Committee Secretary
Legal Affairs and Safety Committee
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28th April 2022

Dear Committee Secretary

Re: Inquiry into Matters Relating to Donor Conception Information

Thank you for the opportunity to provide a submission to the **Inquiry into Matters Relating to Donor Conception Information**. I congratulate the state of Queensland for taking the first step into better understanding past and present donor conception practices.

I write to you as a donor-conceived person, member of peak body Donor-Conceived Australia (DCA), member of delegation of donor-conceived people to the 2019 United Nations Anniversary of the Convention of the Rights of the Child (UN Presentation Committee on Donor Conception, 2019; see Appendix B) and researcher conducting a study on Australian donor-conceived people's experiences, perspectives and support needs which is nearly complete after three and a half years of study (2019-2022) (see Newton et al., 2020). Over the last three years I have conducted 28 interviews, collected 91 survey responses and drawn on Hansard data from the 2010 Senate Committee Inquiry for my analysis of donor-conceived people's experiences. My findings from this study have been published in three peer-reviewed journal articles and two peer-reviewed book chapters to date (see Newton, 2022, forthcoming; Newton, Drysdale, et al., 2022; Newton, Zappavigna, et al., 2022; Newton & Southerton, 2021). As such, my recommendations to this inquiry are informed by my lived experience, advocacy and professional expertise.

My submission addresses the following issues:

a. Rights of donor-conceived persons, including to know their genetic origins;
b. Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;
c. Access to historical clinical records and implications of retrospectivity;
d. Access to support and counselling for donor-conceived persons and donors;
e. Whether a register should be established; and

(a) Rights of donor-conceived persons, including to know their genetic origins, and (b) Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors

Disclosure

After many decades of silence, secrecy and shame in relation to donor conception, there is now a robust and growing literature demonstrating 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, mistrust and deceit (Jadva et al., 2009; Lampic et al., 2022; Turner & Coyle, 2000) and can cause forms of distress and identity disruption (Crawshaw, 2018; Daniels, 2020; Macmillan et al., 2021). In instances in which donor-conceived people have not had this information disclosed to them from their parent/s, there is a very real and increasing possibility that donor conception status will be accidentally discovered through other means such as from family or friends of the family, or through direct-to-consumer DNA testing (Crawshaw, 2018; Darroch & Smith, 2021; Frith et al., 2018; Harper et al., 2016; Klotz, 2016; Newton, Drysdale, et al., 2022; We Are Donor Conceived, 2020). Further, late disclosure can have serious consequences for donor-conceived people such as risk of consanguineous relationships or health issues that may arise from limited or incorrect medical and genetic information.

Birth certificates

It is therefore paramount that donor conception status be included on donor-conceived people's birth certificates from the instance of first issue. Research has demonstrated that parents can experience significant barriers to disclosing donor conception status and while they may intend to disclose early, they often delay, avoid or omit conception information from their child (Lassalzede et al., 2017; Tallandini et al., 2016). It is unclear how inclusion of donor conception status on birth certificates may influence disclosure decisions however, it is likely that disclosure will more often occur earlier if this information is accessible to children on their birth certificate from birth. Early disclosure, i.e. from birth, is in the best interests of the donor-conceived person.

Information & Contact

The right to know one's parentage is clearly articulated in the Convention of the Rights of the Child, articles 7-9 (United Nations, 1989). According to this international legislation all donor-conceived people should be entitled to identifying information about donors (biological parents). Evidence clearly demonstrates that the majority of donor-conceived people view any information about their donors as important and relevant (Blyth, 1998; Rodino et al., 2011) and that most desire contact with their donor and donor siblings (Beeson et al., 2011; Dempsey et al., 2019; Macmillan et al., 2021; Nelson et al., 2013). Similarly, many donors are interested in learning about and making contact with donor-conceived people born as a result of their gamete donations, and others may change their views on their original desire for 'anonymity' over the years (Bolt et al., 2019; Indekeu et al., 2021; Klipstein et al., 2020). Recognising donor-conceived people's 'right to know' also aligns with international legislation recognising donor-conceived people's (Allan, 2017; UN Presentation Committee on Donor Conception, 2019; Unicef, 1989), see Appendix B.

