# The experience and wellbeing of donor-conceived adults

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<b>TABLE OF</b>	CONTENTS
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LIST OF TABLES	5
ATTESTATION OF AUTHORSHIP	6
ACKNOWLEDGEMENTS	7
ABSTRACT	8
CHAPTER ONE: INTRODUCTION	9
CHAPTER TWO: LITERATURE REVIEW	14
Assisted reproductive technology processes	14
History of secrecy and anonymity	
History of adoption and donor-conception in New Zealand	
Donor-conception and offspring wellbeing	
Parents' experiences of donor-conception: attachment, negotiating the lack of ge and resemblance	enetic connection,
Disclosure	
Donor linking	25
Applying for access to information through New Zealand's HART Act	
Movement towards openness and disclosure	
Gifts and compensation	
Donor-conception and religion	
CHAPTER THREE: METHOD	
Design and rationale	
Reflexivity	
Participant recruitment	
Data collection	
Thematic analysis	
Five decisions for Thematic analysis	
Six phases of thematic analysis: :	

Quality and rigour	40
Ethical Considerations:	41
Informed consent and participant wellbeing	41
Confidentiality and privacy	
CHAPTER FOUR: RESULTS	43
Theme One: Donor-conceived as an integral to identity (part of who I am)	44
Nature vs nurture	
Confusion about who I am	
Theme Two: Parent views as influential (my parents' views influence my experience)	47
Strong family ties	
Theme Three: The donor's role in my life	50
I don't need another parent	50
How does the donor fit into my life?	51
Theme Four: Long term wellbeing is a priority (Children become adults with needs)	52
Consider the child, they will grow up	52
Passing on important information	54
Who should I date?	54
Theme Five: The need for openness	55
The earlier the disclosure, the better the reaction	55
Navigating disclosure conversations	57
Understanding parents and donors	59
Secrecy	61
Theme Six: Disclosure for wellbeing (tell me at the right time and in the right way)	62
I can't remember being told	62
Disclosure used for alternate purpose	63
I remember being told	63
Telling others	65
Theme Seven: Searching: a lonely task	66
Sense of having to link on your own	66
Hopelessness and frustration	67
Protect yourself	

Time	69
Expectations	
Theme Eight: Linking: A mixed experience	70
Rejection	71
Welcoming	71
Uncertainty	72
Donor siblings	73
Theme Nine: The need for support	74
Donor-conceived communities	75
CHAPTER FIVE: DISCUSSION	77
The long-term well-being of donor-conceived individuals should be prioritised	
Donor-conception as an integral part of identity	
Parents' views as influential	80
The need for openness	
The need for support	
Searching and linking	
Implications and recommendations	
Limitations and future research	
Conclusion	
REFERENCES	
APPENDIX A- PARTICIPANT INFORMATION SHEET	116
APPENDIX B: INTERVIEW SCHEDULE	
ADDENDLY C. ETHICS ADDOVAL	
$\mathbf{Arrendia} \subset \mathbf{Ernics} \mathbf{Arrnov} \mathbf{AL}$	

# LIST OF TABLES

Table 1: Pseudonyms of research subjects.	
Table 2: Summary of Themes	35

## **ATTESTATION OF AUTHORSHIP**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:

Dated: 5 November 2021

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#### ABSTRACT

Gamete donation and conception has become increasingly more common both internationally and locally. Although New Zealand's current policy and practice support openness, donorconception has historically been shrouded in secrecy. The experience and wellbeing of those who are donor-conceived has received relatively little research attention, partly because of secrecy and the fact that many donor-conceived individuals remain unaware of the nature of their conception. Therefore in this exploratory, in-depth qualitative study, ten donor-conceived offspring -eight women and two men- were interviewed to explore their experience of being donor-conceived and the impact that had on their wellbeing. All participants were born prior to the introduction of the HART Act 2004, meaning that they did not automatically have the right to access identifying information upon reaching the age of eighteen.

The overarching theme identified was of a need to prioritise the long-term wellbeing of those who are donor-conceived, with participants expressing the belief that their needs and wishes had often come second to those of parents, donors and the fertility industry. While the experiences of participants differed particularly in regards to disclosure, searching and linking, all participants recalled a lack of: access to identifying information, openness, and ongoing conversations regarding the nature of their conception and their interest in it. Further, participants expressed a lack of support in navigating their identity and processing what it means to be donor-conceived, and stressed the amount of time and effort they invested trying to track down information about themselves through their donor and donor-conceived communities.

While this research project was based on a small sample size, it adds a relevant and much-needed perspective that few studies have explored. It underscores the value of current legislation and practices which support openness and disclosure. It is hoped that the findings from this study may be used to inform prospective parents and donors, as well as the fertility industry, as regards ways in which to maximise the wellbeing of donor-conceived individuals.

#### **CHAPTER ONE: INTRODUCTION**

Assisted reproductive technologies (ART) are procedures that involve the handling of human gametes (eggs, sperm or embryos) outside of the body (in vitro) with the intention of establishing a pregnancy (National Perinatal Epidemiology and Statistics Unit [NPESU], 2017) and include donor assisted conception. Donor conception involves the donation of eggs, sperm or embryos to those who are not able to conceive naturally. In New Zealand, an estimated one-four per cent of all conceptions are due to ARTs (Allot et al., 2013). Further, approximately five-ten per cent of all fertility treatments in New Zealand involve donor eggs, donor sperm or donor embryos.

Globally, interest in donor conception is increasing, however, demand for donor gametes typically tends to outstrip supply (Northern Region Fertility Service, 2019). Sperm Donor Australia (2020) attributes this to the scientific advances which have allowed IVF clinics to assist more of those wanting a family and the greater acceptance in society today regarding donor conception. Statistics show that those willing to donate eggs appear to be significantly less than those willing to donate sperm. In the United States, estimates of sperm donation have been held to be between 30,000-60,000 annually (Arocho et al., 2019). Due to the largely unregulated nature of sperm donation in the United States, researchers are unable to provide a more accurate number. In contrast, in the United States in 2015, approximately 3,000 live births were the result of egg donation (Imrie et al., 2018).

Waitlists for egg donations tend to be much longer than those for sperm recipients. This is attributed partly to the invasive nature of egg donation and its associated risks. The overall process appears to be both psychologically and physically draining for the donor (Soderstrom-Anttila, 2016). However, in New Zealand, long waiting lists for sperm donors are also typical with Fertility Associates estimating that recipients will wait approximately two years before receiving donated sperm. A range of reasons has been suggested for donor shortages, including conditions of donating such as a lack of compensation and the move away from anonymity. In New Zealand, the 2004 Human Assisted Reproduction [HART] Act prohibits valuable consideration for donated gametes (HART Act, 2004), which means that donors do not receive "inducement, discount, or priority in the provision of a service" (HART Act 2004, part 1, 5). Further, whakapapa (genealogy) is of great importance in Māori culture and gametes are seen as sacred. Receiving compensation for such treasures could have consequences relating to identity

or inheritance (Lovelock, 2010). This means that while donors' medical and treatment costs are covered, donation is completely altruistic in New Zealand, which some (e.g. Gezinski et al., 2016; Pennings et al., 2018) have suggested may discourage individuals from going through the donation process. In addition, the HART Act stipulates that those born after August 22nd 2005 as a result of donor-conception will automatically gain access to the identifying information of their donor once reaching the age of 18, assuming they are aware that they are donor-conceived. All donors whose donation leads to a live birth are placed on a mandatory register, meaning once the offspring is of age, they are entitled to information on their genetic origins. Some (e.g. Pi, 2009) have argued that a lack of anonymity may also deter donors as many may not want contact with the offspring and may not want others to know about the donation. Lack of information campaigns may also be contributing to the low numbers of donations. According to Ross (2018), little effort or funding are put into campaigns promoting gamete donation. Although donor conception is more widely accepted in today's society, some still view this method of conception as controversial. Because of difficulty in accessing donor gametes in their home countries, individuals seeking donor sperm or eggs may travel across borders to other countries where supply is more plentiful (Rodino et al., 2014).

The HART Act forbids the importing and exporting of hybrid and cloned embryos. Additionally it gives Customs Officers authority to confiscate any materials they may have concerns for (Advisory Committee on Assisted Reproductive Technology [ACART], 2013). The HART Act includes several terms in regards to the payment of imported gametes by New Zealand citizens in order to maintain an altruistic standpoint. For example, New Zealand does not accept imported eggs or sperm from donors who have been reimbursed a sum more than the expenses associated with donation (Fertility Associates, 2021). Further, all donors must be identifiable and receive a certain level of counselling before their donation is accepted. Additionally, all imported gametes that have been frozen for transportation must satisfy requirements in New Zealand in order to be utilised (Fertility Associates, 2021). Specifically, New Zealand does not accept or export embryos or gametes where sex selection was/will be involved (Fertility Associates, 2021). The HART Act requires ACART to provide advice for the Minister of Health (ACART, 2013). In 2013, ACART acknowledged that increased compensation for gametes and embryos may decrease the number of New Zealander's travelling overseas to undertake fertility treatment, however, their proposal still retained the distinction between altruism and commercialism. In New Zealand, fertility clinics must operate in accordance with the Fertility Services Standards, and must be audited and certified against this (ACART, 2013). Regardless of the origin of the gametes, it is a requirement that providers write down procedures regarding the safety and quality of embryo and gamete transportation. Additionally, informed consent of consumers must be obtained before transport (ACART, 2013).

Donor conception legislation and practice vary widely across jurisdictions, not only with respect to the information that offspring can access and the compensation of donors but also with regards to the number of donations a donor can make. New Zealand allows donors to donate to ten families. However, clinics can place limits on how many families a donor can donate to. For example, at Fertility Associates, sperm donors can choose to donate up to five families and most women donate their eggs to one or two families only. Similarly, a couple donating embryos can make a donation resulting in full genetic siblings in two families only (Fertility Associates, 2020).

Research regarding donor-conception often focuses on the experiences of donors (Kenney, 2010; Van Den Broeck et al., 2012; Mohr, 2014; Graham et al., 2016) and recipients (Golombok et al., 2004; Mac Dougall et al., 2007; Blake et al., 2014), and has been conducted in Europe, America and Australia. Each country has their own unique culture, legislation, and law that can impact experiences. Much of the New Zealand based research also focuses on donors and recipients (Goedeke et al., 2015, Daniels et al., 2011; Daniels, 2017; Goedeke et al., 2016). However, hearing the voices of donor-conceived individuals is paramount as they are the ones who are most affected. A limited number of studies have explored the experiences of the donorconceived offspring (Indekeu & Hens, 2018; Pennings, 2017; Zweifel, 2015; Mostyn, 2017, Hammarberg et al., 2015; Golombok, 2020). Partly this is due to the difficulty of accessing this population in contexts where donor conception has been conducted under anonymous conditions, and that fact that donation under open identity conditions has been available for a more limited time only - there are relatively few countries where donor-conceived individuals have come of age e.g. Sweden and the Netherlands, and in others, they are yet to do so e.g. New Zealand (2022), Norway (2024) and the UK (2024). Thus, while a few studies have explored donorconception from the viewpoint of the offspring, the target population is often children. This means reflections on experience may be limited (Zweifel, 2015; Pennings, 2017) and experiences are also subject to change as individuals mature. While Mostyn's (2017) research touches on the

experiences of those who are donor-conceived in New Zealand, the study's main focus was the impact donor conception has on family constructs. Research is yet to address the experience and wellbeing of those who are donor-conceived in a New Zealand context more broadly. The present enquiry aimed to explore the experiences of those who were conceived via donor conception in New Zealand.

In this study, ten participants (two men and eight women) were interviewed about their personal experiences of being donor-conceived including, their memories of and reactions to disclosure, changes to their family dynamic and other relationships, views on their sense of self/identity relating to their donor, and the support they received or wished they had received through processing these experiences.

Current research suggests that being donor-conceived may present some challenges, however what these are for those conceived in New Zealand is currently unclear due to a gap in the research. Thus, research in this area is necessary to identify the challenges and issues this population faces. This research is of particular importance given the Coming of Age Project, with the first donor-conceived individuals born under the provisions of the HART Act reaching the age of majority in 2022. Information on the experience and wellbeing of donor-conceived individuals can be used to inform how psychological practice needs to respond, if the provisions of the HART Act are appropriate, and what support may need to be put in place. There have already been suggestions from other parts of the world that this specialised area of counselling is much needed. Thus, it is important to address this emerging need. More specifically, Counselling Psychology places emphasis on supporting resilience and the prevention of longer term issues. Developing an understanding of the challenges donor-conceived people face will enable early intervention and support, reducing the impact this method of conception may have on offspring.

The following chapter critiques existing literature on donor conception, initially explaining the different assisted reproductive technologies prospective parents can utilise to have a child. It examines the history of donor-conception focusing on secrecy and anonymity, as well as how adoption and legislation in New Zealand have impacted the movement towards openness and disclosure. Donor-conceived offspring wellbeing is explored and attitudes towards recognition

and compensation for gametes are considered. This chapter concludes by addressing the literature relating to how religion can impact donor conception.

Chapter Three explains the study's methodology, the qualitative approach, data collection and method of analysis. This is followed by Chapter Four which presents the findings from the thematic analysis and detailed quotes from participants. Finally, Chapter Five discusses the findings in light of the current literature, explores the study's implications, and makes recommendations for future research and practice.

#### **CHAPTER TWO: LITERATURE REVIEW**

Infertility is defined as the inability to conceive after attempting for a year or more, or the inability to carry a pregnancy to a live birth (Heath Navigator New Zealand, 2019). Infertility is something that impacts approximately 15-20% of couples in New Zealand (Fertility Associates, 2019). Infertility is widely reported to be emotionally stressful for those experiencing it and feelings of significant grief are common (Greil et al., 2011). Similarly, infertility has been seen to harm one's self-identity (Greil et al., 2011). A range of Assisted Reproductive Technologies (ARTs) have been developed in an attempt to help couples and individuals build their families, and Allot et al., (2013) estimated that 1-4% of all conceptions in New Zealand are due to ARTs. ARTs include third party reproductive procedures such as egg, sperm and embryo donation. These may be utilised where there is a desire to avoid transmission of potentially inherited diseases, for those whose eggs and sperm are not functioning optimally, and for those who are in homosexual relationships and do not have the appropriate gametes (American Society for Reproductive Medicine, 2018). Approximately 5-10% of all fertility treatments in New Zealand involve donor eggs, donor sperm or donor embryos. These ARTs can however be ethically, legally, and socially complex because they involve the gametes or embryos (and thus also genetic information) of someone other than the intending parents. The following review will explore ART's and how they are used in New Zealand and internationally. The history of secrecy and anonymity will be discussed, as well as New Zealand's pioneering movement towards openness. Research looking at the experience and wellbeing of donor-conceived individuals will also be explored.

#### Assisted reproductive technology processes

In order to donate sperm in New Zealand, several requirements must be met. In general, sperm donors must be between 20-37 years of age, be non-smokers, have a healthy Body Mass Index, and give consent for the release of identifying information (Fertility Associates, 2020). More specifically, a male's sperm count and genetic health must be checked. The quality of a male's sperm will be assessed by a specialised test and the morphology (shape) and motility (movement) will also be inspected (Fertility Associates, 2020). At the same time, it is common for a saliva sample to be taken in order to screen for inherited conditions. If the semen is

adequate, then the male is asked for his medical and family history. Blood and urine tests are conducted to rule out infectious diseases and determine blood type. At this point, a doctor will carry out a physical examination. A counsellor will then make contact to discuss the laws governing sperm donation in New Zealand and explain the implications of donation, including for donor conceived offspring (Fertility Associates, 2020). After this, the fertility clinic will accept the donation or inform the potential donor their donation has not been accepted. Successful candidates will sign a form consenting to donation and fill out a non-identifying profile for prospective recipients. A potential donor's partner is also asked to sign a form stating they are aware and informed. The last step in this process includes a final clearance screening test before the sperm is quarantined for three months before recipient use (Fertility Associates, 2020).

In order to donate, women must undertake a three-month screening process. This begins with an initial blood screen which can take up to six weeks (Fertility Associates, 2020). The woman then has her first consult with a doctor where saliva is collected for genetic testing. It is a requirement that donors engage in counselling prior to treatment. This is because of the potential stress caused by medication and the disappointment some donors feel when the recipient does not fall pregnant, as well as to ensure that donors are aware of the implications of donating and legislative requirements. Counselling sessions often involve the donor's partner and discussions around contraception during this time are important as it is common for a couple of eggs to be left behind after collection. This awareness will decrease the risk of the donor becoming pregnant accidentally. Next, tentative treatment dates are planned, followed by another counselling and consent session with the donor's partner. The donor's partner is heavily involved in this process, so they too understand the implications of donating (Fertility Associates, 2020). Similarly, joint counselling sessions with both the donor and recipient present are common, and either party can make a request for this to occur. In the joint counselling process the motivations, needs and expectations of each party are explored, particularly with respect to disclosure and information exchange going forward.

Final bloods and swabs, as well as a smear test are completed one month before treatment commences. When treatment dates are confirmed, the donor will begin a cycle of IVF and the eggs will be collected during a minor surgical procedure (Fertility Associates, 2020). Eggs are then put with the recipient's partner's sperm/ the sperm being used to create an embryo (Fertility

Associates, 2020). Alternatively, eggs can be stored for later use, although a storage limit of 10 years applies, unless an application for extended storage is made to the Ethics committee on Assisted Reproductive Technology (ECART) (Fertility Associates, 2020).

In New Zealand, donors have obligations towards but no legal rights to the offspring produced. Additionally, the legislation recognises the woman who gives birth to the offspring as the legal guardian/parent. This means that a surrogate who carries the donated gametes to a live birth and their partner are considered the legal guardian of the offspring until they are adopted by the intending parents (Fertility Associates, 2020). Because New Zealand is a small nation because of the and psychosocial implications associated with donor conception, fertility clinics are required to limit the number of women who have an offspring using an egg or sperm donor. This number is currently at seven for new donors but was previously five. However, the donor can decide on a lower limit (Fertility Associates, 2020). Similarly, couples donating embryos can only donate to one couple or one woman. However, the guidelines also specify that there may be full genetic sibling in two families only. This suggests that in theory a donation could happen to more than one family if a first donation is not successful. These guidelines are to minimise the risk of an offspring unknowingly forming an intimate relationship with a half-sibling (Fertility Associates, 2020).

