

# Donor conception and its impact on family constructs – the views and experiences of donor-conceived persons

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A thesis submitted in partial fulfilment of the

requirements for the Degree

of Master of Arts in Psychology

at the University of Canterbury

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2017

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## ACKNOWLEDGEMENTS

I would like to express my gratitude to my supervisors Professor Neville Blampied and Professor Ken Daniels for their time and guidance on this thesis. A special thanks to Ken for introducing me to this research topic, of which he has extensive knowledge and experience, and for reaching out to his connections in the donor conception community, recruiting twenty-one wonderful participants without whom this project would obviously not have been possible. Thank you, Neville, for realising this topic would be a great fit for my research interests and making the connection, and for your ongoing advice and support during the process.

I thank my participants for their time and their trust in sharing their personal stories with me, all of which enriched my understanding of what donor conception means to donor offspring and their families, and will, I am quite certain, do the same for others who read this thesis.

On the subject of family, I am grateful to my own for raising me (or in the case of siblings, growing up alongside me) in a loving environment, albeit one that does not fit into traditional assumptions about family and thereby broadening my own understanding and appreciation of the construct of family. I am further grateful for the memories of my mum and my brother, of whom not a day goes by I don't think about.

Finally, I thank my husband and our three beautiful, amazing children for their ongoing patience, understanding, and support while I worked on this project.

## Abstract

The increasing number of people seeking and accessing assisted reproductive technologies, and the resultant emergence of changing family forms, demand an understanding of the needs and experiences of donor-conceived persons and their families. Because the history of donor conception is a history of secrecy, the needs and experiences of these people and their families have largely gone unexplored. This exploratory study aimed to investigate the experiences and perceptions of donor-conceived persons in relation to family, and to examine what family has come to mean to them. It asks in what ways their donor conception shaped or impacted on their personal family constructs, defined here as one's conceptualisation of *family* (that is, who and what makes a family to this particular individual and why). Twenty-one semi-structured interviews were conducted with fifteen female participants and six male participants, aged between 19-46 years (mean = 30 years). All but one were born to heterosexual couples experiencing male-factor infertility and all were New Zealand born and raised. The interviews were analysed using thematic analysis. The following themes were identified as issues of salience for donor-conceived peoples' experiences and construct of *family*: "secrets and lies" verses "all out in the open" (disclosure and communication); positioning the donor (constructing meaning; conceptualising family; locating the donor), and thinking about family-building (views on assisted reproduction, and thinking about fertility). An overarching theme of empowerment verses disempowerment was identified, indicating that the ability to form self and family constructs based on accurate information about one's genetic roots is an empowering experience, while lack of such information can be experienced as disempowering.

## Chapter One: Introduction

### Assisted Reproduction – An Overview

The term assisted reproduction refers to conception that occurs via the use of donated gametes (sperm or ova) or embryos; surrogacy; and/or assisted reproductive technologies (ARTs). In other words, assisted reproduction is conception that occurs through means other than sexual intercourse between two intended parents.

Assisted reproduction using donated gametes and/or a surrogate is known as third-party reproduction. Of the third party reproductive techniques, donor insemination (DI), or sperm donation, is the most widely used. DI is also one of the oldest methods of assisted reproduction, with its use as a medical treatment dating back to at least the late nineteenth century (Richards, 2014).

Assisted reproductive technologies are “medical interventions that involve the formation of a fertilised embryo with the intention of producing a live birth” (Baron & Bazzell, 2014, p 57). Third party reproductive methods are not technically ARTS (Baron & Bazzell, 2014), but may be used in conjunction with ARTs. In Vitro Fertilisation (IVF), first successfully used in 1978 to treat female factor infertility, is currently the dominant ART (Baron & Bazzell, 2014) and is a necessary component of egg donation. During IVF, egg and sperm are combined to achieve fertilisation outside the woman’s body, and the resulting fertilised embryo is then placed in the uterine cavity of either the intended mother or surrogate for implantation. DI is a comparatively simple procedure whereby donor sperm is introduced directly into the woman’s uterus, usually through a catheter or syringe.

Successful assisted reproduction ultimately results in the creation of families, and families built through donor insemination are the focus of this study. DI is primarily accessed by heterosexual couples of which the male partner is infertile (or may have a hereditary condition he does not want to transmit through his genes); lesbian couples; and single women who wish to conceive. For most children, whether from dual or single parent families, being donor-conceived means growing up without the involvement of the third party with whom they share a genetic link. For children in dual parent families, being donor-conceived means that they will lack a genetic link to one of their parents. Many donor-conceived people will not be informed of the nature of their conception and/or the identity of any third parties involved.

#### Donor Insemination in New Zealand

Much progress has taken place in the field of donor insemination over the last thirty years. Until the late 1980s, sperm donated in New Zealand was done so on the basis that the donor's identity would remain anonymous, and parents were advised not to inform their children of the nature of their conception. This was in line with international policies promoting secrecy around the matter of donor conception. However, around 1987, New Zealand became a pioneering country in its attitude to disclosure, with many fertility clinics refusing to accept donors who would not agree to be identifiable to any resulting donor offspring, and by encouraging parents to share the nature of their family's origins with their children. This became possible because the Status of Children Amendment Act 1987 released donors from any legal liability being owed to the child. Since 2004, sperm donors in New Zealand have been legally required to be identifiable to any resulting offspring upon said offspring reaching the age of eighteen (Human Assisted Reproductive Technology Act, 2004).



Prior to the 1990s, DI was rarely accessed by those outside of heterosexual marriages. Traditionally, families built through DI typically mirrored the heterosexual-led dual-parent family form of the traditional nuclear family. This began to change from 1993 after amendments were made to the New Zealand Bill of Rights Act 1990, legally stipulating all fertility clinics in New Zealand must accept lesbian couples and single women as clients, thus making it illegal to discriminate against people based on their sexual orientation or marital status (New Zealand Law Commission, 2004).