After significant advocacy from donor-conceived people and their allies, Victoria centred donor-conceived people's rights in "Narelle's Law" Assisted Reproductive Treatment Amendment Act 2015 (Vic.). Recently, South Australia, built on this legislation by emphasising the governing principle in the Reproductive Treatment (Donor Conception Register) Amendment Bill 2021: "the welfare of the person born as result of the provision of assisted reproductive treatment is to be of paramount importance and a fundamental principle in the operation of the Act" as described in the associated discussion paper (p.3). The progressive attitudes behind this legislation are also further reflected in the aims to: "normalise donor conception, to validate a person's donor conception story and to encourage openness about the practice" (p.3). As such, it is clear that the rights of donor-conceived people must be prioritised in Queensland line with other states of Australia.

I am strongly opposed to the introduction of contact vetoes as a measure to appease an arguably small portion of donors. Past donors are protected by other legislation from any criminal offences and there is no evidence to suggest donor-conceived people pursue unwanted relationships with their biological family members (Klotz, 2016). Scholars have stated that "donor anonymity does not exist" and secrecy and privacy is "utopian" in the age of direct-to-consumer DNA testing, with features such as 'relative finder' (Harper et al., 2016, p. 1135; Macpherson, 2019, p. 1847). Today, donors can be identified via centimorgans including when they themselves have not engaged in direct-to-consumer DNA testing (see also Appendix A).

(c) Access to historical clinical records and implications of retrospectivity

Currently in many jurisdictions, donor-conceived people's rights are not uniform and differ depending on year and location of conception. As such, there are tiers of donor-conceived people, the "haves" and "have nots". Retrospective legislation is essential to permit access to historical clinical records for all.

If it is found that destruction or modification of donor conception records has occurred in Queensland, as has been anecdotally suggested, a general public apology should be issued, coupled with individual apologies to those affected by past malpractice. These steps are essential to ensure harm and wrongdoings are acknowledged and learnt from, and in order to pave the way for a new era in donor conception in Queensland.

As I am sure this inquiry will make clear, donor conception has been, and continues to be an under-regulated, for-profit industry. A range of unethical practices such as sperm mixing to confuse paternity, use of physician sperm without patient consent, and meddling with medical records have occurred (Adams & Lorbach, 2012; Dingle, 2021; Hewitt, 2002; Rowland, 1985). Unsurprisingly, many donor-conceived people have significant distrust towards these medical institutions, that is yet to be repaired (Newton, Drysdale, et al., 2022) (see Appendix A).

(d) Access to support and counselling for donor-conceived persons and donors

Anecdotal evidence suggests that clinics in Queensland have required donor-conceived people to pay for mandatory counselling in order to access information about their conception and/or contact their biological family members. This misconduct from clinics should be reviewed and acted upon.

It is essential that optional ongoing services and support exist for donor-conceived people. The following services/supports are necessary:

- Free optional counselling delivered by a qualified and experienced professional and in instances where people with lived experience are qualified, these professionals be recommended.
- Detailed information about direct-to-consumer DNA testing and support in navigating testing, for example, from a genealogist.
- A detailed website containing up-to-date information, FAQs, resources, stories and testimonials.
- Peer network meetings with paid lived experience facilitator.
- Webinars/information sessions for parents of donor-conceived people focused on why/how to disclose donor conception status to children (see VARTA, 2021).

(e) Whether a register should be established

Where a national register cannot be established, it is critical that each state and territory in Australia have independent, digitalised, centralised registers to oversee records on donor conception. Reform in legislation is necessary so that those practicing donor conception in a private setting be obliged to record the conception on the register to ensure sibling limits and access to information be upheld. A user-pays model should be avoided, however, in the case that such an approach be selected, in no circumstance should donor-conceived people themselves be required to pay to access information or services.

It is essential that the register function in cooperation with interstate and international bodies. There is substantial evidence that since the early days of donor conception in Australia, gametes have been sent between states (Dobby, 2010). This is also clear from my own experience: I was conceived in the Northern Territory from sperm donated and sent from Western Australia. Additionally, donor-conceived people move between states and overseas throughout their lifetime. Today cryopreservation and storage of gametes, and reproductive tourism is commonplace. Given the challenges in the domestic context, importation and use of international gametes for use in Australia should not be permitted. 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.

It is essential that statistical information about the register be made available to the public via an annual report (see for example VARTA, 2021). This 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.

Ongoing and meaningful engagement with people with lived experience is essential to the success of a register. Multiple scholars have noted that donor-conceived people possess a wealth of expertise and knowledge, and are well-placed to guide policy and practice (Blyth, 1998; Daniels, 2020; Rodino et al., 2011). This should occur via initiatives that align with consumer participation principles, such as the formation of an advisory committee of people with lived experience, in which members are consulted and compensated for their time and expertise.