#### History of secrecy and anonymity

Historically the practice of gamete donation has been shrouded in secrecy, characterised by discourses of selective telling and partial knowledge. In many nations, recipients and donors had no obligation to disclose to the donor-conceived offspring the truth about their conception. It was often thought that by concealing the truth, recipients and their offspring could live a more "normal life" and not feel threatened by an abnormal family dynamic (Glover, 1989). Additionally, the anonymity protected the donors' identity (Frith et al., 2017),was held to safeguard the donors from any claims on them, and served to safeguard the medical profession from external scrutiny in what was considered an unaccepting society (Haimes, 1993).

Several countries around the globe continue to practice anonymity when it comes to donor conception. Examples include South Africa where, although individuals born via artificial insemination do have access to genetic and medical information, they are not entitled to any identifying information unless the donor is known to the recipients (Co-parentmatch, 2019). Similarly, Spain has one of the world's most straightforward jurisdictions, making it a popular location for prospective parents to travel to for fertility treatment. Spain's current view is that a donor is just a person who has provided a gamete for conception (Fenomatch, 2020). Although a donor's personal information is stored in Spain's national database and can be retrieved in life-or-death situations, there is no requirement to inform the offspring of their identifying information or the nature of their conception at all (Fenomatch, 2020). Similarly, in 1994 lawmakers in France decided to enshrine the gamete-donor anonymity doctrine specifically relating to medically assisted procreation. However, it is important to note that the two main principles relating to donation and anonymity were put in place to regulate the donation of all body parts and/or products. In other words, France's legalisation is not specifically tailored to gamete donation.

Many studies have explored the impact that secrecy may have on human relationships (Bok, 1998; Smart, 2011); finding that secrets carry importance not because they reveal truths about family dynamics, but because secrets provide insight and understanding into the complexities behind the personal, social and cultural parts of relationships (Smart, 2011). Studies show that a lack of disclosure can impact recipients as well as offspring negatively. In a study by Lasker and Borg (1989), both male and female parents report stress as they feel they are "living a lie". Subsequently, relief may be felt when bringing this information to the surface. Klock & Maier (1991) found that even when health professionals encouraged recipients to conceal the truth, most ended up disclosing the fact to someone, such as their parents, best friend, siblings, therapist and/or co-worker. However, retrospectively, most couples regretted telling others. This is because telling others may affect whether or not the couple disclosed the fact to their child (Klock & Maier, 1991). Additionally, the more people that knew, the higher the chance the child would find out accidentally and not on their parents' terms (Klock & Maier, 1991).

In addition to effects on the recipients and family functioning, secrecy also affects donorconceived people. Much of the evidence supporting disclosure comes from research on adoption and the impact on adoptees (Walby & Symons, 1990). Adoption studies highlight the importance of knowing one's genealogical background in order to develop a sense of identity and independence (Walby & Symons, 1990). Similarly, Van den Acker's (2006) review of research on donors, offspring and recipients, highlights the negative feelings donor-conceived children who have not been told about their conception but subsequently found out experienced. Feelings included poor self-perception, feelings of mistrust within the family, feelings of not fitting into their families and knowing they were different from a young age as well as experiencing anger and resentment (Van den Acker, 2006). These emotions are similar those that adoptees experienced when anonymous or closed adoption was common.

#### History of adoption and donor-conception in New Zealand

New Zealand has an unfortunate history with Māori, colonisation and adoption. This history has helped set new a precedent when approaching assisted reproduction but does not undo previous wrongs. Firstly, the way in which European settlers and Māori viewed the care of children and the meaning of adoption differed from the beginning. Traditionally, children in European families are cared for by their parents. However, children within Māori culture are seen as taonga (treasure) and are raised by the entire community (Newman, 2013). Meaning, although the European term "adopt" and the Māori term "whāngai" both refer to the care of children, the two words possess different ideals. Informal adoptions were common before the introduction of the 1881 Adoption Act (Newman, 2013). An example of an informal adoption is when a parent offered their child to another couple to raise, or if a child was taken by the state and placed with a European family often believing this was in the children's best interests (thus justifying the actions) (Newman, 2013). The latter was not unusual for Māori Tamariki, with over 45,000 closed adoptions taking place between 1955 and 1985 (Haenga-Collins & Gibbs, 2015). Informal adoption created great anxiety for biological parents as even when written agreements were constructed, there were no legal processes that allowed parents to reclaim their child (Newman, 2013).

The 1881 Adoption Act is thought to have been designed to give the child inheritance rights in their new family and alleviated issues with birth parents reclaiming the child, meaning the child was treated as if it had been born into the new family (Newman, 2013).

Whāngai were registered through the Native land act and recorded in New Zealand Gazette between 1901-1956 (Newman, 2013). Initially, details of the child, their biological parents, surname and adopted parents were recorded. However, by 1951 the biological surname of the child and the names of his or her biological parents were no longer recorded (Newman, 2013). The 1955 Adoption Act promoted the closed adoption of indigenous children into Pākehā families (Haenga-Collins & Gibbs, 2015). Regardless of the differences in the adoption process between Māori and non- Māori, the 1955 Adoption Act placed all adoptions into the same basket. Adoption records would be sealed, with no access to information about the identity of the child or the birth parents. Additionally, the child involved in the informal adoption was not entitled to any inheritance from their biological parents. This Act severed the familial, ancestral and cultural connections for thousands of Māori. The 1955 Act is still current legislation in New Zealand, but in the 1970's open adoption become best practice (Haenga-Collins & Gibbs, 2015). It was not until 1985 with the passing of the Adult Adoption Information Act that it became possible for adoptees to obtain access to their original birth certificates and details, however, this was only if their birth parents (who had the right to remain anonymous) consented (Haenga-Collins & Gibbs, 2015). Alternatively, adoptees could petition for access but it was not openly available.

More recently, Māori beliefs and values have helped shape New Zealand's approach to assisted reproduction. There is a Māori saying that people walk into the future backwards (Daniels, 2007). This means that people should always be aware of their history and particularly those individuals who contributed to the position in which they now find themselves. The word "whakapapa" in simple terms refers to one's genealogy, something that is extremely sacred and treasured in Māori culture. Māori view human gametes as the physical embodiment of whakapapa. Because of the meaning and importance of whakapapa, New Zealand has attempted to develop an approach that practices openness and altruism. Because Māori views on whakapapa link them not only to their genetic linage but also their whanau, the Advisory Committee on Assisted Reproductive Technology (ACART) has determined that in order to align practice with Māori views, gametes should not be traded for compensation (ACART, 2020). However, several countries allow the offering of monetary rewards to donors as a way to compensate for their time and inconvenience, an example being the US, where the fertility industry operates as a free market and is heavily self-regulated (Kalfoglou & Gittlesohn, 2000).

It is important to note that there is inequitable access to donor conception for some individuals. Although in New Zealand, the Māori fertility rate is 2.3 (higher than the national average, 1.8) (Statistics New Zealand, 2017), it is perceived by Māori that there is a lack of education regarding infertility treatment (Glover, 2008). According to a study by Glover, (2008) Māori are saddened and shocked at how costly assisted reproduction technologies are. Māori appeared to be discouraged by the cost and the invasive nature of fertility treatment suggesting

the more invasive and costly procedures got, the more likely they are to withdraw (Glover, 2008). Additionally, it found that Māori believed the exclusion criteria for fertility treatments may be an extra barrier for them. Specifically, Māori have a higher prevalence of tobacco smoking and excess BMI, both of which are exclusionary criteria (Glover, 2008).

#### **Donor-conception and offspring wellbeing**

Some existing research has explored the wellbeing of those who are donor-conceived when they are children, however, Zweifel, (2015) has expressed the importance of continuity when monitoring the wellbeing of donor-conceived individuals. Adjustment is something that will continue throughout their lifespan, and as these individuals mature and develop psychologically, the quality of their mental health and wellbeing may vary particularly as they process the meaning of donor conception. Golombok's (2020) review on the psychological wellbeing of donor-conceived children found that their psychological wellbeing depended on a number of factors, including the wellbeing of their parents, the social circumstances in which they were raised, and the quality of their familial relationships. Further, Mostyn (2017) suggested that the disclosure of one's origins alone is unlikely to maintain the wellbeing of offspring and their family. Rather, if one or both of the parents feel a sense of discomfort or shame, the offspring may internalise these feelings and perceive their origins in a negative way (Mostyn, 2017). Since donor conception has increased in availability, research has started exploring the absence of genetic relatedness between the parents and the offspring, and how a donation may impact the family relationships or offspring's psychological development (Freeman, 2015). Longitudinal studies including research conducted by Shelton et al., (2009) and Golombok et al., (1996, 1999, 2005, 2006) have consistently found little difference in wellbeing when comparing children who have been conceived via gamete donation to those conceived via other reproductive methods (natural conception, surrogacy and IVF). These longitudinal studies suggest that genetic relatedness or lack thereof is not a factor that affects a donor offspring's wellbeing.

Disclosure versus non-disclosure and the impact this decision has on the well-being of donor-conceived individuals has however been heavily contested. Pennings et al., (2017) concluded that there was no difference in the well-being of those who were told about the nature of their conception to those who were not aware at all. Similarly, Mahlstedt et al., (2010) and Hammarberg et al., (2015) demonstrated there were no differences in the wellbeing of those who

were told later in life to those who experienced early disclosure. Alternatively, several studies suggest that the timing of disclosure does have a significant impact on the wellbeing of donor-conceived individuals. Both Javda et al., (2009) and Ilioi et al., (2016) found later disclosure can generate more negative outcomes than disclosing early. As mentioned earlier, perhaps it is the secrecy and lack of openness, and the consequent impact on family functioning and on trust, that impacts the wellbeing of donor-conceived individuals.

A donor-conceived individual's wellbeing may also be demonstrably affected when linking with their donor. Participants in studies conducted by Freeman et al., (2012) and Javda et al., (2010) reported favourable outcomes when linking with their donor. In several cases, that linking increased the offspring's sense of self, identity and family. Similarly, 85% of participants in Freeman et al's (2015) study who linked with their donor siblings reported positive experiences. However, while much of the research paints a positive picture for donor-conceived individuals and linking, there is evidence that meeting is not always positive and can illicit feelings of confusion and conflict (Javda et al., 2010). For example in areas such as Victoria, Australia which has an advanced system for mediating and facilitating contact, varying outcomes have been observed as at times there is a lack of communication regarding boundaries and expectations (Freeman et al., 2014). For example if one party desired continuous contact but the other wanted little, disappointment and feelings of rejection may follow. Both of which can be detrimental to one's wellbeing.

# Parents' experiences of donor-conception: attachment, negotiating the lack of genetic connection, and resemblance

Although there is much to be explored regarding the experience and wellbeing of those who are donor-conceived in a New Zealand context, multiple studies have looked at the experience of parents with donor-conceived offspring. First proposed by attachment theorists, is the idea that parents' thoughts and feelings about their infant guide their behaviour with the child (George & Solomon. 1996). This highlights the importance of exploring parents' perception of their child and the nature of their conception prior to the birth and during the first year (Foley & Hughes, 2018; Vreeswijk et al., 2012). Foley and Hughes (2018) found that a mother's representation of their infant can determine the quality of later interactions. Additionally, research suggests that bonding and attachment begin during pregnancy, and continues into the early postnatal period,

both of which hsve been seen to be associated with the child's future outcomes (Klaus et al., 1995; Mason et al., 2011). According to adoption studies, adoptive parents raise concerns regarding their sense of emotional entitlement to a child that is not related genetically. Sandelowski et al., (1993) termed the process of intellectually and emotionally working to gain a sense of entitlement to their unrelated offspring as "parental claiming". This process may be similar to that of donor conception.

Goldberg et al., (2009) suggested that pursuing non-genetic motherhood requires a woman to reshape their conceptualisations of parenthood and address the feeling of loss when imagining their genetically related child (Daniluk & Hurtig-Mitchell, 2003). Further, according to Wischmann and Thorn (2013), fertility and fatherhood are significant to a male's gender identity. Therefore, the absence of a genetic link can prove challenging for many males with donor-conceived offspring (Wischmann & Thorn, 2013). Similarly, Imrie et al., (2020) found that women engaging in egg donation reported feeling uncertain and concerned as to whether or not the offspring would feel like their child and the impact on attachment.

Discussions regarding the offspring's physical appearance appeared to be common as family resemblance is culturally understood as something representing genetic connections (Mason, 2008). Isaksson et al., (2019) also explored the challenges that heterosexual couples using a sperm donor face in relation to parent-child resemblance. It is suggested that sperm donations may cause an inherent genetic imbalance due to the visible child-parent resemblance between child and genetic parent. Genetic mothers reported feeling guilty and felt the urge to hide their genetic connection to the offspring out of respect to the father. This again may link to stigmatization associated with male infertility and masculinity (Wischmann & Thorn, 2013; Culley et al., 2013). However, as Firth et al., (2018) found, avoidance of disclosure and secrecy may cost the genetic mother's relationship with the offspring. This is because mothers tend to be criticised for choosing to honour the father's wishes for secrecy over the child's need for openness.

#### Disclosure

Disclosure of genetic origin has become an ethical debate and is one of the most controversial issues of reproductive donation. Arguments and views about disclosure vary. It is believed by some that the offspring has a right to their biological origins, while others argue that disclosure is

a private family matter which should be at the parents' discretion. A contrasting ethical stance recognises that not all donor-conceived individuals who are uninformed are harmed, but rather treated wrongly when restricted from obtaining their genetic information (Zweifel, 2015). Several studies have compared the wellbeing of donor-conceived individuals who have been told about the origins of their conception to those have not. Golombok et al., (2002) compared children (aged 11-12) who had and had not been told and found no differences in the child's socio-emotional functioning or variables concerning parent-child relationships. In 2013 Golombok et al., completed a second publication with the same group. Findings were consistent with the 2002 study in that donor-conceived individuals who were not aware showed no difference in levels of adjustment to those who were aware. However, it was found that children whose mothers showed distress in connection with donor conception and disclosure, displayed more difficulties in adjustment (Golombok et al., 2013). More recently, studies such as that conducted by Kovacs et al., (2015) also struggled to find any clinically significant differences in the wellbeing of children aged five-thirteen who have and have not been told about their biological origins. Further the quality of child-parent relationships between those who were told, not told and those apart of naturally conceiving families did not appear to differ greatly. Salter-Ling et al., (2001) conducted a study exploring the intention of disclosure to their donorconceived offspring. It was found that parents who were unsure/undecided about disclosure also expressed significantly higher distress concerning their infertility than parents who intended on disclosing (Salter-Ling et al., 2001).

However, there are also several studies suggesting that disclosure, and specifically early disclosure, is the best option. Nachtigall et al., (1997) found that younger parents who had more than one donor-conceived child and who scored lower on the perceived stigma of donor conception were more likely to disclose to their child their origins earlier. Studies indicate that those whose parents disclose the origins of their conception during the pre-school years react with disinterest or curiosity (Lycett et al., 2005; MacDougall et al., 2007). Similarly, Hertz et al., (2013) suggest that age shapes the views and feelings that donor-conceived individuals have. It was found that those who are told younger are less likely to remember the disclosure and state that it made no difference to them. However, later disclosure made individuals feel "different" and elicited feelings of confusion and distrust. Furthermore, Hammarberg et al., (2015) suggest the optimal age for disclosure was between ages twelve and seventeen and Ilioi et al., (2016)

suggests that it should be between seven and fourteen. It has been found that disclosure before the age of seven resulted in more positive family relations and improved psychological wellbeing at adolescence (Ilioi et al., 2017). The age of seven years old is thought to be of importance as it is when a child reaches a certain level of socio-cognitive development. For example, one's executive function develops around the age of three, but it is not until the child is older that these skills become coordinated. (Garon et al., 2008). Moreover, around age seven, children begin to enter schooling which brings the challenge of explaining their origins to their peers.

Javda et al., (2009) also conducted a study looking at disclosure and the wellbeing of adolescents and adults who were conceived via sperm donation. Results showed that those with single or lesbian mothers were informed of their donor origins earlier than those who had heterosexual parents (Javda et al., 2010). Interestingly, offspring of heterosexual parents appeared to direct their anger relating to late disclosure and being lied to towards their mothers. Alternatively, sympathy was the most common feeling the offspring felt towards their fathers. Some research suggests that those told about their conception in later adolescence and adulthood experience more negative emotions such as anger, confusion and shock (Turner and Coyle., 2000; Javda et al., 2009).

The rising popularity of direct-to-consumer Deoxyribonucleic Acid [DNA] testing has both helped and hindered those who are donor-conceived. Cites such as ancestory.com and 23andMe provide direct-to-consumer genetic testing for information about one's origins and ancestry. In seconds one can be linked to several family members and relations who have also submitted their DNA. This can be problematic for those donor-conceived individuals who are not privy to the nature of their conception (Harper et al., 2016) and inadvertently discover their genetic background. Harper et al., (2016) suggest that donor recipients are now needing to be fully informed that their child's DNA and expanded access to genetic testing will likely expose the fact they are not genetically related. This suggests that more importance should be placed on disclosure, and this it will possibly be more likely to occur. Crawshaw (2017) explored three case studies of offspring who learnt of their conception through DNA testing platforms such as 23andMe. Participants in this study described the adjustment that took place after learning that their parents and others around them had withheld important information. The impact this information had on identity was discussed and feelings of uncertainty were expressed when considering how to broach the topic with their parents. These results are similar to the findings of Turner and Coyle (2000) who found that those who learnt about the nature of their conception through methods other than planned parental disclosure reported the information was an unwelcome shock. Participants suggested that this was because the information challenged their previously-held sense of identity, which created a sense of genetic-discontinuity. Further, many reported difficulties in assimilating their new found identity as being a donor-conceived individual.