Currently, the greatest demand for sperm donors in New Zealand comes from single women, followed by lesbian couples (Pellegrino, 2015). For example, in 2014, Fertility Associates New Zealand, the largest provider of fertility services in New Zealand, treated three hundred women using donor sperm. One hundred and fifty-six of these women were single; eighty-eight were in lesbian relationships; and fifty-six were in heterosexual relationships (Pellegrino, 2015). This may be attributed, in part, to societal shifts, such as a greater acceptance of different family forms - reflected in such legislation as the Civil Union Act 2004 and the legalisation of same-sex marriage (Marriage (Definition of Marriage) Act 2013) - but is largely due to advances in ARTS (Baron & Bazzell, 2014). Use of donor sperm by heterosexual couples has declined in recent years as ARTs have been developed that enable the use of semen from men with exceptionally low sperm counts, such as the Intracytoplasmic Sperm Injection (ICSI), first introduced in the early 1990s, which allows for a single sperm to be removed from the male's reproductive tract to be injected into an egg. If an embryo is formed, it may then be implanted in the female partner's uterus. ICSI has thus eliminated the need for donor sperm for many heterosexual couples experiencing male factor infertility (Devroey & Van Steireghem, 2004).

The implications of donor conception are different for those born into heterosexual-led families than those born to single mothers or lesbian mothers from the point of view that single and lesbian mothers have less choice around the matter of what they will tell their children about the way in which they were conceived. Children in these families will have obvious questions with regards to their conception so concealing the truth is not an option to the same degree as it is for heterosexual parents. In heterosexual-led dual-parent families, there remains the option to follow what was once standard practice and conceal the truth from one's children; to pretend that the child's father is both the social and biological father. Some studies have compared disclosure over different family types and have indeed found that single mothers and lesbian parents were more likely to inform their children of their donor conception voluntarily and earlier than heterosexual couples (e.g. Jadvá, Freeman, Kramer & Golombok 2009). One study by Beeson, Jennings and Kramer (2011), comparing disclosure across different family types, found that disclosure was most likely to be confusing to those in dual-parent heterosexual-led households, but emphasised that this was particularly so when disclosure occurred at a later age.

Nevertheless, for all families built through donor conception, questions will present around their personal and shared family constructs. *Family construct* in the context of this study, refers to one's conceptualisation of *family*; that is, who or what makes up a family, and more specifically, who makes up their particular family, and the role/s each family member hold. The parent/s attitude/s towards the process of donor conception and what that means for them will manifest in the way in which they communicate about the donor, or if they choose to acknowledge him at all.

Donor-conceived people seeking and contacting their donor and donor siblings (offspring from the same donor) is considered one of the most significant recent developments regarding families created via assisted reproduction, and may be expected to rise in future years as more countries introduce open-identity donation (Freeman, Graham, Ebtejah & Richards, 2014). In New Zealand for example, the Human Assisted Reproductive Technology (HART) Act 2005 led to the creation of a central register of offspring and their donors so that donor-conceived persons can access information about their donor after they turn eighteen, while those born before 2005 who wish to trace their donor, have the option to place themselves on a voluntary donor registry. If the donor or other offspring from the same donor also register, connections can be made through the fertility clinic at which the insemination took place. Thus, through these registries and others like them, such as the United States based Donor Sibling Registry,<sup>1</sup> which is open to donors and donor-conceived persons from all around the world and is currently the largest of such registries in the world, donor-conceived persons can potentially locate people with whom they share a genetic link through DI. Should donor offspring succeed in establishing contact with their donor or donor siblings, then parental attitudes and feelings about the donor and donor conception will manifest in how the parent/s respond to their adult children's interests, wishes, and choices around relationships or potential relationships with the donor and/or donor siblings.

How donor-conceived people develop their family constructs is a matter of interest to family psychology. It is important to understand the new family forms that are emerging through assisted reproduction and, in the case of those built with the assistance of third party gametes, it is important to understand what either a lack of information

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<sup>1</sup> (<https://www.donorsiblingregistry.com>)

regarding the third party, or a lack of involvement from the third party in the upbringing of any resultant offspring, could come to mean for the child and their family. Families built through donor conception also raise other questions relevant to the field of psychology such as whether counselling/support groups should be made available to these families as a matter of course, and whether there should be greater community education around the nature of family in the twenty-first century; education that covers such things as changing definitions of family, and how, with other things being equal, families who do not fit into traditional assumptions or constructs can and do function just as well as those who do fit into traditional assumptions or constructs (e.g. Chun-Shin Hahn, 2001; Golombok, 2011; Iloi & Golombok, 2014). Such education may help to reduce misconceptions about alternative family forms.

There are also broader social and public policy issues that arise when considering the recognition of kinship relationships formed through third-party genetic connections. For example, does the definition of family in the New Zealand census need to be broadened from its current co-residence based definition to allow for changing family forms?<sup>2</sup> Of course, any changes to social and legal definitions of family would need to be considered in light of the impact they could potentially have on legal and public policy issues with regards to family, such as which family members have rights around life support and funeral arrangements in the event of sickness or death, or issues that may arise around inheritance claims.

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<sup>2</sup> See <http://www.stats.govt.nz/Census/2013-census/profile-and-summary-reports/qstats-families-households/overview-families.aspx> for current definition of family.

## Chapter Two: Literature Review

### Donor Conception - A History of Secrecy

Donor insemination has been associated with secrecy from its beginnings. The first recorded case of donor insemination occurred in Philadelphia in the year 1884, when a doctor artificially inseminated a female patient with donor sperm without seeking consent from the woman or her husband (who was infertile). The procedure took place when the female recipient was under a general anaesthetic, and by request of her husband she was never informed of what had occurred; as far as she knew the baby conceived was the genetic child of both she and her husband. This was made possible by the climate of the day which valued the opinions and interests of medical professionals over those of the patient.

