (Please select more than one option if applicable.)
- Friend/family member
- Organisation or service: please state
- I received an email or message about it
- Facebook ad
- Facebook group
- Twitter
- Other social media
- Other: please state

87. Is there anything else that you would like to tell us that hasn’t been covered in the survey? If so, please let us know below.
[Open text]

88. Would you like to be contacted to participate in a one-on-one interview about Facebook groups for donor-conceived people? (Your email address will be stored separately to your survey responses and cannot be used to identify you.)
- Yes
- No

89. [If yes] You have indicated that you would be interested in participating in a one-on-one interview about Facebook groups for donor-conceived people.

Please record your contact details below.

What is your email address?
What state do you live in?

90. Would you like to be sent updates about the outcomes and publications from this research?
- Yes
- No

91. To be sent updates about the study, please record your contact details below. Your email address will be stored separately to your responses and cannot be used to identify you.

Email address:

Gift Voucher Draw

92. Would you like to enter the draw to win one of five $50 gift vouchers? If you decide to enter, you will be directed to a separate link to leave your contact details. Your name and email will be stored separately to your response and cannot be used to identify you.
Appendix 5: Online survey instrument

Yes, take me to the Gift Voucher Draw
No

[Separate Qualtrics survey]

Please enter your email address to enter the draw to win one of five $50 gift vouchers. Winners will be contacted by email to collect their prize.

Final Text
Thank you for participating! Your response has now been recorded.

Please contact Giselle Newton g.newton@unsw.edu.au if you have further questions or comments.
Please refer to the study website for information and resources at dcrestudy.org
APPENDIX 6 - Semi-structured interview participant information statement and consent form

1. What is the research study about?
You are invited to take part in this research study because you are a donor-conceived person. The research study aims to explore donor-conceived people’s understandings of identity, community and support in online and offline environments. We’re looking for donor-conceived people who participate in Facebook groups on donor conception to take part in an interview about online communities and support.

2. Who is conducting this research?
The study is being carried out by the following researchers: Associate Professor Christy Newman, Dr Kerryn Drysdale and Ms Giselle Newton (PhD candidate/student researcher), Centre for Social Research in Health, and Dr Michele Zappavigna, School of Arts and Media, UNSW Sydney.

Research Funder: This research is being funded by the Centre for Social Research in Health, supported by the Australian Government Department of Health.

3. Inclusion/Exclusion Criteria
Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:
- You were conceived with the use of donor sperm, eggs or embryo
- You are an Australian resident or citizen, either currently living in Australia or intending to return
- You are 18 years or over
- You have participated in Facebook groups for donor-conceived people

Do I have to take part in this research study?
Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:
- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

4. What does participation in this research require, and are there any risks involved?
If you agree to participate you will be asked to complete the following research procedures. In the face to face interview, you will be asked questions about donor conception, support services you have accessed, and about your participation in Facebook groups for donor-conceived people. Interviews will be arranged to take place at the Centre for Social Research in Health, UNSW, at community organisation offices (subject to permission) or in a public place like a university library meeting room. If you cannot participate in a face-to-face interview due to your location or reduced mobility, we may facilitate a Zoom or telephone interview with you. The interview will take approximately one hour. With your permission the research team would like to audio record the interview. If you do not wish to be recorded but you would like to participate, you can advise the research team and written notes will be taken.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you be paid. However, you will receive a $30 voucher to reimburse you for any reasonable travel, parking, meals and other expenses while completing the interview. The voucher
Appendix 6: Semi-structured interview participant information statement and consent form

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers
Associate Professor Christy Newman, Ms Giselle Newton, Dr Michelle Zapavigna, Dr Keryn Drysdale

will be provided to you in-person following the interview, or via regular mail following Skype/telophone interviews.

Psychological Distress: You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a number of free contactable support services are included at section 9. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

5. What will happen to information about me?
By signing the consent form, you consent to the research team collecting and using information about you for the research study.
The research team will store the data collected from you for this research project for:
• A minimum of 7 years after the completion of the research;
The information about you will be stored in an/a:
• Non-identifiable format where your identify will be unknown.
• Information collected from you in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
• Information collected from you using paper-based measures will be stored on Level 3, John Goodsell Building, Centre for Social Research in Health, UNSW Kensington and only the approved research investigators will have access to this information.
• Audio recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators and will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the UNSW Privacy Management Plan.