It is also important to acknowledge that in the context of direct-to-consumer DNA testing, anonymity is unlikely to be upheld. While this practice is beneficial for many, it undermines past promises of anonymity to donors. Kirkman et al., (2014) explored the views and expectations of gamete donors in regards to contact with donor offspring. While views varied, some participants expressed the fear they had when thinking about contact with their donor offspring. The main concern was the impact the offspring may have on their family, and how their family viewed the donor's loyalty to them. It is important to be mindful of the affects direct-to-consumer genetic testing can have. Safeguarding and promoting the wellbeing of donor-conceived individuals is important, however, we must also consider the wellbeing of the donor. Crawshaw (2017) suggested that the genetic testing industry should provide information and support to those who have been impacted by learning unexpected information.

#### **Donor linking**

When a family is created via donor-conception, it is likely that other families exist who share the same donor and siblings exist in the donor's family. Donor-conceived offspring are not always the only ones who aspire to link with their donor and donor-siblings, some recipient's parents express interest too. Studies including those conducted by Scheib et al., (2008) and Freeman et al., (2009) explored the rationales behind parents linking with their child's donor-siblings and donors. Participants in Scheib et al's, (2008) study suggested that linking was not about them but their child, they wanted their child to have a sense of kinship. Linking their child with donor-siblings provided an opportunity for a "cousin-like" relationship to develop. The rational for linking with their child's donor also included wanting to understand their child's characteristics and medical history (Scheib et al., 2008). Similarly, Freeman et al., (2009) found that 27% of parents participating in their study wanted to link their child to their donor or donor-siblings because of curiosity (similarities in personality and appearance). Of the 27%, 48% were lesbian

couples, 32% were single mothers and 20% were heterosexual couples (Freeman et al., 2009). This indicates that family type can also determine the motivation behind parents linking. The second most common reason (18% of participants) related to parents wanting their child to develop a more secure sense of self or identity (Freeman et al., 2009). This study also evaluated the outcome of, and the impact linking may have on the offspring's welfare and their family dynamic. The majority of parents who successfully reached out to their offspring's donorsiblings reported having ongoing contact with them or their parents. 85% of participants described the experience as 'very positive' with 60% of parents mentioning their child got on 'very well' with their donor-sibling. Although the child's contact was less regular than their parents, approximately half who were in contact maintained this frequently (Freeman et al., 2009). Similarly, over half of the participants reported having regular contact with their child's donor. There were no reports of negative experiences when linking with their child's donor and in all cases, the child got on well with their donor. It was found that once contact was made, children had more frequent contact with their donors than their donor-siblings. Participants commonly termed the relationships they developed with donor-siblings and the donor as "family" or "friend" (Freeman et al., 2009).

Many individuals who are aware of the nature of their conception feel curiosity and decide to try and link with their donor or donor siblings. A study by Van den Akker et al., (2014) explored the experiences of donor-conceived adults searching for genetic family members through DNA linking. Although several participants believed linking to genetic family members would negatively impact their sense of self, sense of family and existing relationships, reports show that this was generally not the case (Van den Akker et al., 2014). Those who did link reported that direct and regular contact was mutually a positive experience and the adverse reactions to linking were low (Van den Akker et al., 2014). Beeson et al., (2011) explored the experience of offspring searching for their sperm donors and how each family make up (single-parent families, dual-parent heterosexual, lesbian families) impacted the process. It was found that offspring with single parents displayed a greater interest in establishing a connection with their donor than those within dual-parent families. Offspring born into dual-parent heterosexual families had the lowest expression of curiosity to connect with their donor. More specifically, one-quarter of participants felt they were unable to discuss their origins with the legal father.

This is consistent with a study by Mahlstedt et al., (2010) who found that only 16% of fathers who raise donor-conceived offspring are supportive in their child's searches.

According to Javda et al., (2010) many donor-conceived individuals utilise donor matching services, with the majority describing a positive experience. Research suggests that some donor-conceived individuals report linking with donors and donor siblings as a redefining moment as it can impact their sense of self (Bylth et al., 2012; Scheib et al., 2020). Additionally, relationships and support networks can emerge when interacting with those genetically related to you, reinforcing a sense of belonging (Scheib et al., 2020). Van der Akker et al., (2015) found that linking with those who shared the same donor felt more complete in their identity and sense of self. Unfortunately, not all those who link with donors or donor siblings report positive interactions. In some cases, linking causes an emotional strain as there is a dissonance when meeting someone who is genetically close but is socially a stranger (Koh et al., 2020; Indekeu et al, 2021). Javda et al., (2010) found that donor-conceived individuals struggled with balancing their loyalty to their social family who raised them with interest in those genetically related to them. Additionally, some donor-conceived individuals report feeling as though the relationships with those who are genetically linked were 'rushed' or did not match their expectations (Hertz & Nelson, 2019).

#### Applying for access to information through New Zealand's HART Act

Prior to 2005 providing information to the HART register was voluntary. It was up to donors, guardians of offspring under 18 years old, and/or offspring over the age of 18 who were aware of their conception as to what information they decided to release. Since 22 August 2005, however, any donations made at the fertility clinic resulting in a birth are automatically included on the mandatory register. Information from the donor, the guardian/parent and the offspring are noted (New Zealand Government, 2017). This includes the donor's name, date of birth and address, the parent/guardian's name and address, and the offspring's name, date and place of birth and gender. After 50 years or if the fertility clinic closes, The Department of Internal Affairs will receive more in-depth details including the donor and offspring's cultural affiliations and family history (New Zealand Government, 2017). If the donor is Māori, you may be able to find out the donor's whānau, hapū and iwi affiliations (New Zealand Government, 2017). ,ation that details regarding a donor or an offspring are held, and \$40.80 for a printout of that recorded information

(New Zealand Government, 2017). Upon reaching the age of 18, those conceived via gamete donation may request identifying and non-identifying information. In special circumstances, if it is decided that it is in the child's best interest, information may be released to applicants aged 16 or 17. However, there must be an order from the Family Court. Once an offspring turns 18, their parents are no longer able to request the information, and that becomes the offspring's responsibility. Similarly, once the offspring turns 18, donors are able to apply for information about the donor-conceived individual, but only if the offspring gives their consent. Note however, that in many cases currently, donors and recipients may meet prior to donation, and make arrangements for information-exchange and ongoing contact if desired. Donors may also be able to access non identifying information about the gender and DOB of offspring born from their donations from the fertility clinic, and the clinic may act as an intermediary upon request between recipients/offspring and donors prior to the offspring reaching the age of 18.

#### Movement towards openness and disclosure

More recently many jurisdictions have moved towards greater openness and disclosure. The international trend to greater openness concerning donor conception occurred mainly from the 1980's. In 1984 the Swedish Government was the first jurisdiction in the world to allow offspring conceived by donor insemination to acquire information about their donor's identity once reaching a certain age (Daniels, 2007). Following Sweden's 1984 Genetic Integrity Act which allowed those conceived via donated gametes to access their genetic information when they are "sufficiently mature", countries such as Norway, the UK, and Germany, Austria and Finland also moved to non-anonymous donation (Pinto et al., 2020). Other countries such as Denmark, Iceland and some states in Canada and the US have implemented a policy that allows a choice between anonymous and non-anonymous donations for recipients and donors. This policy stipulates autonomy and privacy (Pinto et al., 2020).

In New Zealand, the 1987 Status of Children Amendment Act offered a new perspective on disclosure when it stated that donors would be released from any legal liabilities owed to the child (New Zealand Legal Information Institute, 1987). New Zealand's bi-cultural make up and respect for Māori, as well as recognition of adoptees experiences in New Zealand and the small population has resulted in New Zealand's pioneering attitude and views on disclosure. Several New Zealand fertility clinics began only accepting the donations of those who agreed to be identifiable to donor-conceived offspring (Mostyn, 2017). Further progression in this area was seen in 2004 with the introduction of the HART Act (Human Assisted Reproductive Technology Act, 2004). This act recognises the rights donor-conceived individuals have to access their genetic information. The HART act requires all donors to be identifiable to any offspring conceived upon said offspring reaching the age of 18, or earlier by application. Thus, donors have no control over disclosure. On the other hand, there is no legal obligation for parents to disclose and they may choose not to do so (HART Act, 2004).

The HART Act made provision for two government-appointed committees. New Zealand's Advisory Committee on Assisted Reproductive Technology [ACART] was established under the 2004 HART Act (section 32) (ACART, 2021). The two key functions of ACART are to provide advice to the ministry of health and provide advice and guidelines for the Ethics Committee on Assisted Reproductive Technology [ECART] to follow on research and procedures requiring ethical approval (ACART, 2021). ECART is a committee that was established under section 27 of the HART act to review and closely observe applications for procedures involving ART's and human reproductive research (ECART, 2021). Some ART's involving donor treatment require ECART approval for example, the donation of Eggs or Sperm between certain family members, embryo donation for reproductive purposes and research on non-viable embryos and gametes to name a few (ECART, 2021).

Other jurisdictions, such as the United Kingdom and Australia, similarly require donor identity registration. In Victoria, Australia, the jurisdiction goes a step further than New Zealand's as birth certificates contain an addendum, implying that donor-conceived individuals will be aware that there is more information as to the circumstances of their conception/birth on record (Victoria Assisted Reproduction Treatment Authority [VARTA], 2019). This ensures that donor-conceived offspring have access to knowledge about their genetic history and conception.

#### Gifts and compensation

Altruistic motives are commonly reported in non-commercial jurisdictions such as Australia, Sweden and New Zealand (Borgstrom et al., 2019). Altruism can be defined as the selfless concern for others wellbeing (Yee, 2009). Gamete donation allows those who are primarily motivated by helping others to fulfil that desire (Soderstrom-Anttila et al., 1995). Literature indicates that many volunteer donors are against receiving reimbursement for their donation (Shaw, 2007; Purewal & Van den Akker, 2009). Shaw (2007) explored the gift exchange and reciprocity of women who assisted in donor conception. It was found that these women believed that compensation would devalue their donation and that other women may end up donating for the reward rather than for the right reasons (Shaw, 2007; Pennings, 2015). Goedeke et al., (2020) suggest that another reason donors may distance themselves from payment could be due to the way organisations frame donation, as something that is altruistic and cannot be reconciled with compensation. However, altruism can be complicated when it comes to gamete donation due to the organisational practices that can impact it and the potential secondary gain the donor may receive (Healy, 2004). Further, Goedeke et al., (2020) found that fertility professionals, those affected by infertility, donors, and recipients feel that donors should not be left out of pocket as a result of donating. Similarly, in Byrd et al's., (2002) study volunteer donors believe that being offered a payment to cover the personal expenses that accumulate over the course of the process is reasonable, but that this should not result in financial gain. Such costs can include lost working hours, transport etc. Some countries however, such as South Africa still support payment for donated gamete and accept compensation/reimbursement and advertising for sperm donation is permitted (Co-parentmatch, 2019).

In New Zealand, the 2004 HART Act mandated that there is to be no "valuable consideration for the supply of a human embryo or human gametes (HART Act, 2004). However, the donor can receive reimbursement for costs that have accrued along the donation journey. Usually, the recipient will cover the medical and treatment expenses directly or indirectly. For example, in New Zealand, there are set fees when using a clinic recruited sperm or egg donor. These cover recruiting costs, counselling, medical consults, banking, storage and screening costs (reimbursement) (Fertility Associates, 2020). Similarly, for egg donations, various costs associated with donation are covered, as well as extra expenses such as reimbursement for an anaesthetist if required (Fertility Associates, 2020). However, donors can waive the reimbursements if they desire (Fertility Associates, 2020). Note that, for those who have travelled overseas where anonymity and paying for gamete donation are legal, may not bring frozen embryos or gametes back into New Zealand. It is important to reiterate New Zealand's Māori culture and the value placed on whakapapa. Gametes are seen as sacred and therefore not something that can be exchanged for monetary gain. Gifting such treasures may have ramifications relating to inheritance and identity (Lovelock, 2010; Shaw, 2010).

#### **Donor-conception and religion**

It is important to consider the impact that religion has on some population's views of ARTs. Religion is a strong reason why in some societies anonymity still prevails. Sallam & Sallam (2016) suggest that today, nearly all forms of ARTs are accepted in Buddhist, Judaist and Hindi cultures. Because precreation is a core value of Judaism, there is the view that we have an obligation to be "fruitful and multiply" (Silber, 2010). Further, the donation of gametes is often seen as a compassionate act to help another. Similarly, religious groups such as Protestants, Anglicans, Sunni Muslims, and Coptic Christians accept ARTs in most forms, with the possible exception of gamete and embryo donation (Sallam & Sallam, 2016). The strictest view on ARTs come from Roman Catholicism which believes donor conception to be entirely unacceptable.

For many who follow the Jewish faith, assisted reproduction can still be controversial with existing debates surrounding semen collection for any form of ARTs. Many Orthodox Rabbis forbid the "spilling of the seed" (Sallam & Sallam, 2016). This means males are not able to ejaculate to provide specimens. However, non-medicated condoms which prevent spillage are permissible by some Rabbis. If couples are seeking sperm donation, conservative Rabbis who agree with this prefer the donor to not be Jewish. This is because the Jewishness confers through the mother's line and Rabbis wish to prevent adultery and genetic incest among the offspring of genetic donors (Kahn, 2000). Similarly, some Rabbis do not encourage egg donation. The belief is that if the genetic mother is not Jewish, the offspring cannot be Jewish either (Gardener et al., 2018). However, more recently, Rabbis have started to accept this practice and permit egg donations from a non-Jewish individual (to avoid possible incest), explaining the Jewishness can still be conferred through the parturient (Gardener et al., 2018). Pope Pius XII proclaimed in 1956 that artificial fecundation is immoral as it separates normal sexual function and procreation. This proclamation has shaped the Catholic Churches position on ARTs.

Another belief that Pope Paul VI voiced in 1968 was that children are a blessing and God's gift, although science makes things possible, it does not make them right (Sallam & Sallam, 2016). Similarly, there are still existing challenges for single mothers and same-sex couples who belong to the Church of England. The focus is on the Churches perception of child welfare (Sallam & Sallam, 2016). The Church is concerned that by design, the offspring of a

single parent or same-sex couple will never have a father or mother. The Church believed this would portray a message that says that everyone has a right to a child, and this right overrides consideration of a child's welfare (Sallam & Sallam, 2016).

Studies have explored the experiences and well-being of donor-conceived adults but there is limited research with respect to at donor-conception in New Zealand's unique bi-cultural context. This research project comes at a relevant time as 2022 marks a year that the first donorconceived people born under the provisions of the 2004 HART will reach the age of majority. Thus, it is important to explore the experiences and of donor-conceived people to inform prospective donors, parents and the fertility industry to ensure the wellbeing of donor-conceived individuals is prioritised and optimised.

#### **CHAPTER THREE: METHOD**

The primary aim of this research was to examine the experience and wellbeing of donorconceived adults in a New Zealand context. This chapter describes the rationale for the methodology used. This chapter outlines this study's epistemological and qualitative methodological position, and explains the recruitment methods, data collection, and data analysis procedures and discusses the process of employing a thematic analysis to translate the data. Ethical considerations are explored, as well as the actions utilised to ensure research quality and rigour.

#### **Design and rationale**

This study is informed by a hermeneutic phenomenological epistemology that explores the subjective life experiences of participants and denies a singular reality as each individual has their unique perspective (Miles et al., 2013; Van Manen, 2017). Furthermore, this epistemology takes on the approach that perspectives are contextually and socially constructed by the interactions individuals have with others and the worlds they interpret (Doucet et al., 2010). This study aimed to gain a deeper understanding of the perceptions, thoughts and feelings of each participant conceived via sperm or egg donation in New Zealand, rather than constructing causal effects, something that has happened based on something that has occurred (Hudson & Ozanne, 1998).

According to Hargreaves (2001), qualitative research is thought to be a compatible fit for emerging research and research involving sensitive topics. A qualitative approach was deemed the most appropriate for this study due to the emphasis placed on individual experiences/realities (Willing, 2013; Gelo et al., 2008). Reality is a concept that is subjective and socially constructed. The qualitative approach allows researchers to recognise the meaning of individual experiences while utilising inductive reasoning to develop in-depth results in which reflects collective experiences (Gelso et al., 2008; Harwell, 2011). There is limited research in the field of donor conception, and while it is difficult to estimate the number of donor-conceived adults in New Zealand, it is likely that population is a small one. Grant and Giddings (2002) suggest that the assembling of knowledge relies on the relationship between the participant and the researcher. In the present study, information was gathered through interviews and interpreted collaboratively. Participants were regarded as the experts who guided knowledge by providing insight into their experiences. The researcher then interpreted and reflected on the data through the eyes of the participants, later confirming findings with the participant to ensure their true meaning was conveyed (Van Manen, 2017).

#### Reflexivity

There is the assumption that in qualitative research, findings are often influenced by the researcher (Dodgson, 2019). Therefore, the researcher needs to acknowledge their positioning within the research and realise that findings go beyond them and their professional affiliations (Dodgson, 2019). Jootun et al., (2009) suggest that reflexivity allows the researcher an opportunity to either intentionally or unintentionally exert influence onto the dataset. According to Willig (2001), there are two types of reflexivity which the researcher needs to consider: epistemological and personal. Epistemological reflexivity can be specified by reflecting on the research question, how it was defined and limited (Thorpe, 2013), how accurately the data and findings were constructed from the design and methods analysis, and the researcher's existing knowledge and assumptions (Thorpe, 2013). Personal reflexivity refers to considering the way in which the researcher uniquely influences the research through their experiences, beliefs, values, goals and social identity (Willing, 2001).

Before embarking on this research project the only knowledge I had regarding infertility came from my grandparents and other family members who had struggled with conceiving. Furthermore, specific knowledge regarding donor-conceived individuals came from a friend of mine who was conceived via sperm donation. Therefore, my knowledge and experiences were limited, potentially causing bias. Alternatively, in having minimal knowledge, I did not feel as though I was the expert. Rather, I positioned myself as providing a platform for the voice of the experts- my participants. I intended to remain open and curious throughout the research process. By reflecting on the influence my personal opinions may have on this study, my self-awareness increased allowing me to conduct a research project which is richer in quality and rigour. However, despite this, limitations are likely to have arisen.

Of particular importance, my ideologies, beliefs and perspectives are shaped by my training in counselling psychology which places merit on a relational approach and values the personal experiences each participant encounters. Although my role as an academic researcher may have positioned me as a sort of "expert" and created an imbalance between myself and participants, my client-centred focus may have minimised this gap, aiding participants to feel valued and heard (Dodgson, 2019). To enhance the professional relationship, I spent time explaining my motivations behind the study and built rapport by creating an open space that encouraged input and questions. I utilised accessible language and employed an empathetic listening style.