The clinical use of artificial insemination was largely confined to insemination using a husband's sperm until the 1930s (Richards, 2014). In 1924, a survey of the world's medical literature found one hundred and twenty-three reported cases of donor insemination, and a further study extended this number to one hundred and eighty-five, three years later. In 1941, a questionnaire sent to thirty thousand doctors around the United States resulted in reports of over nine thousand successful pregnancies via donor insemination. This shows the number of families built through donor conception was on the rise over the early twentieth century. However, because private practitioners continued to carry out the procedure discreetly and the practice was unregulated, no records were kept that give an accurate figure of how many were taking place (Kramer, 2016). It is known that the number of people accessing donated sperm increased after World War Two and there is anecdotal evidence indicating that

there were babies conceived via DI in New Zealand from the 1940s onwards but, following international trends on the matter, no records were kept confirming how many children may have been conceived in this way (Daniels & Taylor, 1993; Daniels, 2004). Any children conceived via DI were considered by law to be the legitimate offspring of both parents, and silence on the matter was advised (Daniels, 2004). New Zealand's first official donor programme was established as a pilot program in 1972 at Auckland's National Women's Hospital and similar programmes opened in Wellington and Christchurch over the 1970s. Again, to protect the privacy and anonymity of the donor, records were not kept and secrecy was advised to the recipient couples.

Over the decades these attitudes and practices continued with professionals advocating secrecy on the assumption that secrecy was in the best interests of everyone involved. Donors would be protected from bearing any legal responsibility towards the child, and would also be shielded from the stigma of having people know of their involvement in a procedure that some people considered shameful and immoral (Rao, 1996; Richards 2014). Those who considered DI shameful and immoral often did so for religious reasons, objecting to its use on the basis that it involves a third party and therefore could be compared to adultery, and because it requires the donor to masturbate to obtain the sperm, a practice which the Catholic Church for example, regarded as 'gravely sinful'. (Richards, 2014). Criticism was targeted at women for their "willingness to accept another man's semen" (Haimes, 1993, p178) and at donors whose motivations were viewed with suspicion to the extent that it was firmly stated at a UK interdepartmental committee (Ferversham Committee, 1960), that sperm donation "is an activity which might be expected to attract more than the usual proportion of psychopaths" (quoted in Daniels & Taylor 1993, p55). It was

therefore argued that with the risk of this kind of stigma, few men would choose to donate sperm without the guarantee of anonymity, and potential parents would be the losers. Anonymity would protect medical professionals too, from the risk to their medical reputation. Moreover, many sperm donors were medical professionals which further motivated those in the field to promote policies of secrecy (Daniels & Taylor, 1993; Haimes, 1993).

Beyond the rights of donors and medical professionals, it was generally agreed that shielding the donor-conceived child from the knowledge they were not genetically linked to one of their parents would protect families from familial conflict (Daniels, 2004). From this view, acknowledgement of the donor was considered a possible threat to family cohesion. Additionally, the male partner would be protected from publicly acknowledging his infertility and facing the stigma that society places on male-factor infertility, such as the notion that infertility is an indication of lessened virility. The experience of stigma is known to lead to a sense of shame, isolation, or inadequacy, for many infertile men (Fisher & Hammarberg, 2012). Thus, it was maintained that anonymity was best because it would ensure the privacy of everyone in the family. Donor-conceived people themselves were considered to have “no need to know” (Blyth, Crawshaw, Smith & Jones, 2012, p770).

#### The Shift Towards Policies of Openness and Disclosure

The last few decades have seen huge developments in the field of assisted reproductive technologies, and the demand for such services has grown exponentially. Likewise, over the last few decades, a shift has taken place in the thoughts and attitudes of many professionals in the field; a shift towards a climate of disclosure and

openness, with many now recognising that what was once considered to be in the best interests of the donor and recipients of donor sperm is not necessarily in the best interests of the donor-conceived person or the family unit. Of vital importance to this shift were the families who, wishing to avoid the damage associated with secrecy, began to challenge the practice of doctors, and the advocating of secrecy (Blyth et al, 2012; Daniels, 2004).

Now, there is also increasing recognition of the wishes of people conceived through donor conception to be able to obtain information on their genetic origins, especially as donor-conceived individuals have begun sharing their experiences and views through social media and empirical research. A growing body of research supports the idea that information sharing is in the best interests of donor-conceived people, and conversely, that lack of information sharing can have a negative impact on the individual and his or her family relationships (e.g. Beeson et al, 2011; Blyth, 2012; Jadvá et al, 2010; Persaud et al, 2017; Turner & Coyle, 2000). van den Akker's (2006) review of research on gamete donors, recipients, and offspring, for example, shows that studies on donor conception consistently report that donor-conceived children who have not been told about the means of their conception but have subsequently found out, experience numerous negative consequences including: mistrust within the family; lack of genetic continuity; poor self-perception; feeling that they did not fit in with their families because of physical differences; being aware from a relatively early age that something was not said within the family; learning about their conception in shocking and unexpected circumstances, and experiencing anger, resentment and upset.



Recognition of the rights of donor-conceived persons to the knowledge of their conception and information about their donor, though not yet universal, is reflected in the changing policies and practices around donor conception, nationally and internationally. New Zealand was one of the earliest countries to begin to view donor insemination through a biopsychosocial lens (Daniels, 2006), rather than a biomedical lens, and therefore to consider that there are wider implications of third party reproduction for the individual, the family, and society, and to integrate this understanding into policies surrounding donor conception. The move away from a purely medical point of view was largely influenced by changes in adoption policy, such as New Zealand's 1985 Adult Adoption Information Act which recognised the rights of adopted individuals to their genetic information.

In 1985, the Adult Adoption Information Act modified the Adoption Act of 1955, which had promoted secrecy and ensured anonymity of the biological parents by excluding information from birth certificates and denying information about the birth parents to adoptees or adoptive parents. For many years, it was believed that a person had no need to know that she or he was adopted and no need for any genetic information; it was widely accepted that adopted persons could and should be given their adoptive parents' family history and heritage, and be raised exactly as if they'd been born to the adults raising them (Siegel & Smith, 2012). The amendment gave adopted persons the right to apply for information that would help them identify their birth parents and vice versa, while giving each the right to restrict each other's access to such information if they so wished (Henaghan & Atkin, 2013). This shift in policy was influenced by research on best practice which showed it was not in the best interest of the adopted person to deny them access to their genetic heritage. Information about genetic heritage has been found to be important part of identity and self-concept for

many adopted people (e.g. Humphrey & Humphrey, 1989; Krueger & Hanna, 1997, Siegel, 2012). Additionally, in New Zealand there was a growing recognition of the need to align adoption practice with bicultural principles, recognising and acknowledging important Maori concepts such as the importance of knowing one's whakapapa, or genetic lineage (Henaghan & Atkin, 2013). This recognition of the adoptee's right to information regarding their genetic origins led to increased interest in the rights of the donor-conceived child in the mid to late 1980s, and the realisation that maybe they too should have the right to know of their genetic origins.