I urge the Queensland government to prioritise an evidence-based approach which champions the rights of donor-conceived people!

I would be happy to elaborate further including at the hearing, if that would assist the Committee in its deliberations.

Yours sincerely,

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Legislation

Assisted Reproductive Treatment Amendment Act 2015 (Vic.)

Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021 (S.A).

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

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.

Keywords

Australia, DNA, donor conception, family, genetics, identity, qualitative

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 early 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 rolled out 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 and 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; Nordqvist, 2021). 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, 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 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 that 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). 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: 679). 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 unexpectedly reshape or reinforce individuals' sense of identity, both in terms of biological relationships and membership to collective identities (Gibbon and Novas, 2008; Postan, 2016; Rabinow, 1996; Rose, 2009). While information facilitated by DNA testing is often positioned and/or experienced as objective (Lee and Voigt, 2020; Lindee, 2008), DNA testing offers genetic narratives about familial connectedness, which may prove valuable in familial narratives. Scholarship by 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 and Voigt, 2020: 434, emphasis in original)?

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 and 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 and Lorbach, 2012; Crawshaw et al., 2016; Darroch and Smith, 2021; Harrigan et al., 2015; Newton and 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, DNA testing, coupled with experiential knowledge from peers, mark 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 and 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 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, first to address the limited existing evidence base on Australian donor-conceived adults' experiences, and second, 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., 2021; 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 16 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 18 years old and members of 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 and 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 and 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 two 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 18% (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% 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% 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 emo- tional 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 and Voigt, 2020: 441).

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). This 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 perceived 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
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> . . . 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 and 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). This response illustrates that participants were influenced by collective attitudes towards DNA testing as a viable means of accessing information. In this way, DNA testing was legitimated, 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 also 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 him to contact Leah:

> To get that email was like, 'Oh my God!' Like it was really surreal and really just out of the blue. And it, but really nice that he was, yeah, quite warm in his email and not, yeah, 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 their genetic family members were out of reach. This points to the limits to the 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 and Voigt, 2020; Postan, 2016). This article aligns with scholarship on how genetic information has the potential to (re)shape identity (Gibbon and Novas, 2008; Lee and 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 and 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. As such, *who counts* as family is negotiated by individuals, and so DNA testing alone is unable to resolve this question (Lee and 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 the 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 that has begun to identify the range of ways DNA testing is reshaping the meanings of family and identity for donor-conceived people (Crawshaw, 2018; Frith et al., 2018; Klotz, 2016; Macmillan et al., 2021; Newton et al., 2022). 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), 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 method 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 socio-technical webs. In many respects, DNA testing is the 'technology of belonging' articulated by Lee and 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 'post-truth' 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 that impact upon a community's trust in both new and old institutions such as family, medicine and DNA testing services.

Acknowledgements

The research would not have been possible without the donor-conceived people who participated in our study and shared their experiences. I am so grateful for your time and contributions to this research. Thank you to James MacGibbon for advice associated with the survey. Thank you to A/Prof Emma Kirby for discussing an earlier version of this article and for title inspo.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: Giselle Newton is supported by an Australian Government Research Training Program Scholarship.

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Appendix B: International Principles for Donor Conception and Surrogacy

https://www.change.org/p/united-nations-making-humans-international-principles-for-donor-conception-and-surrogacy

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International Principles for Donor Conception and Surrogacy

Purpose:

The International Principles for Donor Conception and Surrogacy (the Principles) have been drafted to provide minimum standards for laws and practice in Nation States where surrogacy and/or donor conception are already permitted or tolerated. The Principles require strict regulation of such practices to uphold the human rights and best interests of people born as a result, in accordance with the principles universally agreed to by Member States as per the United Nations Convention on the Rights of the Child (UNCRC), the most successful human rights treaty in history.

Background:

Donor conception is the commonly used term for the practice of intending parents using third party gametes (such as third party sperm, egg or embryos) to create their own child(ren).

Donor conception also applies to people who are born via surrogacy arrangements, where one or more gametes do not come from the intending parents. These surrogacy-born people are also donor-conceived. The birth mother in surrogacy may or may not be related to the child she carries and births, but she is always also important to the person born as a result.

The Principles are based on the recognition that regardless of the type of assisted reproduction used, all donor-conceived people and people born of surrogacy have a fundamental human right to their full and true identity, a right to preserve relations with their families, and a right not to be bought or sold as enshrined in the UNCRC and other international instruments.