#### **Participant recruitment**

Participants were recruited through the charitable trust Fertility NZ who advertised the study on their website. The possible group of participants was then extended as a result of snowball sampling, which is where the researcher starts with a small number of initial participants fitting the research criteria, who then recommend the study to other potential participants, and so on (Parker et al., 2019). In the present study, individuals who saw the study, then reposted it on other forums such as closed Facebook groups. Interested parties who were willing to share their experiences and perspectives were invited to contact either myself as the study researcher, or the research project supervisor, Sonja Goedeke via phone or email. Potential participants were provided with a participant information sheet that outlined the aims of this research in detail and were encouraged to ask questions about the study. Respondents who decided to proceed with participation were then followed up via email where it was confirmed they met the selection criteria, and an interview time was arranged.

The selection criteria included individuals who were conceived via egg or sperm donation in New Zealand and who were well versed in English. New Zealand's unique bi-cultural make up and legislation that focuses on openness were determining factors as to why participants had to be conceived in New Zealand. A minimum age of 18 was also a requirement for this research for ethical purposes. Further, in New Zealand, 18 years is the legal age for those who are donorconceived to access their genetic information (if they had not already applied for access earlier or if their parent/caregiver had not applied on their behalf). To avoid conflicts of interest and ethical dilemmas, any friends or family of the study researcher or supervisor who were donor-conceived were not included in this study. Potential participants were given two weeks to respond, this was then extended, and Fertility NZ reposted the advertisement.

This study drew on the experiences of the first ten respondents who fit the above criteria. Large numbers of participants are not always required for qualitative research as the objective focuses on depth over breadth (Nicholls, 2009). Ten is deemed an adequate sample size for a thematic analysis according to Braun and Clarke (2013). All participants but three resided across New Zealand (the latter residing in Australia), identified as Pakeha/New Zealand European and ranged in age between 23 and 43 at the time interviews were conducted. Six of the ten participants had children of their own. All ten participants had put efforts into linking with their donor but at the time of the interview only six had made contact. One participant linked with their donor after their interview. It is important to note that all ten participants were born prior to the 2004 HART Act and were all conceived via sperm donation.

#### **Data collection**

Semi-structured interviews were utilised to gather data, a method allowing participants the freedom to express their thoughts, feelings and perceptions on emotionally sensitive issues in their own words (Cohen & Crabtree 2006; Kallio et al., 2016). Interviews were opened with introductions intended to build rapport, this was followed by an explanation of the interview process, confirming consent and the chance for the donor-conceived individual to ask questions. Knox & Burkard, (2009) suggest researchers allow participants to guide the interviews. To allow this process interviews officially began with the question: "How/when and by whom was it disclosed to the individual that they were conceived via donor?". Topics discussed included experiences of obtaining genetic information, contact with their donor, changes in family dynamics and self-identity (see Appendix B for interview schedule). The semi-structured nature of questioning allowed for flexibility and versatility. The researcher was able to focus their attention to concepts that were meaningful to the individual, thereby strengthening rapport and demonstrating respect and collaboration (Kallio et al., 2016; Grant & Giddings, 2002). Openended questions were utilised allowing the researcher to view the information in a way that was comprehensive and holistic (Allen, 2017). This type of questioning encourages respondents to provide more in-depth exploration and opinion (Allen, 2017; Hill 2014). Additionally, closed
questions were used for clarification and to prompt a further response. Follow up questions were asked to elicit a deeper exploration and silence allowed for reflection (Hill, 2014).

All interviews were conducted between June 2021 and August 2021 and ranged between 40-90 minutes. Participants were given the choice of meeting in person, but due to geographical distance, all opted for the interviews to be conducted over Zoom. Participants consented to the interviews being recorded, and the researcher transcribed each one verbatim with the assistance of the Otter app. Interview transcription was then re-checked manually and sent to participants for confirmation to ensure accuracy. Participants were given the opportunity to choose a pseudonym if they wished to remain anonymous. Some asked the researcher to assign a pseudonym to them.

Participant Number	Subject Pseudonym
1	Dani
2	Mark
3	Charlotte**
4	Donna
5	Sophie
6	Anna*
7	Kelly**
8	Matt
9	Carly*
10	Emma

Table 1: Pseudonyms of research subjects

\*Pseudonyms were assigned by the researcher

\*\* Pseudonyms were chosen by the participant

#### Thematic analysis

This research project has employed Braun and Clarke's (2006) thematic analysis to analyse the data collected. Thematic analysis is an inductive method that develops understanding by systematically identifying, organising and interpreting themes across a qualitative dataset (Braun & Clarke, 2012). The main purpose of thematic analysis is to identify the meaningful patterns and commonalities present that are relevant to the research question (Braun & Clarke, 2012). However, it is important to consider that what is common in the data, may not always be meaningful or relevant. Braun and Clarke (2012) posit that flexibility and accessibility are strengths of this method. Further, thematic analysis is considered useful for exploring unknown perspectives and under-researched topics, therefore deeming it appropriate for this study.

A six-step procedure is suggested by Braun and Clarke (2006) to analyse data thematically. Data is rarely linear and often develops over time meaning the six-step process utilises flexibility. However, before commencing these steps, five pertinent questions should be considered (Braun & Clarke, 2012).

#### Five decisions for Thematic analysis

First, it is important to determine what constitutes a theme. Rather than focusing on how often themes appear throughout the data, it is important to establish themes by recognising the importance of them concerning the research question (Braun & Clarke, 2006). The researcher focused on dividing their attention equally across all the themes as they were identified, ensuring all potential themes were linked meaningfully to the research question.

It is also proposed that researchers should determine if the focus of analysis will explore a single detailed account or a broader description of all data collected. The present enquiry employed the latter as it attempts to explore a more in-depth description of the experiences of being a donor-conceived adult in the unique New Zealand context from the entire dataset.

Additionally, it is important to decide if the research is deductive or inductive (Braun & Clarke, 2006). The present research has utilised a bottom-up, inductive approach as themes were derived and developed directly from the dataset (Braun & Clarke, 2006). A deductive or topdown approach would not have been as appropriate as this would have encouraged the researcher to consider their own beliefs, biases and ideologies when interpreting the dataset. To control for this, researchers can have participants review and verify the findings, further results can be shared with one's supervisor as they may be able to comment on or identify gaps that need to be addressed. This process will also allow the consideration of alternative explanations for findings.

There are two different levels at which themes can be identified during a thematic analysis, latent and sematic (Braun & Clarke, 2006). Boyatvizl (1998) describes latent as an approach that explores the underlying assumptions and ideas of the data, whereas semantic is an approach that establishes the more surface-level information. The present enquiry utilised a combination of both.

Lastly, Braun and Clarke (2006) suggest that an epistemology will need to be identified. As previously mentioned, a hermeneutic phenomenology epistemology has been used in order to examine the experiences and wellbeing of those who are donor-conceived and investigate indepth what is meaningful to each.

#### Six phases of thematic analysis:

As proposed by Braun and Clare (2012), the researcher followed the well-established six phases of thematic analysis. Firstly, the interviews were transcribed verbatim which enabled familiarization with the data. Further, reading, re-reading, note-taking about potential patterns and re-listening to audio recordings allowed the researcher to immerse herself in and engage with the dataset (Terry et al., 2017). Taking notes during this first phase can be described as an observational task rather than a systematic one. There is no coding in this phase, instead, the researcher began noticing what information was relevant (Braun & Clarke, 2012).

The second phase involved actively identifying and formulating initial codes (Terry et al., 2017). The dataset was read through multiple times to help the researcher identify the relevant patterns and how they can coherently explain the information. Codes were examined and similar codes were collated to generate more refined and meaningful patterns (Braun & Clarke, 2012).

Thirdly, refined codes were shifted to themes with broader categories and sub-categories. Braun and Clarke (2012) define a theme as something that is constructed to capture the meaningful factors present. Phase three provided an opportunity to explore the relationship between themes and clarify how they can describe the stories of those participating (Braun & Clarke, 2012).

Themes were reviewed and refined in the fourth stage. This process occured on several occasions in collaboration with the research supervisor to ensure their relevance and quality

(Braun & Clarke, 2012). Stage five involved naming and defining the themes established. Themes in this stage should have a singular focus with minimal overlap with others. The researcher engaged in deep analytical work here to generate themes that best illustrated participants experiences. Finally, in stage six, researcher produced the final analysis in the form of a report, in this case, the Results and Discussion chapters. Findings were reported to provide a cohesive and coherent narrative (Braun & Clarke, 2012).

#### Quality and rigour

The term "trustworthiness" is utilised in qualitative research to ascertain how much truth-value can be placed on the analysis and interpretation of the data (Pratt et al., 2019). Readers may not always interpret the results the same as the researcher, however, the process the researcher took to conclude should be clear and able to be followed (Koch, 2006). Trustworthiness incorporates concepts such as credibility, dependability, transferability and confirmability. These can be assessed to determine the study's rigour and quality (Lincoln & Guba, 1986). Aroni et al., (1999) define rigour as a way the research process can illustrate its competence, legitimacy and integrity.

Creditability in qualitative research is parallel to internal validity in quantitative research. Credibility rests on the researcher's confidence regarding the data representation and their transparency in reporting (Koch, 2006; Johnson et al., 2019). More specifically, researchers should honestly identify and address the potential biases and confounding factors associated with the research (Johnson et al., 2019). Further, a researcher's self-awareness is crucial to the study's rigour when considering their existing knowledge, biases and rationale. The researcher reflected on their own biases throughout the reporting process. When asking questions the researcher was careful not to interpret the question for the participant and allowed them to answer fully before continuing. The researcher did not comment on the answer emotively or put forward their opinion in response. The researcher aimed to create an environment that could facilitate the authentic accounts of participants. All data was transcribed by the same researcher to ensure consistency and then checked several times against original recordings for accuracy. Completed transcripts were sent to participants who were encouraged to augment or amend the information, ensuring perspectives and experiences were portrayed accurately. Further, all transcripts were reviewed by the research supervisor. Dependable research refers to its reliability and transparency. All decisions should be described in full and be able to be replicated by others, where comparable and analogous conclusions can be found (Koch, 2006). By following Braun and Clark's (2006) thematic analysis guidelines, a clear audit trail has been established in this research. Additionally, reflexivity is central to dependability, so the researcher maintained a self-critical narrative of their processes, reflections and decisions throughout (Koch, 2006).

Transferability can be described by a study's ability to be positioned into similar contexts outside of the present enquiry (Koch, 2006). Further, transferability is present when different populations from similar contexts can find meaning from the findings and feel the there are parallels in their own lives (Koch, 2006). The results of this study may be applicable to a context where offspring do not know of or have access to their genetic origins, such as adoption.

Confirmability as described by Tobin & Begley (2004), demonstrates that all conclusions and interpretations have been derived from the present data. The concept of confirmability is attained when dependability, transferability and credibility are present (Guba & Lincoln, 1986). Standards of rigour including member checking and triangulation can impact the research's confirmability (Johnson et al., 2019). The above standards address any researcher influence that may manipulate the findings.

#### **Ethical Considerations**

This study was granted ethics approval on 26 May 2021 by Auckland University of Technology Ethics committee (AUTEC reference number 21/136) (Appendix C). Ethical considerations included:

#### Informed consent and participant wellbeing

The purpose and aim of this study were clearly communicated and all participants gave their verbal consent which was recorded before the interview commenced. It was reiterated on several occasions that participation was entirely voluntary and that participants would not be disadvantaged in any way if they wished to withdraw. Because this was a potentially sensitive topic for some participants, the researcher was mindful to address discomfort that participants experienced. A list of potential interview questions was offered to participants before the interview and permission was given to opt-out of answering any. Additionally, participants were

advised they were able to stop the interview if required. Fertility NZ provided some details regarding support. Further, AUT counselling services provide three free counselling sessions for participants in AUT run studies. Information for both was listed in the participant information sheet.

#### Confidentiality and privacy

Zoom calls were organised for all participants due to the broad geographical spread, both across New Zealand and Australia. Each participant was given the opportunity to maintain their privacy by choosing or asking to be assigned a pseudonym that would then be used across the report. The data collected was stored on a password protected AUT server, with restricted access. Because all interviews were conducted over zoom, all participants gave their verbal consent, details of which were also stored on AUT's secure server. Transcripts will be stored for six years in a locked drawer in AUT's Psychology Department. Once this electronic/hard copy – see above where you say data is on a secure drive) time has elapsed, these transcriptions will be disposed of by shredding and discarding them into a confidential waste bin at AUT and deleting electronic copy? Check the ethics application. Respondents willing to participate contacted the researcher directly, who then organised an interview time that suited both parties. There was no involvement of third parties and no identifiable information was passed on to third parties upon this report's completion. No identifying information was provided in the research report.

## **CHAPTER FOUR: RESULTS**

Themes and subthemes were established from the interviews that were conducted, as represented in the table and described in more detail below.

Table two: Summary of themes

Primary themes	<b>Sub-themes</b>
Donor conceived as an integral to identity (part of who I am)	Nature vs nurture Confusion about who I am
Parent views as influential to linking/searching (my parents' views influence my experience)	Strong family ties
The donor's role in my life	I don't need another parent How does the donor fit into my life?
Long term wellbeing is a priority (Children become adults with needs)	Consider the child, they will grow up Passing on important information Who should I date?
The need for openness	The earlier the disclosure, the better the reaction Navigating disclosure conversations Understanding parents and donors Secrecy
Disclosure for wellbeing (tell me at the right time and in the right way)	I can't remember being told Disclosure used for alternate purpose I remember being told Telling others
Searching: A lonely task	Sense of having to link on your own Hopelessness and frustration Protect yourself Searching takes time and energy
Linking: A mixed experience	Rejection Welcoming Uncertainty Donor siblings
The need for support	Donor-conceived communities

#### Theme One: Donor-conceived as an integral to identity (part of who I am)

Several participants expressed the belief that a part of their identity is linked to their genetics. However, others appeared to minimise the importance of genetics and placed importance on social factors and their upbringing, or on nurture. However, the knowledge of being donor conceived also led to some experiencing a sense of confusion as to who there were, and attempting to weave this into their narrative, as is detailed further below.

#### Nature vs nurture

Several participants wanted to learn about where their physical and personality traits come from and ascribed these partly to genetics.

Do we actually look like him or not at all? Do we get any of our traits from him? Or anything? Are there any medical conditions that we've got to be aware of?

Dani

I would have liked to have heard like what his traits were, what he was interested in and all sorts of things like that what his family was like and it wasn't like I wanted to force my way in and be a part of it but I wanted to understand what came from him and what came from my upbringing.

Carly

Medical history seemed to be of particular importance.

When you go through the doctors, they always ask about family history and my wife knows all about hers, but I can't answer some of it and that was a bit of a driving force behind linking. Not so much for myself, but for the kids growing up and stuff, just have the answers there for them.

Mark

I would've liked a picture and to know what he did for a job, and yeah some personality traits and medical information. I think if I had those medical records that may have

satisfied my curiosity. When you asked to talk about your family medical history, you're like, well I don't know, half of it.

Alternatively, others attributed their traits to their social family also.

I think, the way your parents bring you up, I know there's not total science around it but I think they've definitely had a big impact on me and who I am as a person. I feel like he's only just a small part of who I am and I don't see him as a big block for me to carry on with my life. Yes, my genetics came from another person but the other stuff is bigger than this person.

Charlotte

Kelly

Anna was similar to Charlotte in that she believed that the cultural habits and beliefs that one learns or witnesses during ones upbringing, forms a part of identity.

My social dad was from York where most things can be solved with a cup of tea. I still feel like it's part of my identity as well so I don't think it has to be genetic to be a part of your identity.

Anna

Kelly made it clear that being donor-conceived did not cause her to feel as though a part of her identity was missing.

I never really had a burning desire to find out about my donor, it was a mild curiosity of like does he look like me, are we interested in the same things, but beyond that, I didn't feel like a big part of my life was missing, or that there was some big mystery that I needed to solve. Yeah, being donor conceived doesn't really occupy, well, it didn't, I should say, occupy much of my headspace.

Kelly

#### Confusion about who I am

Several participants however, expressed that knowing they were conceived via donor created some confusion about who they are, that some part of them was unknown and linked to their donor. Sophie combated that confusion by weaving the fact she was donor-conceived into her identity narrative, making it a central part of who she is.

The first few years, of truly knowing, it was a horrible secret. I felt like everyone could tell I was different. It really abnormal. And then it became this quirky feature that I'd tell everyone really proactively. I'd tell people at high school deliberately to make them awkward. And I became a real advocate for donor conception in my early 20s. And then when I met him I kind of wove his story into mine.

Sophie

It was not until after Carly linked with her donor that the confusion about who she was escalated. Her donor was not welcoming causing Carly to question why he donated and why she was conceived.

I think since I've found him, I'm starting to really question everything about me, and I know it doesn't change how I was the day before I found out vs the day I found out but I do feel I don't know, I feel like I should've had some counselling or something.

Carly

Anna spoke about having to change her view of herself after disclosure. She also touched on the idea that she was still not able to fully create a picture of who she was because there were still so many unknown details.

I had this idea of myself and then had to change it. I think that knowing early on was helpful. On the other hand, I didn't even know my ethnic group, until I was in my late 30s. Anna

On the other hand, searching and linking could be extremely healing for some individuals. While at times Matt explained that he has looked in the mirror and wondered who he was, he also

expressed that finding out little bits of his family's history aided in filling some gaps and pacified some confusion.

Searching fills a bit of a hole I guess in terms of the identity thing. Sort of knowing where you've come from and having pictures of your grandparents and great grandparents and all the stories, from all the generations. It certainly fills part of the hole. Facebook's a wealth of information. It's like oh, here's my half siblings, here's my half nieces and nephews. You feel like a bit of a stalker because you don't actually know the people but it's all on a public domain.

Matt

Similarly, Emma stated that just knowing that her donor was a real person who existed helped.

In the process of doing the DNA test I had to acknowledge to myself that this is who I am. But knowing who he was, even before I spoke to him, just knowing a name. It was like a key turned in the lock, one of those old-fashioned ones where you feel everything kind of turning, I just felt better.