The Status of Children Amendment Act was thus established in 1987. This Act clarified the legal relationship that existed between donors and donor-conceived children (phrased as "a father with no rights or liabilities of a father") so that it was made clear donors were free from any legal or parental responsibilities to any subsequent offspring (Henaghan & Atkin, 2013). This effectively removed from the debate, the argument that a shortage of donors would result from release of identity due to fear of legal and parental responsibilities. The act was a significant factor in the change of culture from secrecy to disclosure in New Zealand as, from this point on, most fertility clinics would only accept donors who were willing to provide some identifying information about themselves to the child and his or her family, and who were willing to be contacted later by the clinic to consider disclosing their identity (New Zealand Law Commission, 2004). Clinics also began advising parents to disclose to their children. New Zealand now has a relatively high level of disclosure as a result (Adair, 1996; Hargreaves and Daniels, 2007).

The Status of Children Amendment Act 2004 and the Human Assisted Reproductive Act 2004 legislated for even more openness around sperm donation, legally requiring

donors to be identifiable to any offspring once they reach the age of eighteen. The Status of Children Amendment Act 2004 removed any uncertainty about the status of children conceived via third party assisted reproduction, clarifying that donors are not considered for any purpose a parent of any child of the pregnancy, as opposed to the earlier definition of a father without rights or liabilities (Henaghan & Atkin, 2013). This enabled the HART Act which saw the establishment of a mandatory register for donor-conceived persons born after 2005 and their donors, allowing donor offspring to obtain genetic information about their donor and the right to request contact. Also established was a voluntary register for those born before 2005, who wish to trace their donor or donor siblings (New Zealand Government; 2016).

Many countries, however, including the United States, Canada, France, Spain, and Japan, still protect donor anonymity by law, while others, like Denmark, allow the donor to choose. Arguments in these countries typically centre around the rights of the donor and the shortage of donors that may result from laws that fail to protect anonymity. For example, a recent report in a Canadian medical journal quoted a director at a clinic for reproductive medicine: "Countries that already banned anonymity have experienced a donor semen shortage that is even worse than Canada. In 2009, we received around 600 applications and interviewed almost 20% of them. The overwhelming majority of the donors interviewed indicated that they will not commit into becoming semen donors if their identity is automatically disclosed" (Collier, 2010, p232). However, Collier (2010) also points out that not everybody in the field of fertility believes that donor shortage is reason enough to uphold anonymity: "Some doctors, though, suggest that just because allowing people to donate sperm anonymously increases donation levels, doesn't mean it's the right policy. 'You are bypassing the ethical argument and going

straight to the pragmatic argument,' says Dr Ian Mitchell, a professor of pediatrics and bioethics at the University of Calgary" (p 232).

Furthermore, advances in genetic testing mean donor anonymity cannot be guaranteed even in countries where donor anonymity is upheld. To date, over three million people have used direct-to-consumer genetic testing to find information about their ancestry, and many are participating in international genetic genealogy databases that will match them with relatives (Harper et al, 2016). This has obvious implications for the ability to conceal a person's genetic information. Co-author Professor Joyce Harper explained: "DNA tests are increasingly being used to solve unknown parentage cases for adoptees and donor-conceived persons. People are finding half-siblings and even biological parents in online databases that are open to the public. A sperm donor does not have to be in the database to be identified as identification can be made from matches with other close relatives such as second or third cousins." (quoted in Walker, 2016, para. 4).

Other countries that have banned donor anonymity include: Sweden (which was the first country to ban anonymity for sperm donors in 1985), Norway, Switzerland, Germany, Austria, Australia, Ireland, and the United Kingdom. Legislation is an essential step towards acknowledging the rights of the donor-conceived person and encouraging disclosure and transparency. However, laws banning donor anonymity do not guarantee that every donor-conceived person will have access to their genetic information: "Lack of disclosure effectively prevents true implementation of legislation; if someone has not been informed that their conception was the result of donated gametes, then they cannot take up the legally available option of accessing identifiable

information about their donor” (Van den Akker, 2006, p 91). Some legislation now deals directly with this issue, for example, Ireland recently introduced the Children and Family Relationships Act (2015), which provides a national register where all donor-conceived children will be able to trace their donors, and will be informed of their donor-conceived status when they apply for a copy of their birth certificate, in effect making disclosure mandatory by permitting all donor offspring to know their genetic origins, whether or not they have been informed of their donor-conceived status by their parents (Harper et al, 2016; Lyons, 2017). Similar legislation exists in Victoria, Australia, where “a donor-conceived child’s birth certificate is marked and annotated with identifying information about the donor. Where a donor-conceived person above the age of 18 applies for a copy of their birth certificate, they will be informed that an annotated version of the certificate exists, and will then be permitted to view the annotation should they wish to do so.” (Lyons, 2017, p32). However, as Daniels (2005) explains: “while governments may change policy in this area and bring in new regulations or laws it needs to be acknowledged that policy is always a blunt instrument for changing attitudes and in this area, it is the attitudes that seem to be of great significance. It may well be that the policy change is one step in the process of attitudinal change but it would be all too easy to think that having achieved policy change, the task has been completed.” (p 269).

Indeed, ‘fertility tourism’ is a thriving trade, partly because of the donor shortage that exists in many countries, but also due to those parents-to-be who seek to circumvent laws preventing donor anonymity in their own countries by travelling to more lenient destinations, such as Denmark which has the largest Sperm Bank in the world and allows donors to choose whether they wish to be anonymous to future offspring or not (Cahn, 2013).