6. How and when will I find out what the results of the research study are?
The research team intend to publish and report the results of the research. All information will be published in a way that will not identify you.
If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

7. What if I want to withdraw from the research study?
If you do consent to participate, you may withdraw at any time. You can do so by completing the ‘Withdrawal of Consent Form’ which is provided at the end of this document or you can ring the research
Appendix 6: Semi-structured interview participant information statement and consent form

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
Seeking Someone Like Me: Affiliations and Interactions among Donor-Conceived Peers
Associate Professor Christy Newman, Ms Giselle Newton, Dr Michele Zappavigna, Dr Kerry Drysdale

Team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

8. What if I have a complaint or any concerns about the research study?
If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

<table>
<thead>
<tr>
<th>Position</th>
<th>UNSW Human Research Ethics Coordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td>HC Reference</td>
<td>[HC reference number TBC]</td>
</tr>
<tr>
<td>Number</td>
<td></td>
</tr>
</tbody>
</table>

9. What should I do if I have further questions about my involvement in the research study?
The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following members of the research team:

Research Team Contact Details

<table>
<thead>
<tr>
<th>Name</th>
<th>Giselle Newton</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position</td>
<td>Project Manager, PhD Candidate</td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
</tbody>
</table>

Chief Investigator

<table>
<thead>
<tr>
<th>Name</th>
<th>Associate Professor Christy Newman</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position</td>
<td>Chief Investigator</td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
</tbody>
</table>

Support Services Contact Details
If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

<table>
<thead>
<tr>
<th>Name/Organisation</th>
<th>Lifeline (free 24-hour phone support or web chat 7-12pm AEST)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web</td>
<td><a href="https://www.lifeline.org.au">https://www.lifeline.org.au</a></td>
</tr>
<tr>
<td>Telephone</td>
<td>13 11 14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name/Organisation</th>
<th>Beyond Blue (free 24-hour phone support or web chat 3-12pm AEST)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web</td>
<td><a href="https://www.beyondblue.org.au">https://www.beyondblue.org.au</a></td>
</tr>
<tr>
<td>Telephone</td>
<td>1300 22 4636</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name/Organisation</th>
<th>QLife (free LGBTI specific phone support or web chat 3-12pm AEST)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web</td>
<td><a href="https://qlife.org.au">https://qlife.org.au</a></td>
</tr>
<tr>
<td>Telephone</td>
<td>1800 184 527</td>
</tr>
</tbody>
</table>
Appendix 6: Semi-structured interview participant information statement and consent form

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers
Associate Professor Christy Newman, Ms Giselle Newton, Dr Michelle Zappavigna, Dr Kerryn Drysdale

Consent Form – Participant providing own consent

Declaration by the participant
- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- Recordings: I understand that the research team will audio record the interviews; I agree to be recorded for this purpose;
- I provide my consent for the information collected about me to be used for the purpose of this research study only;
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.
- I understand that I will be given a signed copy of this document to keep.
- I understand that the results of the research will be made available on the Centre for Social Research in Health website.
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: ____________________________
Address: ____________________________
Email Address: ____________________________

Participant Signature
- Name of Participant (please print): ____________________________
- Signature of Research Participant
- Date ____________________________

Declaration by Researcher*
- I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*
- Name of Researcher (please print): ____________________________
- Signature of Researcher
- Date ____________________________

*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.

Note: All parties signing the consent section must date their own signature.
Appendix 6: Semi-structured interview participant information statement and consent form

Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with UNSW Sydney.

I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
APPENDIX 7 – Semi-structured interview verbal consent script

1. Introduction
   I am Giselle Newton, from the Centre for Social Research in Health at UNSW, Sydney. I am conducting a research study about donor-conceived people's understandings of identity, community and support in online and offline environments.

2. Invitation
   I would like to invite you to participate in this research study. Before we go any further I need to let you know that participation in this research study is voluntary. If you do not want to take part, you do not have to. Are you happy for me to provide you with further information on the research study?
   ☐ If no, thank the participant for their time and end the consent process.
   ☐ If yes, proceed with the following information.

3. Description of participation
   If you decide to take part in the research study, we will ask you questions about identity, community and support in online and offline environments. It should take approximately one hour to complete. We don’t expect the interview to cause any harm or discomfort, however if you experience feelings of distress as a result of participation in this study you can let the research team know and they will provide you with assistance.

4. Data storage and use
   During the research study we will collect information from you relevant to this research study. Any information we collect from you will be stored in a way that will not identify you. The perspectives you share with us verbally will be audio recorded, then transcribed and deidentified, so that the final interview data can not be used in any way that might identify you. We will also collect basic demographic data, but that that information will be used only to describe the characteristics of the whole participant group, and will not be linked to the data. Any information we include in research publications, will not identify you. Your data will be kept for 7 years after the project’s completion.