Emma

# Theme Two: Parent views as influential to linking/searching (my parents' views influence my experience)

Several participants made it clear that their social families played a role in the decisions they made in regards to searching and linking. They spoke of being able to pick up when their parents were feeling uncomfortable and often took on their discomfort, and in contrast, how strong family ties helped with integrating donor conception into their identity.

In the cases of Mark and Carly, whose parents were uncomfortable with their children's donor conception, their subsequent behaviour and openness with their parents was impacted

My dad put me off- I kind of didn't want to discuss it with him. It was like a thing I kind of wanted to do but I didn't want to risk our relationship. Yeah it put me off.

I haven't actually spoken to them (parents) about it (linking). Mum was just so anti it that I haven't bothered to talk about it.

Carly

Matt's lack of openness and communication come from a place of wanting to respect his father's discomfort.

I've talked to Mum but not dad at all. Mums always said that it's not something that he is very comfortable with. He's kind of ashamed of it and it's just sort of respecting his wishes I guess.

Matt

Alternatively, Dani's parents are curious and were encouraging of her searching for her donor.

Mum and Dad are actually quite keen for us to reach out to our donor father and find out anything about him. They are curious to see what he looked like and his traits as well, and his medical history and stuff that we need to be aware of.

Dani

Charlotte's family do not talk about donor-conception openly. When linking she did not feel as though she should share this information with her parents. As a result, Charlotte experienced feelings of guilt.

When I did meet him, I did kept feeling a bit guilty about mum and dad and that I'm doing this and they don't know. How would they feel about it they knew?

Charlotte

Kelly also said that she would have felt uncomfortable linking with her donor if her social father had still been alive, and there was a sense of wanting to protect her social parent's feelings

49

If dad was still alive, I think it would be hard for me to have any contact with my donor cause I would feel really bad.

## Strong family ties

Charlotte suggested that having a strong relationship with her family helped her appreciate the fact that she was donor-conceived in more neutral way.

*I think the strong relationship we had was strong enough to make it not matter too much. But I'm glad that they told me and didn't keep it any longer.* 

Charlotte

Kelly

Similarly, Kelly's strong relationship with her social father prevented her from not seeing him as anything but her father.

I was really close to dad and so I kind of was like, I don't know, it just didn't change the way I felt about him. I was just like well this is the only Dad I've ever known and he raised me and loves me and he takes care of me. He's always going to be my dad.

Kelly

Alternatively, a lack of closeness could paradoxically also help with processing knowledge of donor-conception. Anna's relationship with her father was strained, however, she was close with her mother. Anna said that she would have been more upset to learn she was not related to her mother's side, as she identified with them strongly.

I really didn't get on very well with my social father, who's quite abusive and so there was actually a bit of a feeling of relief that I'm not actually related, genetically, so that wasn't a bad thing. I wasn't as upset as if I would have been if I'd found out that about my mother say, I would have been like really devastated. I was very attached to my mum, and to her family.

Anna

#### Theme Three: The donor's role in my life

Navigating the role that one's donor plays in their life can be challenging. Participants reiterated the fact that there was no guidebook informing them on how they should view their donor. Although donors and offspring are related genetically, the relationship that comes from relations is not an automatic one, but instead something that is developed.

#### I don't need another parent

All participants expressed that they did not begin searching for their donor to find a parent. Most stated that were more interested in finding their donor to learn more about themselves, and that a relationship was seen as an added bonus.

Meeting once is enough- unless he wants a relationship but I'm not fussed.

Dani

Mark explained that he was not in need of another father, that his social father was enough for him. What he was after was what his social father could not provide, knowledge about his history.

*My* dad's been there from well before I was conceived, like we may not be biologically connected, but he's my dad. I couldn't ask for a better dad. I'm not looking to replace him. It's just the knowledge.

Mark

Similarly, Donna mentioned that she would have been content with gaining information. However, the fact that her donor was willing to engage with her on a more personal level was an added extra that she did not expect.

*I personally would have been happy if I only had access to that history and information, but the fact that he was willing to meet, it was an added bonus.* 

Donna

Kelly's motivation to link was based on a curiosity rather than wanting a parental relationship.

I always had a curiosity but I didn't feel like I needed a parent, and even now I don't need a parent.

In contrast, Emma was not close with her social father and after disclosure their relationship became distant. When Emma then met her donor, he was willing to fill that space and since then, their relationship has developed into that of a father and daughter.

I think for me because my relationship with my dad broke down, there is a space for him (donor) to be like a father, whereas, if you had a really good relationship with your dad then there wouldn't be a space, you might just want a fun uncle or something like that.

Emma

Kelly

Although Emma had space in her life for a parent, she said that she did not search for her donor with the expectation that a relationship would form. She went on to say:

I reflect back on the sense of relief I found out his name, that he existed as person. That enough was so healing, the relationship was just a bonus.

Emma

## How does the donor fit into my life?

Navigating a relationship with the donor could be a difficult process. Donor-conceived individuals are faced with the fact that they are genetically half of their donor, however, donors do not fit within the framework of normative societal relationships as would be the case for other genetic relatives.

I found it really hard to process how I should feel about him (donor).

Kelly

Some discussed this with their donor to come up with an appropriate arrangement, for example, referring to their donor as a type of extended family member.

We talked about what we wanted this to be. I mean for a while he was more kind of just like, you know an uncle or something who I didn't really know that well.

Sophie

However, others did not believe that there needed to be a special space for their donor.

*Just cause you share genetics, doesn't mean you're going to be best friends.* 

Charlotte

#### Theme Four: Long term wellbeing is a priority (Children become adults with needs)

Many participants felt that at the time of their conception, fertility clinics, doctors, donors and parents failed to consider the long-term health and well-being of the offspring, and that consideration needed to be given that donor-conceived children would become adults with their own rights and needs, including with respect to their prospective intimate partners and passing on relevant information.

The donors happy because they've got anonymity, the doctors happy because they've helped people and created this person. But they've completely forgotten about the offspring.

Matt

Kelly mentioned that while this practice may have been the norm previously, the emergence of new technologies and heightened awareness implied that this practice needs to evolve.

It was anonymous at the time, and they were assured anonymity but modern science has, you know, changed things.

Kelly

Consider the child, they will grow up

Participants felt that some parents lacked foresight in that children will grow into adults who are curious about who they are.

I get it parents want to have children and that is the supreme drive, but this is not an accident and the children then have to deal with the aftermath.

Emma

Matt suggested that parents should consider the offspring's needs before their own, and remember they are creating a human-being who will have their own thoughts, feelings and emotions about this topic which may evolve over time.

I think the main thing is to consider that you're creating a human-being, not just a child to make you happy, or make a family. You're creating a child who wants to know about their identity and who they are. The whole disclosure thing needs to be more open. They need to consider the needs of the person, before their own.

Matt

Amy pointed out that parents rarely have children for the child's wellbeing.

They (parents) are not thinking about the well-being of the kids, they're thinking about their own well-being. I mean for all of us, having a baby is kind of a selfish thing. I didn't have my kids because I was thinking about them, I was thinking about me and that I wanted kids.

Anna

Participants thus emphasized that it is important to note that a donor's actions can impact the offspring meaning that donors should recognise that their donation act should not be considered as a once off event, but that they would need to consider the longer-term implications of the choices they had made.

He's (donor) created this giant freaking web of people, and his actions still affect us. I just don't think donors think that far down.

Sophie

Kelly notes that receiving support and gaining knowledge about those conceived via donation should be something prospective parents consider and access.

*I think that prospective parents should get counselled on what it will be like, how to tell children, when to tell them and what expectations there should be.* 

Kelly

#### Passing on important information

Frustration was expressed when donor-conceived individuals wanted clinics to pass on important health information to their donor siblings that could prevent future harm. In many cases participants reported that clinics were unable to pass on the information as the onus to disclose is on the family and there was no way to communicate this information without disclosure.

It was obviously really good meeting him (donor) because he told me about his bowel cancer. The clinic hadn't told us that, and haven't passed information on (to my other donor-conceived siblings). I've sent a letter to the clinic to pass it on, it's so preventable. Sophie

You hear about all these people who've been rejected or they've inherited the cancer gene and the clinic refuses to tell this donor-siblings because the parents haven't disclosed to them. It's just really upsetting.

Emma

#### Who should I date?

A concerning part for participants of being donor-conceived and not being aware was the possibility of entering a romantic relationship with a half-sibling.

I've only just discovered this horrifying thing called genetic sexual attraction, which apparently adopted people know about, and we're not necessarily learning the lessons from that. You might be sexually attracted to you half brother or sister, and not even know because it hasn't been disclosed to them, or it hasn't been disclosed to you.

Emma

Could you imagine if you started dating, and then married and had your own offspring and then all of a sudden you find out you married and reproduced with your half-brother. I'm like you need to tell people and also for the health reasons. That's the thing I would make 100%.

Donna

I have a partner and I know he's definitely not related to me. I don't know if it goes through my brothers' minds, like am I dating my sister?

Dani

I think I got an email (from the fertility clinic) with some information. I'm pretty sure I remember them telling me about the consanguineous relationship thing.

Sophie

#### Theme Five: The need for openness

A common view amongst participants was that all parties involved in their conception including, parents, donors and fertility clinics, should to strive for openness. Openness was not seen as something that one party needed to focus in isolation as all parties interact and have the potential to impact the offspring's wellbeing.

#### The earlier the disclosure, the better the reaction

Several participants said that early disclosure is best even if the child is too young to fully understand. They felt that knowing or having an idea of their origins was better than parents waiting to disclose when the offspring is "old enough to understand".

Tell them as soon as possible. They don't have to meet them, they don't have to get anything more than that or understand, just let them know.

Donna

*I think definitely before the teenage years. You need to be aware of it, even if you don't fully understand.* 

Matt

Mark's parents told him that he was donor-conceived at the age of 14. He felt as though this was too late and refers to his sister who was younger at the time of disclosure, crediting her more neutral reaction to knowing early but perhaps not fully understanding.

I don't think there's an actual ideal age. It's a real tough one because when you're young, you don't really understand it. Like my sister, I don't know if it was because she was a bit younger and didn't understand it as much but she took it so much better than I did. Mark

Dani suggested that early disclosure can prevent donor-conceived individuals from feeling as though the disclosure conversation is a "big reveal".

Early disclosure is best. Because that way there are no secrets. There's no big reveal at the end. It's all out in the open.

Dani

Similarly Donna regarded being young with a lack of comprehensive understanding and a level of naivety which prevented the news from seeming as monumental.

I think because I was ten, I didn't really know what that really meant (being donorconceived). They (parents) kind of explained it, but as a 10 year old, you're kind of like whatever, he's my dad. Kelly touched on the idea that being told something important so early on can be a lot to process. However, from her perspective, the earlier the disclosure, the more time donor-conceived individuals may have to figure out how to process the information.

I don't really know. I mean, it feels like a lot (being told at a young age), because I didn't know how babies were made. But, it meant that I had my whole life, most of my life to get my head around it. It wasn't like I felt I'd been lied to my whole life.

Kelly

Charlotte had gone her childhood and adolescent life not knowing she was donor-conceived. Charlotte expressed feeling in complete shock and as though the world as she knew it had changed. This quote suggests that it may be harder for those who are older to process this information.

I was 18 and it felt like I was in a movie. You're just like, this is not real. Like this is not happening to me. It's just a complete turnaround of what you knew and what you thought. I guess it's just the family that you trust, they've had this hidden away for so long. I couldn't take in.

Charlotte

#### Navigating disclosure conversations

It appears that several parents struggled to have ongoing conversations about donor-conception. Donna states that if she had been younger than the age she was at disclosure she may have forgotten, although of course this would be mitigated by undergoing conversations. However, conversations regarding donor-conception do not appear to be common after it has been disclosed. I think if I had have been any younger than 10, I wouldn't have really understood or even really remembered it. Because it doesn't come up at family dinner every time, it's not talked about.

Donna

Sophie was told at a young age but did not quite understand what she was being told the first time. When she was older it had to be clarified and explained to her again, which was a more traumatic experience.

It felt like it was a horrible secret. Things feel like a secret when they're not talked about openly.

Sophie

In several cases, it appears that the infertile parent is not involved with subsequent conversations. Additionally, their discomfort can impact who else in the family is aware.

It probably was never discussed outside of me, my mum, maybe my brother, possibly not even my dad (infertile). And certainly not anyone else in the family. And I think most of them probably don't know.

Matt

Parent discomfort can impact how the offspring feels about discussing the topic of their conception further.

Since they told me, I've always got the feeling that it's an uncomfortable subject. It's come up a couple of times in conversation but we've never had that big heart to heart about it. Charlotte

Kelly suggested that parents use an aid when disclosing and that it was also important not to frame this information in a way that was secretive or shameful. Having regular conversations was also regarded as reducing the stigma and discomfort.

I think any kind of prop that you can have that helps you explain something that is complicated, and a way that helps the children feel like they are still incredibly loved and incredibly wanted, that they're special, and, you know that it's not something to be of ashamed of.

Kelly

Simply put, Anna suggested that if openness is not something parents are comfortable with, then an alternate method will need to be considered.

Parents if you don't want to tell your kids that they're donor conceived, then don't have donor conceived kids.

Anna

#### Understanding parents and donors

Many participants expressed that they did not blame their parents for later disclosure and instead placed blame on medical professionals including doctors and fertility clinics.

*I kind of excuse my parent's generation there wasn't the internet and you know, clinics, told them not to tell their children.* 

Sophie

I don't actually blame my mum, because I think they trusted the doctors. I think our doctors now know better. But they should have known better at the time, they had all these adoptees that they were dealing with.

Anna

Some participants empathised with their parents and understood the difficult situation they were faced with.

I'm not angry at my parents or anything. I can totally understand how hard it would be for them. Especially having done it when it wasn't well known, or when people didn't support it or. I really understand from the point of view that perhaps it was better at the time to keep it a secret. I can understand that it must be so hard to tell me, not knowing what I would say

Charlotte

Some participants respected the donor's decision to not be contacted, but reiterated that this does not mean the offspring should be kept in the dark.

I understand donors not wanting to be available to be contacted. I'm 100% keen on that still being an optional thing, but I really just wish there was something where if you were donor conceived, you had to know about it. There's so many people who aren't told.

Donna

Kelly empathised with the situation that her donor was in as his family was unaware of the donation. This suggests that donors also need to be open with their families and include/consider them in their decision making process.

I do have sympathy for him (donor). I think he struggled to tell his family. As hurtful as it was, I do understand the reaction of shutting the door in someone's face because they never expected this, they did not sign up for an extra child. I think, when they realized that I wasn't after money and there was legal protection in place, things calmed down slightly.

Kelly

Kelly went on to say:

They (donor's family) lived for 40 and almost 37 years not knowing anything. Not knowing that their dad had ever donated, it never been discussed. And so, it would be shocking to have someone show up and disrupt what was a core group of four people. Kelly

## Secrecy

Many participants expressed that the secrecy impacted them more than the knowledge that they were donor-conceived. The idea that they had been lied to hurt more than knowing that one of their parents was not genetically related.

I don't remember being upset about the fact that dad wasn't my dad. I was upset that they had lied to me for 14 years.

Mark

Additionally, if disclosure was done in a way that encouraged secrecy, how the offspring felt about being donor-conceived and talking about was affected.

I've always felt really uncomfortable about it because it was always framed when we were younger as not being our secret to share. And I've definitely had to overcome that in recent years myself because it's not my mum and dad's story, it's my story.

Carly

When Carly linked, her donor denied that he had given consent for his sperm to be used as a donation. She went on to say:

I was totally blindsided and linking kind of just changed everything for me... my whole life mum and dad said "we wanted you this much and this person was trying to help others have a family and they've done such an amazing thing and given us this gift". And then to have it turn out that that's not at all what happened, its actually quite deceitful. Carly Further, if the information was presented in a way that was negative, offspring reported feeling like they needed to keep it a secret too, and consequently could not fully accept and acknowledge who they are.

Earlier I never told anyone because I think, looking back, the way that it was presented to me it was like it's terrible, so that is how I took it on. Like this fact is a terrible thing or like shameful, you know. And so obviously it's not the kind of thing that you bring it up.

Emma

#### Theme Six: Disclosure for wellbeing (tell me at the right time and in the right way)

Disclosure has the ability to hinder the wellbeing of donor-conceived individuals. It is not only the timing of disclosure that is important, but also the way in which the nature of their conception is presented. Disclosure conversations can impact the way donor-conceived individuals perceive their conception, and further, disclosure conversations can impact the way donor-conceived individuals perceive themselves.

#### I can't remember being told

Two participants had been told and understood about their conception from the youngest age possible. There was no big reveal or secrecy involved.

Apparently, we found out as soon as we were born. We had a bedtime story growing up about how we were conceived.

Dani

I've known all my life. I don't remember a specific time that I was told or anything. It was always very openly discussed. They had the one page of information and any trait that we displayed that was in line with that, was always attributed back to the donor. So, it was always very open. But yeah, something changed when I tried to look for the donor.

Carly

#### Disclosure used for alternate purpose

In the cases of Emma and Kelly, disclosure was used in a way that was not to inform but in the interests of a different agenda. For Emma this impacted her relationship with her social father.

I was still really young, and they got divorced. And mum told me all this bad stuff about how he'd been violent and I guess that drove a bit of a wedge between us, plus, then she told me that he wasn't even my dad and I was like I'm 11 I can't handle this. So, I'm going to completely reject you (social father), and I kind of didn't really see much of him after that.

Emma

Kelly felt as though disclosure was used as a method to manipulate her into choosing her mother over her social father.

Mum asked us to hop into bed next to her, and then kind of proceeded to tell us that dad wasn't really our dad, and that we had both been conceived by anonymous sperm donor, and that our donors were different. That was also kind of the first time I realized how babies were made. I think her logic for doing it then and doing it in that way was because they had a really nasty divorce, and a really horrible custody battle. She didn't want us to choose to live with him. It felt to me like she was trying to kind of poison us against him or give us a valid reason for not wanting to see him.

Kelly

#### I remember being told

Most participants recall the moment that it was disclosed to them that they were donorconceived. Each story of disclosure was unique. For Matt, his parents independently sought a counsellor to disclose the information.