This brings us to the question of what it is that holds back some recipients of donor sperm from being open with their children about the nature of their origins, even while raising them in a climate that promotes disclosure and transparency. Yet, with such a long history of secrecy and stigmatisation surrounding both male infertility and donor insemination, it is not surprising that some parents of donor-conceived children may well be stuck in the mindset of shame and stigma, and thus are not experiencing donor conception as a healthy alternative way of building a family. As van den Akker (2006) states, “Those who are confident about having made a positive decision to use gamete donation to have children, do not pretend no intervention was used and disclose this to their social and family networks, including the donor-conceived child. Recipients who feel a certain amount of anguish about the underlying reasons to need to resort to gamete donation have concerns about their self-image (e.g. their masculinity/femininity is challenged), and therefore feel the need to disguise not only their ‘problem’ but the truth about the child’s conception to the child and the wider network.” (p 95-6).

On the other hand, some parents may be coming from a place of outdated insecurities around negative implications for the family, while others may still feel that the child simply has no need to know. For instance, Readings, Blake, Jadvá and Golombok (2011) compared disclosure across families built via sperm donation, egg donation, and surrogacy. They found that families built through DI had the lowest rate of disclosure and that the most common reasons given for not disclosing were “no need to tell”; “to protect the child”, and because they considered it “a personal matter”. Those who cited protecting the child as their motivation for secrecy were concerned the child would not feel “normal” knowing that they were donor-conceived or that they were

carried by a surrogate (however, almost all the families built with the assistance of a surrogate had disclosed). In a study of DI families only (Lycett, Daniels, Curson & Golombok, 2004), 61% of families were not inclined towards disclosure, some stating that they felt that “there was “no reason to tell”, and others that they wished to “protect family members”.

Contention between professionals is unlikely to make things any clearer for those uncertain as to whether they should disclose their family's origins: “Information sharing—often dichotomized and represented as disclosure and secrecy—has been, and to a certain extent remains, one of the most controversial and debated issues between professionals working in the field of third party reproduction” (Indekeu et al, 2013, p 714).

It is understandable and reasonable that parents who choose to build their families with the assistance of third parties want to be sure that if they are going to disclose to their children, it is in the best interests of their children and the family to do so. Up until recently, discourse in this area has tended to focus on the voices of the parents and/or donor, and the body of research has reflected this. This is a logical outcome of DI's history of secrecy, and the fact that many donor offspring do not possess the knowledge that they are donor-conceived. More recently though, such trends as the growth in the use of assisted reproductive technologies, advances in DNA testing, and increasing numbers of donor-conceived people growing up and choosing to speak out about their experiences via social media and other avenues, has led to subsequent growth in public interest in the topic and an increase in research from fields such as psychology, sociology, social work, anthropology and philosophy. The voices of donor

offspring themselves have been sought and research has begun to focus on their experiences and perceptions. Overwhelmingly, these voices add weight to the legislation and recommendations calling for recognition of the donor conceived person's right to know.

#### Experiences of the Donor-Conceived: Current Research

Research into adoptees who have searched for their biological connections has found the main reason given by adopted individuals for wishing to meet their biological relatives is to gain a more complete understanding of their family history to enhance their own sense of identity (Golombok, 2015). For example, adoptees who have met their biological relatives have stated that benefits of meeting their birth families include a better sense of self and psychological wellbeing. Golombok (2015) states that similar factors may be at play for donor- conceived persons, and recent studies are consistent with this view.

Blyth, Crawford, Smith and Jones (2012) conducted a meta-analysis of DI research via a search of four electronic databases from 1990-2011. In line with policies of secrecy and lack of disclosure, this search turned up no studies recording donor offspring's experiences and perceptions prior to the year 2000. From 2000 onwards, the authors located nineteen research articles focussing on the experiences and perceptions of donor offspring; more than half of these published after 2008. The majority of participants in these studies were conceived via anonymous sperm donation, thus most were unable to learn the identity of their donor or any genetic relatives.



Some key themes Blyth and colleagues identified throughout the literature were the impact of disclosure on relationships, and the desire for knowledge of the donor and/or a wish to build a relationship with their donor.

Blyth and colleagues found that most studies highlighted that early disclosure was associated with neutral to positive impact on parent-child relationships and later disclosure was often associated with negative outcomes such as anger and mistrust.

They also found that the studies consistently reported that “most donor-conceived people have an interest in securing information about their genetic and biographical heritage – more information than most of them have been able to obtain” (p 769). Desires for social, familial and medical history were routinely expressed across the studies. As a result of their analysis, they concluded that “the evidence is sufficiently robust to promote the implication of policies and practices that promote transparency and openness in collaborative reproduction.” (p 769).

One of the studies included in their review was Blyth’s (2012) study in which a group of donor-conceived persons, who shared a donor and were collectively referred to as Clan X, were interviewed regarding their experiences of: discovering they were donor-conceived; learning of their (deceased) donor’s identity; and meeting with one another. All eight participants described the initial discovery of their donor conception as a shock. Most expressed some form of disruption to their sense of identity, particularly in relation to the realisation that they did not share a genetic link with their father, an experience Blyth refers to as genetic discontinuity. Learning about their donor and donor siblings however, gave them the opportunity to redefine their identities. This and the positive experience of the donor sibling interaction itself were identified as the key benefits of learning of their donor’s identity and subsequently meeting their donor

siblings. Blyth states that, “overall, they articulated deeper and more informed understandings of their genetic and social relationships and interactions than they felt they would have otherwise possessed.” (p 723).

Participants also clearly expressed that the family they grew up with remained their family, and that their feelings about their family did not change with the possession of this new knowledge about themselves. Thus, while the importance of the family they had grown up with, and the love and experiences they shared, were not undermined by acknowledging their genetic connections, these genetic connections became important also, and learning the identity of their donor and meeting their donor siblings were invariably enriching experiences. This study illustrates Blyth and colleagues’ assertion that donor-conceived people have a vested interest in being given the opportunity to secure information about their genetic and biographical heritage.