5. Withdrawal from the research
   If you decide to leave the research study, we will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Australia.

6. Questions
   Do you have any questions in regards to the information that I have provided?
   ☐ If yes, answer any questions the participant may have
   ☐ If no, continue to collect consent.
   If you would like, I will send you an email/letter containing the details of the person for you to contact if you have any questions or complaints about the research study.

7. Consent
   Now that I have explained what your involvement in the research study requires, are you happy to provide your consent to participate in the study?
   ☐ If no, thank the participant for their time and end the consent process.
Appendix 7: Semi-structured interview verbal consent script

INTERVIEW VERBAL CONSENT SCRIPT
Seeking Someone Like Me: Affinities and Intimacies among Donor-Conceived Peers

☐ If yes, ensure you record the time and date the verbal consent was collected from the participant. Furthermore, you will need to ask the participant if:

  o they would like a copy of the participant information sheet sent to them;
  o They are happy to be audio recorded (if applicable to the study).

→ Commence with data collection.
APPENDIX 8 - Semi-structured interview guide

Participant background
To start, can you tell me a little bit about yourself?
Can you tell me how you found out you were donor-conceived?

Family
Can you describe the family you grew up in?
If knew as a child Thinking back to your childhood and adolescence, how did you feel about being donor-conceived? If didn’t know Do you have any ideas about why your parent/s didn’t talk to you about your donor conception in childhood/adolescence?

Information, formal services
What kinds of information did your parents give you about your conception?
Can you tell me about what you have done to find out anything additional about your conception?
If you met someone who was donor-conceived, and they asked you about where to go for information, advice or support, what would you tell them?
What kind of support do you think DC people need?

Peers
Do you know any other donor-conceived people? Is this important to you?

Social Media and Facebook groups
How important is social media to you, in terms of being donor-conceived?
Which Facebook groups related to donor conception are you in? How are they different?
Do you remember when and how you first found out about the group?
Talking about the group more generally, what kinds of topics are discussed? Which topics gain the most responses?
Are you aware of any tensions in the group? How have they been apparent? How have they been resolved, if they have?
Do you know if the group has explicit or implicit rules/guidelines?

Role as an admin [Optional if Admin of FB group]
How did you become an administrator?
Why did you take on this role?
What is your role as administrator of the group?
Appendix 8: Semi-structured interview guide

What are important aspects of being an admin?

How is your relationship with the other admins? How do you divide the labour?

How much time do you spend on running the group?

How do you decide who can join?

What are the rules governing the group? How do you enforce them?

Would you mind searching back to your first post in the group and telling me about what was happening around that time for you? *search for name and scroll back to first post*

Can you tell me about how you first contributed yourself? When and how did that happen?

What were your first impressions of the group? What did you think about the posts you read there?

How have you used the group since then?

How often do you see posts (prompts: come up in feed all the time, or check specifically on occasion, only look when want to find info/post)?

What kinds of posts do you tend to reply to, with comments or reactions?

Has the group helped you deal with any challenges, or given you advice you have valued?

Have you ever made a decision (big or small) based on information or opinions offered by the group?

How does it feel to be connected to other donor conceived people?

How do you feel about other people in the group?

Do you think people care about each other?

Do you trust other people in the group?

Do you feel like the other group members are your friends? How would you describe them if not?

Have you met in person anyone you met originally through this online group?

Have you referred anyone you know offline to the group?

Do you think that your experience of this group has influenced your experience of being donor conceived?
What difference would it make in your life if the group disappeared overnight?

**Facebook groups in general and during covid-19**
Are you part of non-DC FB groups?

What are the advantages/disadvantages of online support?

During COVID-19 what do you think has been learnt or will be learnt about online support?

**DNA testing**
Have you participated in direct-to-consumer DNA testing?

How did you hear about direct-to-consumer DNA testing?

If yes What were your motivations for participating in direct-to-consumer DNA testing?

If yes Did you think about matching with potential siblings or a potential donor? Was it something you were aware of at the time?

What does DNA testing offer donor-conceived people?

**Advocacy/Activism**
Have you ever taken action to change information, services or laws regarding donor conception?

Could you tell me about how you have been involved in advocacy or activism related to donor conception over the years?

Do state and territory governments currently provide enough information, support, and services for donor-conceived people?

What responsibility do governments have to donor-conceived people?

How important is it that donor-conceived people are involved in the design and delivery of policy, programs and services for donor-conceived people?

What motivates you to want to change laws, policy, practice in donor conception?

What barriers are there to achieving change?