We were told we have to go into town, because we lived in the country. We've got to go meet this person (who my parents organised independently). I'm not sure if they said she

was a counsellor at that point or not, but she told us that we were conceived by donor. As a 10 year old I was probably just sorta like, okay, can we go to dinner now? It didn't really bother me. It was relatively painless I guess.

Matt

Donna does not recall learning anything about her donor at the time of disclosure however, when she reached the age of 18 received further details.

Mum and Dad had actually just separated and they kind of brought us together and were like, hey, just a heads up, dads not actually your biological dad, we had to use a donor. I don't recall being given any information when I was younger, but I got profiles once I've turned 18.

Donna

Sophie was told from a young age. However, due to lack of understanding and no continued conversations, felt as though it had been disclosed to her twice, the second time being more traumatic.

Apparently they (parents) always tried to tell me from like the youngest age. I certainly remember having books. But it was only when I was about 11 that I understood it. I remember it quite vividly because I must have been saying something really clueless and mum was like, Oh God, I thought she got it, she really doesn't. And she says you do know he's not your biological father don't you?

Sophie

Disclosure for Charlotte, because she was older and had that level of understanding, was done in a more serious way.

They sort of sat me down, very formally, and just told me. I think dad was the one who started the conversation.

Charlotte

#### Telling others

Disclosing to others was another challenge faced by donor-conceived individuals. Because donor-conception could still be a taboo topic for some, many people that participants told had not been confronted with a conversation like this before and so were unsure what the "right" reaction was.

No one's ever reacted badly. I think most people just don't know how to react.

Kelly

The lack of knowledge and education about donor conception however, could sometimes cause others to feel uncomfortable and make comments that perhaps were not thought through.

And people are like you're a sperm donor? That's a bit gross, don't you think? And I was like, well, no, it's someone who's willing to give another family a chance to have a family. Donna

Others the participants told of the nature of their conception preferred to ignore the facts and found the donor-conception process difficult to comprehend.

There's definitely a stigma. And with the secrecy and donors and stuff, people are sort of like, I don't even want to think about that, and then they're faced with this person that's the product of it. You can tell there's some cognitive dissonance there. Nobody thinks about people being made from it. They're just like oh lovely babies and now we've got this adult woman, like here I am.

Anna

However, for many donor-conceived individuals, the information was met with curiosity or interest.

It's been good (telling others) like friends have been amazing, obviously it's a super weird thing, as adults, they're just really curious.

#### Theme Seven: Searching: a lonely task

Deciding to search for one's donor is an important milestone. However, it is not always a simple and easy task. There are many barriers for donor-conceived individuals including secrecy, a lack of support from family members, and a lack of accessible information from fertility clinics.

#### Sense of having to link on your own

Due to the strict views on anonymity that existed when the participants were conceived, many participants struggled to find any information about themselves and their donors. Because records were not kept or were lost, participants experienced a lack of support when trying to find information although there was a sense of solidarity with other donor-conceived individuals . Matt spent thousands of hours meticulously connecting the dots.

It's taken a while. I nailed down the (donors) family tree within a few months over lock down just by researching what trees I could and doing the through lines thing on ancestry. Other DNA connections popped up and that showed how I might be related through the tree. And so I used that to sort of plot the different lines of his tree. And there's probably about, 50 different DNA connections that that prove who he is.

Matt

Emma felt that reaching out to fertility clinics would be a waste of time and so searched on her own.

Because Mum had already said she looked, I actually didn't bother approaching the clinic. So, no one was given the opportunity to support me because it was all done by myself at home.

Emma

Similarly, Mark was advised that there would be no way to access records through clinics as they had been lost.

I was told stories. I was told I had no records about my donor, because they had to be destroyed after conception and stuff. But then another story I got told was the clinic had burned down, and all the records are lost.

Mark

Lack of family support could also increase feelings of solidarity and in Carly's case, isolated her from her mother.

Mum was really against me doing it (linking) and that kind of put a barrier between us about it.

Carly

#### Hopelessness and frustration

Searching and linking often led to nothing, which elicited feelings of hopelessness and frustration. Despite participants' best efforts, searching and linking could feel out of their control.

They (fertility clinic) had taken on the files, or what was in the files which, wasn't really anything. And mum had a meeting with them and they basically told her that there was nothing (information). It's is a bit of a lotto, a sort of one in a million chance of anything ever coming back. It felt a bit pointless really, it didn't feel great.

Matt

Many tried to accept that fact that they may never know and succumbed to the idea that it could be impossible to learn more.

As an 11 year old, I got the basics and thought, well, we all thought that there would never be any way of tracking down a donor. Although the fertility clinic attempted to assist Carly and Dani in linking, often there was only so much they could do.

They (fertility clinic) are really great but it took like 2 years for them to track down the right information so it was a lot of chasing. They are willing to help where they can but it always seemed to be: sorry we can't do this or that.

Carly

I actually emailed last year to see if we could meet our donor, but that never eventuated. The clinic said that we have got donor siblings out there but we haven't heard anything further. We've also tried to find them (donor and donor siblings) through the DNA matching. Nothing.

Dani

### **Protect yourself**

Because donor-conceived individuals often felt as though linking was not a possibility, many attempted to minimise the importance of linking and tried to convince themselves it was not a reality they would face.

When I saw a picture of the man who was my donor, and his children, then I was like, oh, they've got my nose or I've got their nose that sort of thing. And so then you do become more invested in it, but before then, I think I'd really just kind of protected my emotions and being like, He doesn't exist, I'll never find them, who cares.

Kelly

Emma and Anna both mentioned that in supressing their thoughts, they were able to continue on without too much distress.

There was nothing, it was hard to search and so over the years while I've been curious, there wasn't really anything I felt I could actually do. I just basically squashed it down

and was like well you can never think about this because you're never going to know. So, don't like get too worked up about it because it'll destroy you.

Emma

Most of my life I've just coped by pretending that it doesn't exist. The time I would've wanted to link was when I was a teenager and young adult, but there was no information so I couldn't. Unless I parked it and just pretended it didn't happen, I probably would've gone a bit mad.

Anna

#### Searching takes time and energy

Searching and linking took time and effort. Many donor-conceived individuals lead busy lives and did not always have the energy to continuously search.

It's finding the time to like, do the research, or then do I like employ someone to do genetic research for me. It makes me feel tired.

Anna

I've got lots going on. I've got three kids and a big job, and I just can't, you know, I don't have the emotional energy for this (searching and linking).

Kelly

My cousin (who is also donor conceived) has been digging into family trees and reckons he's spent about 2000 hours tracking his donor down. And I'm talking about it all the time now, my wife's helping me out. It's taken a huge chunk of space really.

Mark

#### **Expectations**

Although some donor-conceived individuals initially thought they had low expectations and knew what they want when attempting to link with their donors, Carly realised that what she wanted and what she got differed greatly, causing more confusion.

I went into discussions with this guy (donor) thinking I knew what I wanted and what I was looking for out of it. I thought I went in with no expectations at all but the sense of rejection that I got, that was quite difficult to come to terms with actually, it was like the Fantasy (expectations) had been ripped away so what did that mean for everything else I was doing.

Carly

Dani is yet to link with her donor but has considered that linking may not be all she imagines it to be.

That's one scary thing about potentially meeting them, they could be a let down.

Dani

It seems as though knowing what to expect and what not to expect can be a difficult thing to navigate. It seems as though knowing what to expect and what not to expect could be a difficult thing to navigate

I guess my expectations were fairly low, I didn't have any expectation of having any kind of relationship, but I guess I didn't expect to necessarily be rejected. I didn't necessarily expect to be like served with a legal cease and desist, like some people get. I guess I expected to maybe be acknowledged, find out who he was, and maybe that was about it. I didn't necessarily expect to be like welcomed or anything like that.

Emma

#### Theme Eight: Linking: A mixed experience

The experience of linking with one's donor varied for each participant. There are several parties to consider and according to participants, linking does not always go as one expects.

#### Rejection

Rejection was a very real reality for many donor-conceived individuals. Carly felt her donor misunderstood her intentions and decided against having her in his life before hearing about what her intentions for contact were.

He (donor) hated the idea of me being involved at all. He basically put up a big wall and insisted that I hide and not be around. And I wasn't asking for anything you know, I was asking for health information, I wasn't asking to be his daughter or anything.

Carly

However, while the donor may be welcoming, Kelly experienced rejection from the donor's family which was equally detrimental.

I just sent a message on Messenger, and then the next morning he messaged back and was just like "I'm almost certainly your guy" with a love heart. And over the course of that day, we must have sent, I don't know, 85 messages back and forth just text chat. It's fairly superficial now, his family initially had a bad reaction.

Kelly

#### Kelly went on to say:

There is a part of me that feels like really rejected by his family. You know I sit there and go, these people haven't even met me and they already decided they don't want to know me.

Kelly

#### Welcoming

Alternatively, many donors were open to getting to know the offspring. While awkward at first for Donna, she valued the experience of learning about her donor and seeing herself in them.

It was obviously very awkward to be like, oh hey, I'm a part from you. Yeah, but it was actually really fine. We chatted about what we've been doing and finding out similarities. Yeah, it was really cool.

Emma also had a positive experience.

So I'm pretty sure he sent me the first email. And yeah, he was really friendly, really welcoming. He was really happy, and was happy to be asked questions. Yeah, so it was very positive.

#### Emma

It is important to note that a good experience with linking did not guarantee a lasting positive relationship.

First I met my donor sister and brother. The first time I met him was with his now ex-wife and his other child. The second time my dad, my mum and my brother came. He's really enthusiastic and always really welcoming. And to his credit never pushy, like we always led and instigated the contact and relationships. But now it's kind of complicated because I don't have any relationship with the donor

Sophie

## Uncertainty

Many experiences when linking, attempting to link or deciding to link could leave donorconceived individuals feeling uncertain. Matt managed to track down his donor but due to the circumstances was uncertain as to whether or not linking was the best course of action.

Because of who the donor is (the doctor), I wasn't really sure what to do. He's old, and I don't want to give them a heart attack. Like it's a bit different if you're just the donor but if you're the doctor too. And I know that he's been covering it up from his wife from my conversations with his connections, I don't think she knew. She probably does now.

Matt
Similar to Matt, Anna tracked down some genetic family members but also felt uncertain as to whether or not linking would be appropriate. Anna also touched on considering others when linking and the fact linking takes courage.

On ancestry I've worked out who my family is, like the family name, and there are first cousins. But I've never contacted them and at first I was like, wow, I don't really want to upset anyone. I just haven't quite got up the courage to do that

Anna

Charlotte did link with her donor but the experience left her feeling uncertain

He came to visit but he overstayed. He talked and talked and talked, and he looked around the property and he kept asking to take us out for lunch. We kept trying to fob him off. He stayed nearly all day, he was really nice, but I just felt like it was too much. Charlotte

#### **Donor siblings**

Donor siblings are also people that a donor-conceived individual can link with. In Charlotte's case this was a positive experience.

It was very cool to meet her (donor sister). At her wedding, her mother in law kept looking at us saying I can't believe you guys look so similar. It was fun. It was way more fun to meet her than it was to meet my biological father.

#### Charlotte

Similarly, Sophie saw her donor siblings in an extremely positive light.

I love my messy web of a family. I love that I've got all these siblings.

Sophie

And while Matt is yet to link with anyone, his interest in linking with donor-siblings was mentioned.

Just meeting him (donor) would be good. And if he doesn't want to do that, you know, at some stage, getting to know our half-siblings would be good.

Matt

# Theme Nine: The need for support

Several participant expressed the lack of support provided for them and their families over the course of their journey, although donor communities offered some form of support. Sophie mentioned that the props her parents utilised when disclosing the information were the only support she received, and that these did not appear to help.

There was a definite lack of support for me. I don't remember getting any support during that traumatic time of being told. My poor parents, they had no support apart from random books that were obviously not helpful.

Sophie

Carly had never been told that donor-conceived individuals may need support and that this was an option for her.

If I was told to do that (go to counselling) from the start I would have done it I didn't know to do that. I didn't know I needed that.

Carly

It was suggested that perhaps it needs to be clearer where one can go for support.

Ongoing support would be good. The way it was done then, I think was solely done for the parents, solving their problem, creating this child, everyone's happy. We had nothing

to support us at all though. They needed regular support and a place where you could go for that, like a part of the health system.

Matt

There were different points in time that each individual felt they needed help in processing the information. In Charlotte's case, because she was a bit older at the time of being told, she believed that receiving therapy after disclosure may have been beneficial.

It probably would have been helpful for me to have somebody to talk to about it. I think, in the very beginning after being told, just to have someone work through it with me would have been helpful.

Charlotte

# **Donor-conceived communities**

Donor-conceived communities can help normalise one's experience. Participants felt this could be beneficial from a young age as donor-conceived people will realise that there are other individuals similar to them who can provide support and share their experiences.

I think giving them a community and connecting them to people like them is a huge part of it. Being able to find other families like our family, and it doesn't mean you love your dad any less, but yeah finding people who are like you would have made a difference.

Carly

It is hard for those who are not donor-conceived to fully understand what this population experiences.

You do get a sense of solidarity because I think other people don't really understand what it's like to have been conceived in this way. They might feel empathy but you can't actually understand what it feels like. So, being able to just share stories with people and just feel like you're not completely alone has been really good.

However, Anna and Kelly mentioned that there was also a potential downside to being a part of these communities. Anna advised that there are several experiences shared that are not favourable which may be distressing to some.

They are quite distressing communities to be a part of because there's a lot of really horrible stories. You know people who are finding out at my age that they've been lied to their entire lives and also people who have been rejected by donors. So I will probably leave those communities.

Anna

Similarly, Kelly suggested that these communities are places where comparison may exist which can bring negative emotions such as envy or guilt.

I was told to join the FB group and all that kind of stuff but I was just like, it will make me sad or guilty, because I'm the kind of person that does compare things. I would look and go, this person has been welcomed with open arms and has this really lovely second family, but I don't have that. Or this person got completely denied and had the door slammed in their face, and I'm so much better off than them.

Kelly

### **CHAPTER FIVE: DISCUSSION**

The objective of this research was to gather information regarding the experience and wellbeing of those who are donor-conceived. Prior research on this topic was limited, with several studies concentrating on the parents of donor-conceived individuals and donors. The hopes of this study were to foster awareness of what some donor-conceived individuals experience and to inform prospective parents and donors, as well as the fertility industry, ways in which to maximise the wellbeing of donor-conceived individuals. This study demonstrated the need to prioritise their long-term wellbeing. Participants in this study spoke about how this should be prioritised by parents, donors and healthcare providers in the fertility industry. Many felt as though there was a lack of forward thinking and consideration from all those involved in the process. Several participants stressed that children grow up and become adults with needs of their own. In particular, the need for openness and support in terms of affecting longer term wellbeing was raised consistently among participants. Navigating one's identity can be challenging for anyone, but being donor-conceived comes with extra obstacles to overcome. For several participants, the lack of support from families and fertility clinics negatively impacted their perception of donor-conception and their sense of self. Alternatively, those whose families were open and encouraging did not feel that their wellbeing was impacted. Similarities and differences were identified in participants' experiences of disclosure, searching and linking.

Findings suggest that disclosure can impact the long-term well-being of donor-conceived individuals. Early disclosure was encouraged by participants, with many stating that knowledge from a young age was more important than understanding. Parents should approach disclosure with the child in mind, meaning it should not be used to reach a different agenda. Further, disclosure should be seen as a series of continuous conversations rather than a one-off event to avoid feelings of secrecy. In regards to searching for their donor, the majority of participants felt they were on their own. Due to the restricted access to identifying information and lack of support from family and fertility clinics, participants invested significant time and effort tracking down their donor alone, generating feelings of hopelessness.

Furthermore, factors such as parents' views and donor reactions were important in shaping the experiences across participants. While some were welcomed by their donors, others were rejected by the donor or their families. Several who had knowledge of their donor or other

genetic relatives expressed feeling uncertain while contemplating linking. One participant suggested that linking requires courage and she often debated whether or not linking would be "the right thing to do". Similarly, linking could also generate feelings of uncertainty. One participant who had linked grappled with how meeting her donor made her feel and what sort of role she wanted them to play in her life.

This research contributes to psychological practice as it explores and highlights the lack of support donor-conceived individuals have in New Zealand. Unlike Australia which has the Victoria Assisted Reproductive Technology Authority (VARTA), New Zealand does not have a formal donor-conceived support structure or organisation that assists donor-linking, and provides information and support for donors, recipients and offspring. Easy access to counselling throughout the offspring's life would enable them to continuously process the nature of their conception, disclosure, and navigate their identity. Counselling can facilitate open conversations between offspring and their parents, preventing secrecy and feelings of discomfort. This would align with the strength-based, humanistic and person-centred approach that Counselling psychology employs (Woolfe et al., 2016). Integrating counselling and support into the process of conceiving via donor-conception is particularly relevant today as 2022 marks a year where the first individuals born with donated gametes under the 2004 HART Act come of age. These individuals will automatically gain access to their donor's identifying information and may need support navigating the linking process and the relationship they wish to have with their donor. It is hoped that this study will not only inform policy and practice in the area of donor conception but also serve as a helpful resource for prospective donors and recipients in New Zealand.

In this chapter, I will discuss how the long-term well-being of those conceived via donated gamete should be prioritised, including considering that the child will grow up, how being donor-conceived and parents' views of donor conception affect identity and experience, and the need for openness and support, including with reference to the experience of searching and linking. Additionally, this chapter will include the implications, future research and limitations of this study.

# The long-term well-being of donor-conceived individuals should be prioritised

78

As identified in this study, donor-conception is a practice that impacts offspring throughout their life and may be central to the identity of donor-conceived individuals. While the participants of this study understood their parents' desire to have a child, they frequently expressed the view that their needs were considered secondary to those of the donor, parents and the fertility industry. Several participants expressed that parents of donor-conceived individuals tend to forget that their child will grow up into an adult with needs of their own. Specifically, participants highlighted the need for **openness** and the access to **support for wellbeing**, including in **searching** for and **linking** with their donors, and negotiating the role and meaning of the donor in their lives. While there is little existing research on the lack of foresight a parent may have in regards to their donor-conceived child growing up, this study has demonstrated that it is a consideration that donor-conceived individuals feel must be noted. Being able to see one's child as an individual who will evolve, change, and develop their own opinions as well as realising donor-conception will continue to impact their child into adulthood may be something prospective parents can ponder.