Persaud and colleagues (2017) explored the motivations and experiences of twenty-three donor-conceived persons between the ages of twelve and nineteen years on the experience of contacting donor siblings. They found that the primary motivations for seeking contact with donor siblings were curiosity about the donor and genetic origins, and forming relationships to extend family. As with Blyth’s (2012) study, the opportunity to redefine one’s donor-conceived identity within the context of a shared experience was identified as a key benefit of the meetings. Additionally, many participants expressed appreciation for the opportunity to “form a relationship that was unlike others” (p19). Participants reported either normal/neutral or positive experiences of meeting donor siblings, and some participants had subsequently formed close sibling relationships with donor siblings. While most considered the relationship to be a familial one, it was also acknowledged to be a relationship that

came with complex layers, including the expectation that there would instantly be a sense of closeness between donor-siblings.

## Family Constructs and the Changing Face of the Family Unit

*Donor families both reinforce and complicate the meaning of family, offering lessons for all families by questioning what makes a family (Cahn, 2013 p3)*

## Defining Family

There has never been a universal definition of family. The institution of family is a fluid social construct so not only do notions of family and kinship differ from culture to culture, they can alter from one generation to the next. One attempt to define family as it stands in New Zealand, comes from The Families Commission Act of 2003 which states that family is “a group of people related by marriage or civil union, blood or adoption, an extended family, two or more persons living together as a family and a whanau or other culturally recognised group” (Henaghan & Atkin, 2013 p21). This definition recognises the contemporary concern of acknowledging diversity in families and understanding and accepting that all families are not formed or experienced in the same way. Because, despite much opposition from people who hold fast to traditional notions of nuclear families connected via bonds of marriage and blood, the face of the family unit is changing. Current trends in western society include: a declining marriage rate; de-facto relationships and civil unions on the rise; de-facto partners openly having and raising children together; the age at first marriage continuing to rise as does parental age at birth of first child; the number of children per family decreasing; more single parents; same sex marriages; more people living alone; more step families; more working mothers, and as a result increased use of and need for day care; and less connection to wider kin networks (Nordqvist & Smart, 2014; Olsen &

Defrain, 2000). Such trends can be alarming to those who wish to “preserve” the traditional family unit.

Rao (1996) states that families built through assisted reproduction highlight the fluidity and social constructedness of the institution of family. Such families are threatening to individuals and groups who perceive families as a reflection of the ‘biological fact’ that reproduction results from the sexual union of a man and woman alone. Appleby and Karnein (2014), argue that donor families are cause for celebration due to the doors they open for diverse family types and structures, including same-sex marriages and homosexual-led families; the very reason that others may fear or oppose them.

#### Conceptualising Family

Traditional models and conceptual frameworks of the family are too restrictive to encompass all the different types of families that result from cultural shifts and trends. Traditional stage models, for example Duvall’s well-known eight- stage model, offered a step by step prescription it was expected families would follow in order to constitute or be recognised as a proper family (Duvall, 1971). Family strengths models and family systems models have emerged in recent years with the aim of expanding our view of family and to move the focus away from trying to define or confine the concept of ‘family’ to one particular way of being. This has practical purposes for those who work with families such as family psychologists and therapists.

#### Family Strengths Models

Olsen (2000) developed the circumflex model of family which emphasises the importance of cohesion, flexibility, and communication as family strengths. Cohesion is defined as the emotional bonding that families have towards one another; flexibility

focusses on how well families balance stability and change; and communication is seen as critical for facilitating change across both cohesion and flexibility. Olsen proposes that families should be able to: 1) "cope with stress and problems in an efficient and effective way;" 2) "have and use coping resources both from within and from outside the family;" and 3) "have the ability to end up being more cohesive, more flexible and more satisfied as a result of effectively overcoming stress and problems" (1986, p. 104). A definition of a strong family based on this model is, therefore, dependent on such things as the quality of interactions within the family, and the availability of resources such as professional and social support, rather than the structure and make-up of the family or the characteristics of individual family members.

There is no evidence to suggest that families built through donor conception are not as strong as families built through traditional means. In fact, research exploring the implications of donor conception for child development and family functioning has consistently reported no significant difference in parent-child relationships or child development in donor-conceived families when compared with natural conception or in-vitro fertilisation (IVF) families, across a number of measures (e.g. Chun-Shin, 2001; Golombok, 2011; Iloi & Golombok, 2014). There is evidence however, from the family therapy literature, to suggest that secrecy in families can potentially lead to negative consequences. Brown-Smith (1998) explains that secrets are detrimental to family functioning because they create boundaries between those who are aware of the truth and those who are not and can cause anxiety when topics related to the secret come up.

## Family Systems Models

Family systems models originate from systems science which aims “to understand man and his environment as part of interacting systems” (Skyttner, 2005, p3), and “to study this interaction from multiple perspectives, holistically” (Skyttner, 2005, p3). Family systems models thus conceptualise the family unit as a system consisting of different sub-systems that interact and influence one another, maintaining or upsetting the balance of the whole. Family systems models recognise each family member and their interactions with one another as important parts of the whole, and view the system as fluid; changing in response to internal and external influences (Olsen and Defrain, 2000). These influences could be psychological, biological, environmental, economic, or socio-cultural, for example.

Daniels (2006) describes the biopsychosocial model as a systems model that can be used to conceptualise the family built through donor conception. In most families, he explains, the psychological and social dimensions are more prominent in terms of family functioning, but the biological dimension is a more prominent feature for the family built through donor conception, due to its very nature. The way in which parents respond to the biological aspect of infertility and its treatment (in this case DI), and the way in which these biological facts are incorporated into the life of the family, will in turn be influenced by psychological factors and social factors. Psychological factors might include a tendency to focus on painful feelings like shame, guilt, and loss, as opposed to a focus on resolution, acceptance and confidence. Social factors include a professional or social climate that encourages the donor and recipients towards secrecy (reinforcing shame and stigma), or one that is more supportive and openly encouraging of disclosure. Disclosure of the biological fact of the family’s origins will probably not in itself be enough to maintain the wellbeing of the family. If, for example,

there is a sense of shame or discomfort emanating from one or both parents, the donor-conceived person may internalise this and feel less positive about his or her origins than if the parents take a more open and/or celebratory approach. Thus, a systems approach to the welfare of the family would address any issues that may be prevalent for the family or for a particular individual in the family, knowing that the health and wellbeing of one family member impacts on the health and wellbeing of all family members.