The Principles originally arose out of a presentation by the drafters at the Conference on the 30th anniversary of the UNCRC, at the Palais des Nations, Geneva, November 19, 2019. They are informed by the lived experience of the drafters as donor-conceived. They respond to practices past and present that have impacted and/or continue to impact their lives. Many feel that they are the products of an international industry in human eggs, sperm, embryos and wombs which profits from human life – their lives. Yet as of this writing there is no jurisdiction in the world that fully protects the human rights of donor-conceived or surrogacy-born people despite all UN Member States having signed, and all but one having ratified, the UNCRC.

The Principles are also informed by extensive engagement by the drafters in advocacy on behalf of their community at local, national and international levels, and examination of laws and policy that directly impact them and their genetic, social and gestational families. In addition, the drafters draw upon their professional legal, communications, policy, social services, scientific and other qualifications and experience to inform their work.

In drafting the Principles, it is recognised that many countries maintain prohibitions on assisted reproduction including surrogacy and/or donor conception, as contrary to their values and the human rights of men, women and children. The Principles are not intended to be used to condone, widen or to encourage such practices . Rather, they are intended to set minimum standards that should be adhered to by nations that already permit such practices, and to require strict regulation where such practices occur. They are relevant to all donor-conceived people, including those born of surrogacy – past, present, and future.

Former and current initiatives to formulate policy and/or principles on donor conception and surrogacy by government agencies and not-for-profits are unacceptable. They have failed to adequately consult with donor-conceived and surrogacy-born people. They often choose to ignore the voices of donor-conceived and surrogacy-born people who do not support certain practices in favour of the interests of the fertility industry and intending parents. All policy-making, both national and international, henceforth must include meaningful consultation with a broad representation of donor-conceived and surrogacy-born persons in recognition that the people created by reproductive technology are overwhelmingly those most affected by it. These voices need to be heard, listened to, and acted upon.

We call upon all governments, agencies, and lawmakers to hear directly from this constituency, to recognise the rights of donor-conceived and surrogacy-born people and to enact laws that uphold and implement the following principles.

The Principles:

Best Interests and Human Rights of the Child Paramount

1. The best interests and human rights of the child who will be or has been born as a result of donor conception and/or a surrogacy arrangement must be the paramount consideration in all relevant laws, policies and practices and in any judicial and administrative decisions relating to donor conception and surrogacy.

Pre-Conception Screening and Post-Birth Review

2. Pre-conception assessments and screening of donors, intended parents and potential surrogate mothers and post-birth review of the best interests and human rights of the child born as a result must occur in every case of surrogacy and donor conception.

The Right to Identity and to Preserve Relations

3. All donor-conceived and surrogacy-born people have an inalienable right to identifying information about all of their biological parents, regardless of when or where they were conceived or born.

4. All donor-conceived and surrogacy-born people have an inalienable right to identifying information about all of their biological siblings, be they half or full siblings, regardless of when or where they were conceived or born.

5. All surrogacy-born people have an inalienable right to identifying information about their surrogate mother, regardless of when or where they were conceived or born.

6. All donor-conceived and surrogacy-born people have the right to preserve relations with biological, social and gestational families, regardless of when or where they were conceived or born. Such relations should be able to be maintained if mutually agreeable.

7. Anonymous donation of gametes and embryos, and anonymous surrogacy must be prohibited.

Record Keeping, Birth Records, and Access to Information

8. Comprehensive and complete records of the identity and familial medical history of all parties involved in the conception and birth of donor-conceived and surrogacy-born people must be kept. Such records must be held by each Nation State in which the conception and birth is commissioned and/or occurs, in perpetuity and for future generations. Verification of the identity of donors, surrogate mothers, and intending parents must occur.

9. All children s births should be notified to and registered with the appropriate competent authority in the Nation State of birth. Truth in registration, noting the child is donor-conceived and/or surrogacy-born, must occur. Birth records must be maintained in perpetuity and for future generations that recognise biological, social, and birth parents.

10. All donor-conceived and surrogacy-born people have the right to be notified of their status and to access records pertaining to their identity, familial medical history, and birth registration.

11. Parents should be encouraged and supported to tell their children of their donor-conceived or surrogacy-born status as early as possible, and preferably from birth. This should be coupled with efforts to reduce stigma related to infertility.