# Donor-conception as an integral part of identity

In this study, several participants were interested in seeing where their physical and personality traits come from and ascribed these partly to genetics. In particular, information about medical history appeared to be of importance for identity, and thus wellbeing. While several participants appeared to place less importance on genetics and felt their social family had a more significant impact on their identity, as in other research (e.g. Ravelingien et al., 2015) a common motivation for information-seeking was for donor-conceived individuals to explore 'unknown' parts of themselves i.e. those they inherited from the donor. Velleman (2005) suggests that genetic relatives may act as a mirror and that there is a biological aspect of connecting to our past which offers continuity. When developing a sense of self, people may ground themselves by referring to their elders and where they are from. This may be especially significant in New Zealand with respect to the importance placed on Whakapapa (one's genetic lineage/genealogy). Voids or gaps can lead to disruptive and uncomfortable feelings of incompleteness, with potential longer-term implications for wellbeing.

In linking with their donor, many offspring hope to uncover and verify capabilities, traits, and talents including as a reference point to infer how their lives may progress. In Indekeu &

Hens's (2018) study, genes were varyingly regarded as building blocks that influence development, as unique combinations that make one who one is, and as things connecting and locating them to a family and their origins all. As also acknowledged by Melo-Martín (2014), all these understandings of genetic relatedness can inform a sense of identity. Some participants in the present study expressed that not knowing their donor had impacted their sense of self, and others who had linked with their donors mentioned feeling as though a piece of the puzzle had fallen into place.

While Melo-Martín (2014) suggests there is evidence indicating some donor-conceived offspring feel distressed as a result of the minimal genetic information being available, they also mention there is no robust empirical evidence indicating that overall, donor-conceived people experience genealogical bewilderment (identity problems). Indeed, Leighton (2012) believes the role that genetics play in constituting identity is highly contested. In the present study, while several donor-conceived individuals believed that genetic knowledge was integral to their identity, others denied feeling as though their identity was tied to their donor and reported a healthy sense of their identity without full knowledge of their genetic history. For those who did not regard genetic knowledge as critical for identity, their parents – those who raised them – were regarded as significant others and influential in affecting their sense of identity. This ties in to the relational theory of the self (Brewer & Gardner, 1996; Deaux, 1992), which asserts that self-knowledge is often linked to knowledge about significant others. In contrast, those who do not deem their social family as significant, as was the case for some participants in this study, may place more importance on their donor to assist with identity construction.

It is also important however, to recognise that while many donor-conceived individuals may attempt to minimise the importance of genes, everyday life experiences (e.g. medical checkups) tend to bring these to the fore. Further, Indekeu & Hens (2018) state that genetic relatedness can play a role in the formation of one's identity/sense of self, but the role that this plays may be "different for different people at different times" (p. 28), for example, genetics may assume a more important role over time, for example as donor conceived individuals become parents themselves.

#### Parents' views as influential

Several studies (Zadeh et al., 2018; Schrijvers et al., 2019; Javda et al's., 2010) have found that donor-conceived offspring recognised parental discomfort or sensitivity when they expressed interest in their donor. Donor conceived offspring often do not wish hurt their parents by communicating their interests in the donor (Zadeh et al., 2018) and/or siblings (Javda et al's (2010). ). Further, similar to the findings of Beeson et al., (2011) and Javda et al., (2011), participants in the present study suggested that their searching behaviour and comfort levels when discussing their interest was impacted by their parents. Participants whose parents demonstrated discomfort or disinterest were more apprehensive or hesitant to follow through or delayed linking. However, as demonstrated by some participants in this study, and as mentioned by Indekeu et al., (2020), while donor-conceived offspring may be apprehensive to follow through, many still search and link without their families' support or knowledge. Some participants who had searched or linked expressed feelings of guilt as they felt they were doing something their parents did not encourage. On the other hand, one participant in the current study shared how their parents wanted them to link with the donor to provide them with the opportunity to express their gratitude, and to see what similarities their child shared with them. As a result, this participant felt comfortable reaching out to fertility clinics and as though linking was not a significant challenge. This shows that both positive and negative parental reactions can influence the offspring's perception of the situation and impact their behaviour.

Some studies have explored the connection between the quality of a family relationship and the offspring's interest in their donor. Vanfraussen et al., (2003) for example, failed to find any statistical significance between the quality of the parent-child relationship and the donorconceived offspring's interest in the donor. Similarly, Kelly et al., concluded that those who have a strong and positive relationship with their parents may still be interested in finding their donor. These observations align with the findings of the present study. Many of the participants described their relationship with at least one of their parents as strong, however, all participants expressed some curiosity about their donor. Interestingly, however, several participants suggested that the quality of their relationship with their parents helped with processing the fact they were donor-conceived. While there is little research to support this particular finding, Lycett et al., (2004) found that families who were more inclined to disclose the nature of their child's conception had a more positive parent-child relationship and reported significantly less severe and less frequent arguments. Further, children of disclosing families displayed lower levels of conduct issues than those whose parents had not. Lycett et al., (2004) noted that parental openness did not necessarily result in more positive parent-child relationships. However, parents who are more inclined to openness may take a more relaxed or authoritative approach to parenting and may be less likely to perceive behaviour as negative. For the present study, it appeared that those who were close with their parents accepted the nature of their conception more neutrally. Strong family ties prevented offspring from seeing their non-genetic family member as anything but their parent. Alternatively, it appears poor family relationships could increase the likelihood of offspring rejecting their non-genetic parents. Two participants stated they felt relief when they discovered their non-genetic parent was not related to them and that they would have been more upset if they had found out it was the parent with whom they had a good relationship.

# The need for openness

A lack of continuous conversations and openness caused many participants in the current study to perceive donor conception as a secret. Participants stressed that all parties involved, including parents, donors and fertility clinics should strive for openness to prioritise the well-being of offspring. Further, offspring felt that open conversations would provide them with important information such as medical concerns and concepts such as consanguineous relationships (where people who are related by blood marry or have sexual relations) (Hamamy, 2011).

Secrets, as explained by Brown-Smith (1998), can be detrimental to the way a family functions causing barriers to emerge between individuals who know the truth and those who do not. Secrecy itself is not described as problematic, it is what the secret is and from whom it is kept that determines how secrecy is perceived. Turner & Coyle (2000); Blyth (2012); and Daniels et al., (2011) found that where parents kept the nature of their child's conception a secret many offspring intuitively felt as though their parents were keeping something from them. This uncertainty would often come after children learnt about genetic connectedness at school and would start to question their physical similarities or lack thereof to their parents. Similar to the findings of this study, Turner & Coyle (2000) concluded that those conceived via anonymous donation, whose families were not open to discussing the nature of their conception felt alienated from them.

Mostyn (2017) suggested that disclosure of one's origins alone is unlikely to be sufficient for the offspring and their family's wellbeing, but that parents' discomfort or shame with donor conception could impact offspring e.g., the offspring may internalise these feelings and perceive their origins in a negative way (Mostyn, 2017). This aligns with participants from the present study who suggested that a lack of openness caused them to feel as though their conception was or should be kept a secret, or that it was not their secret to share. There is little research in the current literature exploring how a lack of openness after disclosure impacts the offspring, their wellbeing and their relationship with their family. Further, participants in the present study expressed that their frustration and anger concerning disclosure came from feeling as though they had been lied to. Simply put, the fact that one was conceived in this way was not as upsetting as it being kept a secret. These findings are supported by Frith et al., (2017) who found that donor-conceived offspring felt resentment as they felt they had been deceived. Konrad (2005) goes further as to say that anonymous donation is a double concealment. Not only does the offspring feel as though they have been deceived by their parents, but also the secrecy surrounding who their donor is can feel mendacious. A study conducted by Frith et al., (2017) with reference to children born from sperm donation suggests that disclosure following secrecy caused the offspring to feel as though their mothers put the needs and wants of their father before theirs. Mothers were perceived as not fulfilling their duty as a "good mother" because they prioritised the needs of their partner.

While the participants in this study felt the needs of donor-conceived individuals often came second, they did not appear to place blame on their parents for their lack of openness. Blame was placed on doctors and the fertility industry for encouraging non-disclosure. Participants felt as though the fertility industry let their parents down and did not think about the long-term consequences that non-disclosure and secrecy would bring. Similarly, participants in Mahlstedt et al's study, (2010) felt their needs and feelings had been overlooked throughout the process of conception, disclosure, and information sharing. However, it must be recognised that not all participants in the present study felt that secrecy was a part of their narrative as they "had always known". Further, participants suggested that strong family systems enabled them to process and understand their parents' position. Mostyn (2017) suggests that communication, flexibility and cohesion strengthen families. This can be seen for a couple of participants who experienced early disclosure, open conversations and the inclusion of their extended family. For these participants, donor-conception was not something that divided their family but instead brought them closer together. This aligns with Mostyn's (2017) findings. However, despite the majority of participants being told early, as mentioned, open dialogue regarding conception was not always present. Despite this most participants still had a strong relationship with their parents.

Very few participants in this study remembered their parents being open to continue discussing the nature of their conception after disclosure. This resulted in several participants feeling uncomfortable discussing this themselves and as though their conception was not something they were able to talk about or gain information on. Much of the research looks solely at the age of disclosure and refers to disclosure as a single incident. While the present study and several others suggest that early disclosure is ideal suggesting that offspring react more favourably (with curiosity or disinterest) (Lycett et al., 2005; MacDougall et al., 2007), many participants expressed the importance of ongoing openness. It was suggested that knowledge is more important than early understanding, and that constant conversations about conception were required to normalise the fact and develop an understanding of the meaning of donor conception and its implications over time. According to Piaget (1955), a child's ability to process information and learn depends on the stage of cognitive development at which they are. It was contended that during the pre-school years (pre-operational stage), a child can grasp information intuitively, rather than logically or on a mental level. Meaning information can be remembered but socialised meanings take some time to be understood. When a child reaches the age of seven-12 (concrete operational stage), they can process logical thoughts and develop reasoning. Relating Piaget's stages of cognitive development to donor conception, Dudley & Neave (1997) suggested that while young children may not understand the information and stories that their parents disclose, over time the information will gradually be processed and incorporated into understanding. This is evident in the questions that children ask regarding babies and their conception, as well as their responses to information provided. Dudley & Neave (1997) suggest that details will need to be repeated as the child develops, indicating disclosure is not an isolated incident (Hajal & Rosenberg, 1991).

Participants in the present study suggested that disclosure and conversations about their conception should be continuous and open. This aligns with Schrijvers et al., (2019); Beeson et al., (2011); and Hertz et al., (2013) who found that offspring wished their parents had spoken

openly and continually about their conception and that disclosure conversations were repeated during childhood development.

As previously stated, the participants of the present study believed that all parties involved with donor conception should aspire to be open. This includes being open and passing on important and relevant information. Many participants mentioned their motivation to link was to learn about their medical history to prepare and pass that onto their children or donor-siblings. This aligns with results from studies conducted by Ravelingien et al., (2015) and Turner and Coyle, (2000) who found learning medical history was among the main motivation to link with donors. However, because disclosure is the responsibility of the recipient parents, fertility clinics in New Zealand are not able to pass on important information like this to donor-conceived individuals unless parents have disclosed or written consent has been obtained. Further, the HART Act makes it challenging for donor-conceived individuals under the age of 18 to contact their donor siblings directly, particularly if they have not yet been made aware of their conception. This frustrated the participants of the present study as they felt that passing on this information could help save lives. Allen (2016) suggests this places donor-conceived individuals (particularly those born in the 1970s or 1980s) at risk and particularly as people age because many conditions develop later, and people are not aware they may be carriers. Ravitsky (2010) suggested that follow-ups with donors should be put in place as many medical conditions develop over time. Often at the time of donation, donors are younger and do not exhibit health or medical issues. Having ongoing contact with donors to monitor their evolving medical records allows clinics to contact recipient parents and pass on the relevant information as it becomes available. While this process is now employed by New Zealand fertility clinics, it was not operating at the time of the present study's participant's conception.

Several participants also shared their concerns about consanguineous relationships. Although the fertility industry limits the number of donations a donor can make to minimise and avoid these relationships from developing, the risk still exists. This is because a large number of donor-conceived people are not aware of their conception and would not consider this as a possibility. In New Zealand the maximum number of families to whom a donor can donate is 10. However, many clinics use a lower maximum of four-five families (Cryos International, 2020; Ferility NZ, 2021). Although the probability of such an occurrence cannot be determined, this may pose a significant risk in smaller populations such as New Zealand's (Allen, 2016). The participants of the present study presented good evidence that several half-siblings were born around the same time, to a variety of families, who lived in the same vicinity. There were two participants who later found out they went to school with donor siblings. Bennett et al., (2002) warn about the legal ramifications of engaging in consanguineous relationships. Further, if a child were to be born as a result, the risk of chromosomal or genetic abnormalities is high (Bennett, 2002). The Senate Legal and Constitutional Affairs References Committee (2011) found that in Australia, the threat of these types of relationships forming may impact the emotional and social wellbeing of those conceived via gamete donation.

# The need for support

A common wish among participants of the present study was more access to support throughout the process for themselves and their families. Much of the research on access to support has explored the thoughts and feelings of parents regarding disclosure. Mac Dougall et al., (2007) concluded that most parents felt frustration due to the perceived lack of appropriate language and "scripts" available to broach the topic of their child's conception. Many donor recipients (parents) have criticised the fertility industry and support groups for fixating on pregnancy. Like the participants in the present study, parents felt they needed ongoing support and guidance from peers and professionals throughout the offspring's life not just at the beginning stages (Mac Dougall et al., 2007; Murray & Golombok, 2003). Further, Thorn & Daniels (2007) found that support groups normalised the experiences of donor recipients which can lessen feelings of isolation and stigma. This aligns with the findings of the present study where participants suggested that parents introduce their offspring to support groups from a younger age. In doing this parents are not only gaining support for themselves but providing a community for their offspring to interact with. Similarly, participants felt that parents should have more access to support prior to their conception. Specifically, counselling on what it is like to raise a donorconceived offspring. A study by Schrijvers et al., (2019) supports this and also found that those conceived via donated gametes felt their parents needed more support and should have received more specialised counselling. They believed this would have helped with explanations during disclosure and with navigating these conversations through the different stages of the offspring's life. It is important to note that the participants in this study were born prior to the introduction of the HART Act, and that counselling for prospective donors and recipients is now required by

clinics, and includes the implications of donor conception for offspring and information about resources to support disclosure.

Further, many donor-conceived individuals in this study and a study conducted by Schrijvers et al., (2019) wished to know where they could go for support, with many not knowing that support could be of use to them. The type of support participants believed would be beneficial included ongoing counselling from the start to make sense of being donor-conceived, guidance when searching and linking with donors, and support from family throughout the entire process. Participants in Kirkman et al's (2007) study suggested that donor-conceived individuals should be the ones to decide on the support they need, however, it is the responsibility of the parents and clinics to provide that information should they need it. Several participants in the present study mentioned they had "stumbled" across support groups online and prior, had very little connection to other donor-conceived individuals.

Many participants expressed their appreciation for donor-conceived support groups and similar to the findings of Schrijvers et al (2019); Cushing (2010); and Mahlstedt et al., (2010), valued the exchange of lived experiences, information and stories with donor-conceived peers. Currently there are several support structures that are available to donor-conceived offspring and their families. This includes the VARTA website which not only has a section specifically for donor-conceived individuals but for donors and prospective parents to read through. This website has helpful publications and resources including information on the current legislation, support groups and written experiences of those who are donor-conceived. Other helpful websites include the Donor Conception Network which is parent led and child focused and We Are Donor Conceived. Although these structures provide a wealth of information, very few are specifically for those who have been conceived in New Zealand. The recent creation of the Donor Network in New Zealand may address this in the future.

One participant in the present study pointed out that at times it could be hard to express and explain one's personal experiences to those who are not donor-conceived. While others may empathise with the donor-conceived population, they will never understand what it is like to be conceived in this way, and thus support groups offered a unique form of support. However, a participant in Cushing's (2010) study mentioned that support groups were not an environment they enjoyed. The participant explained that some support groups have angry members who share their experiences of pain and frustration which is not always pleasant. This is similar to a participant in the present study who expressed similar views, saying they felt some support groups created a distressing environment. Further, another participant in this research project explained that support groups caused her to compare her experience to others which was not something she wished to engage in.

Indekeu et al., (2020) suggested that searching, linking and establishing a relationship with one's donor and donor-siblings can come with challenges. As found in the present study searching for one's donor can impact the offspring's relationship with their parents. A participant noted that searching for her donor put a barrier between her and her mother. Others felt the topic of searching was simply too uncomfortable for parents to discuss, leaving them feeling alone in their search. Similarly, 63% of Javda et al's., (2010) participants reported their parents had mixed responses when being told of their intentions to search for their donor, and felt searching was an isolating experience. Counselling would be beneficial during this time for donorconceived individuals. Feeling supported through this process may aid in reducing these feelings of isolation. It was proposed by Indekeu et al., (2020) that counselling may need to be refined towards a framework more specific to these challenges. An initial challenge some offspring face when deciding to search and link is the naming and description used for donor-siblings and donors (Indekeu et al., 2020; Hertz et al., 2013). Language can set certain expectations that may or may not align with the context some offspring find themselves in. For example, the word "sibling" implies the sharing of history, norms and values, as well as how families interact with one another (Hertz & Nelson, 2019). Participants in Indekeu et al's. (2020) study suggested that establishing the "right" degree of closeness with donors and donor-siblings can be difficult as time and effort must be invested. Similar to Indekeu et al., (2020), Indekeu et al., (2021) found counselling was helpful in preparing donor-conceived individuals with linking. This is because professional support provides a space for offspring to consider their hopes and expectations, and understand feelings that may be triggered. Follow up calls after linking or interacting with donors or donor-siblings were positive as offspring could reflect on the meeting aloud.