### Challenging Traditional Assumptions

Family strengths models and family systems models are an attempt to move away from earlier, more restrictive, models of the family which operated on generalisations that did not necessarily cross over different family types and cultures and were thus limiting when attempting to work with or understand different family types and cultures (Olsen and Defrain, 2000). Just as traditional models and frameworks of the family are too restrictive when trying to conceptualise something as broad and diverse as family, so too are many traditionally held assumptions about the family; yet these traditional assumptions can and do pervade certain factions of society and can influence decisions around such things as policies and education as well as impacting on individual's feelings, attitudes and choices regarding their own families. Such assumptions can also be hard to reverse even as the society itself shows evidence of change.

One such traditional assumption is: "being a family means a blood tie exists and that as a result family members will be closer and their relationships more significant than the relationships they have with non-family" (Daniels, 2006 p 265). If such an assumption were true, then the obvious implication is that fathers of children conceived

via sperm donation would not be as likely to form as strong or healthy bonds with their children as fathers who do share a genetic relationship with their children. With more than one million people born from donor gametes worldwide (Cahn, 2013), such implications could have serious consequences for the wellbeing of many individuals and the functioning of many families. Fortunately, this is not what the evidence from past and current research indicates. As previously mentioned, no significant difference has been found in parent-child relationships, or child development, in donor-conceived families compared to other families, and many donor-conceived people are telling us that “Dad is Dad” whilst speaking of the close, loving ties they share, though these ties are not based on any genetic connection (e.g. Blyth et al, 2012). Moreover, a genetic link between parent and child does not in itself, necessarily ensure a strong or healthy bond.

Freeman (2014) explains that the “blood is thicker than water” assumption endures despite conceptual and empirical challenges, at least in part, because the ideal of mother, father, and their biological children has become so enshrined as an ideal through Western socio-legal and cultural definitions of parenthood that fatherhood is often automatically identified with conception and the provision of sperm through sexual intercourse, while motherhood is associated with gestation and birth. There is a gender bias around such essentialist rhetoric, as the paternal line has long been given precedence over the maternal line, for example with inheritance of father’s surname, property etc. Freeman states that the verbs “to father” and “to mother” further illustrate gender-biased and essentialist rhetoric; “to father” typically means to beget, whereas “to mother” typically means to nurture, thereby father has biological undertones and mother more emotional and social undertones. This observation perhaps provides some insight as to why there is such shame and stigma associated



with male-factor infertility in particular, and why there appears to be more discomfort around the use of donor sperm than donor eggs (Cahn, 2013), along with the biased perception (in countries where sperm and egg donors are both paid for their gametes) that “egg donors are altruists; sperm donors are in it for the money” (Cahn, 2013, p 280).

### Do Genes Matter?

Current trends of people waiting later in life to marry and have children (while fertility declines with age), more same-sex couples marrying or cohabitating, and more adults remaining single, mean that having a child or children who do not share a genetic link with at least one of their parents is a reality for many families and will continue to be so for future families.

While the ‘blood is thicker than water’ approach has implications for how people think about donor conception and the relationships that ensue, there is on the other side of the coin, the argument that genes don’t matter - that the importance of nurture overrules the importance of nature - and this argument also has implications for how people think about donor conception and the relationships that ensue.

As Appleby and Karnein (2014) point out, many people do attribute great significance to genetic ties, and the choice to access assisted reproductive technologies, often at considerable financial expenses and sometimes at high medical risk, to ensure genetic relatedness to one or both parents is a reflection of this significance. However, these very technologies that allow for genetic relatedness to one biological parent often make it necessary for those seeking genetic relatedness to deny its significance through the severing of genetic ties to the third party. In Appleby and Karnein’s view, the contradiction is not a negative one. In fact, they see ARTs “and the mixed message

they involve” (p92) as something to be welcomed for the way in which they confront novel family forms and challenge traditional assumptions and understandings, therefore slowly building a society in which children of all different family forms receive acceptance and understanding from the society in which they live.

Philosopher Charlotte Witt (2014) uses the term ‘bionormative conception’ of family to describe the ideal of genetic relatedness, explaining that a bionormative conception of family is the recognition that society holds families where parents are genetically related to their children as superior to families where they are not. Witt asks why the bionormative family is held up as the gold standard of families, and examines the moral philosopher David Velleman’s (2008) argument that anonymous gamete donation is harmful to any resultant offspring because it damages development towards healthy human flourishing. Witt says Velleman’s central argument in support of this claim is the argument from family resemblances; that we need direct acquaintance with biological relations to develop an adequate sense of self. Hence, children who are conceived via anonymous gametes are denied the material necessary for development towards human flourishing. The same argument, he says, is true for adopted children, but for these children it may still be the best option available. Velleman thinks that self-understanding is usually accomplished by seeing resemblances between oneself and one’s biological relatives. Witt responds that being a biological relative is neither necessary nor sufficient to establish a likeness between individuals. Thus, it does not follow that people need direct acquaintance with biological relatives to form a psychologically adequate self-image.

Velleman’s argument however, speaks against anonymous gamete donation not gamete donation per se, and there are many in the donor conception community who agree that the genetic link does matter and that donor-conceived people should have

the right to knowledge of their genetic origins and to information on such things as the physical characteristics and medical background of their donor. In his paper, *The Gift of Life* (2008), Velleman reminds us that the debate of the importance of biological relatedness is not new as he recalls Aristotle's response to Plato's idea that all children would be well served to be raised by government institutions from birth. Aristotle stated that many people would seek out their mothers, fathers, and siblings, as soon as they could, thereby illustrating his awareness that human beings have a 'natural tendency' to find and associate with their biological relatives.