Prohibitions on commercialisation of eggs, sperm, embryos, children and surrogacy

12. All forms of commercialisation of eggs, sperm, embryos, children, and surrogacy must be prohibited. This includes, but is not limited to any kind of consideration (payment or other consideration) for a) the recruitment of potential donors and/or surrogate mothers; b) gametes or embryos; c) services , time, effort, pain and suffering related to the conception, pregnancy and/or birth of a child, or termination of pregnancy.

13. The sale and trafficking in persons and/or of gametes in the context of assisted reproduction and surrogacy must be prohibited.

14. The participation of paid intermediaries or agents in arranging surrogacy and/or recruiting or procuring women or donors of gametes for the purposes of surrogacy or gamete donation for profit, should be prohibited on the basis that their participation increases the risks of the sale and/or trafficking of women and children.

Prohibitions on transnational surrogacy and donor conception

15. It is not in the best interests of the child to be conceived or born in circumstances in which the intending parents have circumvented or breached laws within their own country by engaging in cross-border assisted reproduction, including but not limited to donor-conception and/or surrogacy. States that prohibit such practices should include extraterritorial prohibitions in their laws. States that allow such practices should limit access to their own citizens. Extraterritorial prohibitions should be enforced.

16. It is not in the best interests of the child to be intentionally separated from their genetic families by geographical, linguistic or cultural barriers. As such, inter-country transfer of gametes should also be prohibited.

Family limits

17. To avoid the risk of consanguineous relationships, and the psychological impact of an unlimited number of potential siblings, the number of families that may be created using one donor s gametes should be limited to five.

Requirement for Counselling and Legal Advice

18. Independent counselling and legal advice must be a requirement prior to entering into donor conception and surrogacy arrangements. All parties to donor conception and/or surrogacy must be able to give their informed consent after receiving information about the processes involved, material risks, legal and financial implications and their rights and responsibilities. All information must be delivered in a language the person receiving the counselling and advice can understand. All decisions must be made autonomously and free from duress, coercion, and/or exploitation.

19. The provision of counselling and legal advice must always uphold and convey the best interests and human rights of the child(ren) born to be the paramount consideration.

Transfer of Legal Parentage (Surrogacy)

20. Upon the birth of a child conceived as a result of a surrogacy arrangement, the child should share the birth mother s nationality to avoid the situation that a surrogacy-born child is stateless , and records to this effect must be kept.

21. Transfer of legal parentage in cases of surrogacy from a surrogate mother to intending parent(s) should never be automatic nor based solely on intention. Intending parent(s) do not have a right to exclusive legal parentage or parental responsibility of a child born through surrogacy, regardless of any expenses they may have incurred through the process. The surrogate mother must never be compelled to relinquish the child(ren) she has given birth to.

22. Where a surrogate mother has carried the full genetic child of another couple and does not wish to relinquish the child, legal parentage of the child should be determined by a Court dependent on the best interests of the child.

23. Enforcement of contractual terms that purport to transfer legal parentage is not consistent with the best interests or human rights of a child.

Posthumous Use of Gametes

24. Gametes or embryos which a) have been retrieved posthumously from a person, or b) are stored by a clinic on behalf of a person who has since died must never be used in donor conception or surrogacy arrangements, regardless of whether any consent had been given by the person from whom those gametes were obtained prior to their death.

Commentary:

The Principles express the common view of the members of the November 2019 UN presentation on The Rights of the Child in the Age of Biotechnology as part of the 30th anniversary conference on the UNCRC.

The Principles recognise that, pursuant to the UNCRC, donor-conceived people and people born of surrogacy have a fundamental human right to:

- as far as possible, know and be cared for by their parents (Article 7);
- preserve their identity, nationality and family relations, to not be deprived of any elements of their identity, and to seek State assistance to re-establish their identity (Article 8);
- maintain personal relations and direct contact with both parents on a regular basis (Article 9);
- express their views in all matters affecting them (Article 12); and
- seek, receive and impart information and ideas affecting them (Article 13).

Most importantly, ALL children have a fundamental human right not to be bought or sold.

Donor-conceived people and people born of surrogacy also have the right to:

- have their rights in the Convention respected by States Parties without discrimination of any kind, irrespective of the child s birth or other status (Article 2); and
- have the best interests of the child as the primary consideration in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies (Article 3).

States Parties should undertake all appropriate legislative, administrative and other measures for the implementation of these human rights as recognised in the UNCRC (Article 4).

As noted in the background to this document, all policy-making, both national and international, must henceforth include meaningful consultation with a broad representation of donor-conceived and surrogacy-born persons, as they are the population overwhelmingly affected by the practice of third-party reproduction.

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