# Searching and linking

Searching and linking can be a nerve-wracking, exciting, frustrating and uncertain time. Lack of information and records has pushed donor-conceived individuals in this study to use DNA-based voluntary register services such as ancestory.com and through the voluntary donor-conceived

registry. However, the introduction of 2004 HART Act means that going forward many will have access to identifying information automatically. Of particular note is the first group of donor-conceived individuals born under the HART who will be coming of age in 2022. It is important to note that even with the HART Act, however, access depends on individuals having the knowledge that they are donor-conceived. Van der Akker et al., (2014) explored the experiences of donor-conceived individuals and donors searching for genetic relations through online DNA matching platforms. It was concluded that the experiences of those who had linked were generally positive. While feelings of apprehension were reported due to DNA testing being less stringent and reliable than paper trails, donor-conceived offspring and donors using these services maintained positive beliefs regarding the value of linking this way. Further, those who had linked expressed strong support for the service these platforms offer and stated that overall, regular contact was mutually pleasant (Van der Akker et al., 2014).

Blyth et al., (2012) researched the experience of donor-conceived individuals and views of their genetic origins and concluded that while many participants classed the search for their donor a success, however, it was also described as incomplete as it was unknown how many unidentified genetic relatives still existed. Further, this study highlighted the disappointment that followed when false-positive results were presented. A participant in the present study experienced this stating "it was like a wild goose chase". Cushing (2010) mentions that while popular media often gives the impression that searching is easy and ends positively for the offspring and their donor, this is not always the case. Participants interviewed in Cushing et al's (2010) study stated they spent years searching and had not found their donor. Further, many of those who did link experienced rejection or were ignored. Two participants in the present study experienced rejection, one from their donor, and one from their donor's family. Both felt that their intentions were misinterpreted and felt as though the parties involved made judgments before getting to know them.

The experiences of searching and linking for the other participants in the present study varied. Participants linked with their donor through online voluntary DNA testing services, through donor-siblings that had already linked, and through fertility clinics that had their records intact. Those who had to search for their donors through platforms such as ancestory.com reported differing experiences. Some suggested they had spent hours tracking down family trees and connecting the dots, while others expressed it was a relatively quick process. One common

experience that emerged was the feeling that they were on their own and that searching and linking was something they had to do without support from others including parents and fertility clinics. Those who spent time trying to track down their donor expressed feeling drained and frustrated. Many referred to their busy lives and felt searching was taking up unnecessary time and space. Similarly, Indekeu et al., (2020) found that donor-conceived offspring who had linked with donor-siblings quickly found that establishing and maintaining relationships took significant energy, time and effort. Participants in their study expressed that work and family life often took priority.

#### **Implications and recommendations**

As studies on the experience and wellbeing of donor-conceived adults are still evolving, this research offers a useful addition to the current literature. Not only are the findings informative for fertility clinics and prospective donors and recipients, but also donor-conceived individuals wanting to learn about and relate to the varying experiences of others. Several recommendations are suggested. For example, disclosure is often seen and reported as a single incident. While most remember the first time the nature of their conception was disclosed to them, it appears that a one-off conversation may not be enough. There is the idea that a lack of openness can be perceived as secrecy or as if the topic should not be discussed freely. As a result, offspring tend to feel uncomfortable and may not develop a positive outlook of their conception. Further, offspring may struggle with expressing themselves regarding donor conception as they may lack the dialogue to do so.

Continuous conversations appear to normalise donor conception and validate the innate curiosity that exists. Further, continuous conversations may model acceptance which could reduce offspring's feelings of apprehension when expressing interest in donors. Additionally, given the impact secrecy and non-disclosure can have on one's sense of self, perhaps New Zealand should follow Victoria, Australia's lead. Their legislation requires an addendum to be noted on donor-conceived individuals birth certificates (VARTA, 2019). ). Introducing this measure would ensure that the nature of the offspring's conception is on record, which could help prevent non-disclosure. Further, in Victoria the Assisted Reproductive Treatment Amendment Act 2016 amended the Assisted Reproductive Treatment Act 2008. This amendment gives all donor-conceived people access to identifying information and the right to know their

genetic origins, regardless of the year in which they were born (VARTA, 2019). New Zealand's 2004 HART Act is a step towards openness. However, donors will still not be automatically identifiable under the HART Act for donations made prior to 22 August 2005. This prevents a large number of donor-conceived individuals, including all participants in the present study, from easily accessing their genetic information.

The findings of this study imply that donor-conceived individuals feel there is a lack of support for them, reporting they often felt on their own when processing information, searching and linking. Easy access to support such as counselling and donor-conceived community groups would be beneficial for donor-conceived offspring. Although such services and groups do exist, several participants expressed feeling lost and stumbling across networks themselves. Counselling could provide a non-judgmental space to discuss and process complex emotions, and support groups may encourage normalisation. Being around others who relate to your experience and feeling as if one is a part of a group harbours a sense of belonging and connection which can enhance overall wellbeing (Enayati, 2012). Parents should be encouraged to join donor-conceived support groups so their children can interact with others like them from a young age. This again, would normalise their conception and encourage an open dialogue. It is difficult to place the onus/responsibility on one person or an organisation to provide counselling and support services. However, the Victoria Assisted Technology Reproductive Authority (VARTA) can be used as a model. Their website has copious amounts of information for donor-conceived individuals, parents, donors and donor-siblings. This website provides resources including links to Facebook groups, VARTA run donor-conceived peer-support groups, research and publications and personal stories. This easy access to information can decrease the time and effort spent by donor-conceived individuals trying to track down information and communities. Fertility NZ offers counselling services for the recipients of gamete donation, however, while fertility clinics, such as Fertility NZ and Fertility associates can aid contact between offspring and their donor, little is mentioned about counselling specifically for donor-conceived individuals to process this contact. Only one participant in the present study had counselling through the fertility clinic that aided her conception. Others whose records were lost upon their conception were not offered this same opportunity. Regardless of the organisation one is conceived through, access to a trained counsellor should be available.

The above recommendations link to the idea that the long-term wellbeing of the donor-conceived individuals should be prioritised. Participants suggested that parents, donors and the fertility clinics often neglect to consider the impact of their actions on the offspring. Anonymity protected the donor, non-disclosure prevented hard conversations for parents and fertility clinics will make money regardless. Findings suggest that donor-conceived adults want all parties involved to understand that the baby grows into an adult who has the right to access information about their origins.

#### Limitations and future research

The present study has several limitations that must be addressed. Ten respondents were interviewed for this research project, and while Braun and Clark (2013) consider six participants to be ample for a thematic analysis, the small sample prevents findings from being generalised to all those conceived via donated gametes in New Zealand. Further, this study was originally advertised via Fertility New Zealand and was then shared on several donor-conceived support networks including Facebook and Instagram pages, meaning this study may have attracted those who had specific views and experiences they wanted to voice (Purewal & Van de Akker, 2009). This may have resulted in skewed data/data that is one-sided and not representative of the many existing perspectives. However, there were a few respondents who suggested their motivation to participate was related to wanting to show a diverse range of experiences, including positive ones. These participants had an awareness that there was a lot of frustration and negativity, however, this was not representative of all experiences (hence the contradicting results). Additionally, secrecy is still common meaning studies on donor conception are limited to those who are aware of the nature of their conception, automatically excluding those who are yet to be told.

The participants of the present study were born prior to 2004, meaning they were not able to take advantage of the HART Act regulations. Despite the study being open to those conceived via donated egg and sperm gametes or embryos, all of the participants were conceived via sperm donors. Similarly, all participants came from dual-parent households with heterosexual parents. Therefore, the experiences and accounts may differ from those who were conceived via egg donor and those who come from different family make-ups such as single-parent households or same-sex couples. It is important to note that donors have the right to set restrictions with respect to recipients, and up until 1996, some fertility clinics in New Zealand decided to pick and choose recipients, often excluding same-sex couples or single parents, thus partially explaining the demographics of this study, as was the case for Mostyn's study (Mostyn, 2017).

All participants who responded to the present study identified as New Zealand European, therefore, do not represent New Zealand's diverse cultural make-up. Unfortunately, the voices of Māori were not heard in this research project. It estimated that currently, Māori have limited access to donor conception. Given that whakapapa, an important Māori concept which informs understanding of gametes as sacred and stresses the importance of knowing ones origins, the accounts and experiences of Māori are likely to differ and would add to research greatly. To fill this gap future research projects could consider consulting local iwi to identify Māori donor-conceived offspring who may be willing to share. This would assist not only Māori recipients but also healthcare professionals and those in the fertility industry in providing better care for Māori donor-conceived offspring.

# Conclusion

Donor conception provides an opportunity for those who are not able to conceive naturally to have a child. Additionally, it allows donors and fertility clinics to assist in creating a family. However, often, the most important aspect of donor-conception: the long-term well-being of the donor-conceived offspring, is overshadowed by this incredible technology and what it can do for families. Previously the privacy of the donor and the preferences of non-disclosure were prioritised, resulting in a lack of openness and high levels of secrecy. This prevented many donor-conceived offspring from gaining access to their genetic information and feeling comfortable discussing the nature of their conception. The 2004 HART Act has meant that those born after 22 August 2005 will have automatic access to identifying information and their genetic origins upon turning 18, assuming they are made aware of their donor conception. 2022 is a significant year as the first group of donor-conceived individuals born under the provisions of the HART Act will be coming of age. However, there is a large population born prior to this Act who will not reap the benefits: donor conceived individuals for whom records have either not been kept or have been destroyed, or whose parents and donors were encouraged to maintain secrecy. Even for those born under the HART Act, disclosing donor conception to offspring remains the responsibility of the parents who may choose to conceal this information. Being

donor-conceived forms an important part of their identity of many donor-conceived individuals and they have the right to be made aware of, and given access to this information, in an environment of ongoing openness and dialogue, and with appropriate support mechanisms to support them in negotiating the meaning of being donor conceived, searching for and linking with their donors. These measures are crucial for prioritising the long-term well-being of donorconceived offspring.

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#### **APPENDIX A- PARTICIPANT INFORMATION SHEET**

#### **Project Title**

The experience and wellbeing of donor conceived adults in Aotearoa/New Zealand

#### **An Invitation**

Kia Ora! My name is Samantha Best (Sam), and I am a Master of Health Science (Psychology) student at Auckland's University of Technology. If you were conceived in Aotearoa/New Zealand with the help of a donor, and you are over the age of 18, I would like to invite you to participate in this research.

#### What is the purpose of this research?

The purpose of this research is to better understand the experiences and wellbeing of New Zealanders who are donor-conceived offspring. Findings may help inform practice around donor conception and appropriate support for donor-conceived offspring. The research findings will be published in academic journals and will form part of the research and dissertation requirements which are part of the AUT Master of Health Science Psychology qualifications.

#### How was I identified and why am I being invited to participate in this research?

You have responded to an advert posted on webpages and social media sites which asked donor conceived adults in Aotearoa/New Zealand who were interested in participating to make direct contact with me. I am hoping to interview approximately 6-8 adults conceived in New Zealand with the assistance of sperm or egg donation. Participants must be fluent in English. Recruitment will cease once a sufficient number of participants have been recruited. Family, friends or students of myself or my supervisor will not be able to participate in the study.

#### How do I agree to participate in this research?

Individuals interested in participating are invited to make direct contact with me, Samantha Best, as the Project researcher, via email (see below), I will address any questions you may have about the research, and if you agree, will arrange an interview at a time and place convenient to you. Only my supervisor and I will have access to your contact details. You will be asked to complete a Consent Form immediately prior to the interview taking place. If the interview is via online media or phone, verbal consent can also be used as evidence that you agree to participate. This consent will be recorded. Your participation in this research is entirely voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

#### What will happen in this research?

If you agree to participate, the research will involve an interview at a time and place convenient to you. Where this is outside of Auckland, you have the option of being interviewed via zoom, skype or similar media, or via phone. The interview is anticipated to take approximately 1 hour.

#### What are the discomforts and risks and how will these be alleviated?

Talking about your personal experiences may involve some discomfort, however I aim to ensure a comfortable and safe environment for you to talk. You can choose to stop the interview at any time or choose to stop talking about any issue about which you feel uncomfortable. Further information and support for people affected by infertility challenges may be available through Fertility NZ and the Donor Conception Network, details below:

1. Fertility New Zealand

Phone: 0800 333 306 Email: <u>support@fertilitynz.org.nz</u> <u>https://www.fertilitynz.org.nz</u>

2. Youthline

Helpline: 0800376 633 Free text: 234 Email: <u>talk@youthline.co.nz</u> <u>https://www.youthline.co.nz/</u>

3. Lifeline

For counselling enquiries: 09 909 8750 For counselling enquiries: <u>info@lifeline.org.nz</u> Helpline: 0800 543 354

Suicide crisis helpline: 0508 828865

http://www.lifeline.org.nz/corp\_Home\_378\_2001.aspx

AUT Student Counselling and Mental Health offers three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

• Go to the City Campus at WB203, email counselling@aut.ac.nz or call 921 9998.

• let the receptionist know that you are a research participant, and provide the title of my research, my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on:

https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health

## What are the benefits?

You will have an opportunity to share your experiences of being a donor conceived adult. This research may be useful to other donor conceived individuals and their families as well as to donors, recipients, prospective donors and intending parents. This research may contribute to policy development and guide practice in this area. The research also forms my Master of Health Science Psychology qualification.

## How will my privacy be protected?

You will be asked to provide a pseudonym by which you will be known in the study, or a pseudonym can be chosen for you. All references made during the interviews to names of other people (e.g. practitioners), place names and organisations, or any other details that could compromise confidentiality will either be deleted or altered to protect confidentiality as much as possible. Only the researchers will have access to data during the data collection and analysis stage. Only my Supervisor, Sonja Goedeke, and I as the project researcher will have access to the data after the final reports are produced. Audio-recordings of interviews will be destroyed following transcription. Consent forms and transcripts will be kept for six years in a locked filing cabinet in the Psychology Department on AUT premises.

## What are the costs of participating in this research?

There are no costs to you other than your time. We anticipate that the interviews will be approximately  $1 - 1 \frac{1}{2}$  hours in duration, and that you may spend approximately a further hour in reviewing your transcript should you wish to do so.

## What opportunity do I have to consider this invitation?

The advert on websites and social media pages will ask those interested in participating to make direct contact with Sam, the Project researcher, within a two-week time-period. If insufficient participants have been recruited, the posting will be made again.

# Will I receive feedback on the results of this research?

All participants who would like a copy of the results will receive a summary report via email at the end of the study.

## What kind of questions will I be asked?

You may choose to talk about aspects of donor conception relevant to you. Questions may include:

- How, when and by whom was it disclosed to you that you were conceived via donor. What was your experience of this?

- In what way, if any, did the knowledge you were donor-conceived affect your sense of self, your relationships with others and your family dynamics?

-What contact, if any, do you have with the donor, his/her family, or any other individuals conceived using the same donor and what is your experience of this?

-What support have you received in relation to being donor-conceived?

## What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project

Researcher, Samantha Best, Email: kjy8347@aut.ac.nz or the Project supervisor Dr Sonja Goedeke,

sonja.goedeke@aut.ac.nz, 9219999 ext 7186

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Carina Meares, <u>ethics@aut.ac.nz</u>, 921 9999 ext 6038.

# Whom do I contact for further information about this research? Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher and Project Supervisor Contact Details Researcher: Samantha Best, <u>kjy8347@aut.ac.nz</u> Project Supervisor: Dr Sonja Goedeke, <u>sonja.goedeke@aut.ac.nz</u>, 9219999 ext 7186

Approved by the Auckland University of Technology Ethics Committee on *type the date final ethics approval was granted*, AUTEC Reference number *type the reference number*.

#### **APPENDIX B: INTERVIEW SCHEDULE**

-Experiences of disclosure: How/when and by whom was it disclosed to the individual that they were conceived via donor. What were their reactions? How/when did the individual disclose the fact they were conceived via donor to others (friends and family) and what were their experiences of this?

-Identity: In what way, if any, did the knowledge they are donor-conceived affect the individual's sense of self and relationship with others

-Experiences of relationship with parents/family dynamic: How did they experience their relationship with their parents and family dynamics, and what role if any, did Donor conception play in this? To what extent have parents encouraged information-exchange with donor or donor siblings?

-Role of donor, donor's family, donor siblings in their life: What contact do they have, when did this first occur, how do they see the donor's role, what sort of relationship exists, how do parents feel about this and do parent's feelings impact the individual?

-Expectations and experiences on an ongoing basis including, support they received, support they wished they received, advice for prospective parents/donors/donor-conceived people.

## **APPENDIX C: ETHICS APPROVAL**

9 June 2021 Sonja Goedeke Faculty of Health and Environmental Sciences

Dear Sonja

Re Ethics Application: 21/136 The experience and wellbeing of donor-conceived adults Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 9 June 2024.

Standard Conditions of Approval

- 1. The research is to be undertaken in accordance with the <u>Auckland University of Technology</u> <u>Code of Conduct for Research</u> and as approved by AUTEC in this application.
- 2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
- 3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3\_form.
- 4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
- 5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
- 6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
- 7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken. Please quote the application number and title on all future correspondence related to this project. For any enquiries please contact <u>ethics@aut.ac.nz</u>. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)The AUTEC SecretariatAuckland University of Technology Ethics CommitteeCc: sambest021@gmail.com; Mark Thorpe

## **APPENDIX D: INFORMED CONSENT**

*Project title:* The experience and wellbeing of donor-conceived adults

## Project Supervisor: Dr Sonja Goedeke

Researcher: Samantha Best

O I have read and understood the information provided about this research project in the Information Sheet dated March 2021.

O I have had an opportunity to ask questions and to have them answered.

O I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

O I understand that I may talk about aspects of donor conception relevant to me and that questions may include:

- How/when and by whom was it disclosed to the me that I was conceived via donor. What was my experience of this?

-In what way, if any, did the knowledge you were donor-conceived affect your sense of self and your relationships with others?

-Has the knowledge you were donor conceived changed your family dynamics?

-What is the Donor's role in your life?

-What support have you received in relation to this?

O I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

O I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

O I agree to take part in this research.

O I wish to receive a summary of the research findings (please tick one): YesO NoO

Participant's signature: Participant's name: Participant's Contact Details (if appropriate): Date:

Approved by the Auckland University of Technology Ethics Committee on type the date on which the final approval was granted AUTEC Reference number type the AUTEC reference number

Note: The Participant should retain a copy of this form.