The idea that genes do not matter is challenged by parents who choose assisted reproduction as a means of family building; by donor offspring who seek their donors and/or donor siblings; and by adoptees who search for their birth families. Certainly, the million-plus people who have used direct-to-consumer genetic testing and international genetic genealogy databases attest to the importance they ascribe to genetics. Velleman's position on the matter is again clear, when he states that during the eugenics movement, "people who claimed to know better than common sense believed that a person's biological heritage was all-important; today they believe that it is utterly insignificant. Neither belief is true; either belief can lead to a wholesale violation of rights. The rights violated in the present case are the rights of the children." (p 117). Current research suggests that some donor-conceived individuals, who perhaps would not go as far as comparing the emphasis on nurture over nature to the eugenics movement, would however agree with the central premise of this statement - that both environment and genes matter and to deny donor offspring knowledge of their genetic origins is (morally) a violation of their rights.

It is also the case that while some donor-conceived people would be satisfied with access to their genetic information alone, information which may or may not include

evidence of shared resemblances, others may be seeking something more, such as the potential for a social connection or relationship of some kind. For some donor-conceived people, the concept of family undoubtedly extends beyond the family they have grown up with. In Naomi Cahn 's book, *The New Kinship* (2013), she discusses two types of families that are being constructed through donor conception. The first is the immediate or primary family that is built through donor conception. The second type, she refers to as donor-conceived family communities or donor kin networks - relationships between donor and donor offspring and/or donor siblings that are recognised as familial as well as social. Cahn explains: "These extended donor kin networks could include dozens (or even hundreds) of people who are all linked via the same donor's eggs or sperm. While the individual families are connected by genes, a traditional marker of family, they enact few of the other conventional and legal trappings of family life such as living in the same house, pooling financial resources, or enjoying the legal protections accorded to family life. There may be no shared cultural orientations or belief systems ... yet the genetic ties among the children cause many to feel strong kinship towards each other." (p3).

Families built through donor conception stretch definitions of family beyond those that serve to narrow down a broad social and personal construct so it can be understood, framed, and regulated within certain laws and jurisdiction. These families show that (1) family is not defined by biological bonds alone and (2) for some, biology has a strong enough pull that people who are otherwise essentially strangers may experience a sense of connection and relatedness, and may as a result wish to build family relationships, initially founded on genetic links alone.

Clearly, there is no single way to experience family or to experience being donor-conceived. Donor conception is part of a larger picture of family diversity, and the

voices of donor-conceived persons are important to the discourse on family and diversity. In answer to the question 'do genes matter?', current literature (and donor-conceived people speaking out via such mediums as television and the internet) tell us that yes genes are important, but for some more than others, and in different ways depending on the meaning that each family and individual places on them. There is no right or wrong way for a donor-conceived person to feel; genes may have much stronger implications for one individual's identity than for another's.

#### Research Question and Rationale

This thesis seeks to identify how donor-conceived people experience, conceptualise, and manage family; family relationships; and issues of genetic and non-genetic connectedness. My research question is: *How do the experiences and perceptions of donor conceived persons shape their family constructs?*

The current research adds to the existing body of literature because researchers have only recently been able to interview donor offspring due to the secrecy that has surrounded the process for so long. The experiences of donor-conceived people are important to those who are in the position to make policy around donor insemination; those who are considering using donor insemination to build a family; and to parents of donor-conceived children who are considering the matter of disclosure. Thus, these findings may have implications for social policy and informing therapeutic practice. Donor-conceived people are also interested in the voices of other donor conceived people as the growth in donor registries, blogs and community forums for the donor-conceived attests to.

As this literature review has demonstrated, New Zealand is a pioneering country in the matter of donor conception and acknowledging the rights of the donor-conceived. As

a result, there is international interest in the experiences of donor-conceived people who have grown up New Zealand and other societies where open communication and early disclosure is encouraged (Blythe et al, 2012). Additionally, there is currently little research into how donor conception impacts on the family unit as a whole (Daniels, 2006), and this is the gap which this project aims to address.

## Chapter Three: Method

### Design and Rationale

On considering the choice of qualitative verses quantitative research methods, Hammarberg, Kirkman, and de Lacey (2016) explain that quantitative methods are appropriate in circumstances where: “general or probability information is sought on opinions, attitudes, views, beliefs or preferences; when variables can be isolated and defined; when variables can be linked to form hypotheses before data collection; and when a question or problem is known, clear and unambiguous” (p499). These authors point out that there are some topics in the field of donor conception that can and have been examined through a quantitative approach, such as “what percentage of the population supports assisted conception ... the number of donors and donor siblings located by parents of donor-conceived children; and the relationship between the attitude of donor-conceived people to learning of their donor insemination conception and their family type.” (p498).

Qualitative methods, on the other hand, “are used to answer questions about experience, meaning and perspective, most often from the standpoint of the participant. These data are usually not amenable to counting or measuring.” (p499).

Meaning-making was at the core of this inquiry as the aim was to capture and interpret the stories of the participants: their experiences of family life and of learning of their donor origins; what being donor-conceived means to them now and what it meant growing up; if, how and where their donor and any donor siblings fit into their family construct; and ultimately how their family experiences have shaped their family constructs. Thus, qualitative methodology was applied to this study rather than

quantitative or mixed methods as these are all questions that clearly lend themselves to a qualitative approach. Qualitative research has an important role to play in facilitating change. By asking deeper questions about what is going on and inquiring into assumptions about why things are happening, qualitative researchers and evaluators contribute to knowledge about what works, what doesn't and why (Patton, 2015). This is an important point as this study has both therapeutic and socio-legal policy implications.

Interviews were the obvious choice for this study as interviews allow for the collection of a large amount of relevant information about views and experiences which would be difficult to obtain in other ways. Interviews enable the interviewer to establish rapport with the participant that naturally leads to the sharing of complex thoughts and experiences (information-rich data). Surveys would therefore be too restrictive as they are less flexible and personal. Focus groups may have been useful for discussion and elaboration around themes, but were not practical given the geographical spread of the participants.

#### Thematic Analysis

Thematic analysis, "a method for identifying, analysing and reporting patterns (themes) within data" (Braun and Clarke, 2006, p79), was chosen as the method of data analysis for this study. Although thematic analysis is a technique often used in conjunction with other research methods rather than a research method in itself, Braun and Clarke (2006) argue, "thematic analysis should be considered a method in its own right" (p78). These authors consider it appropriate to use thematic analysis as the sole method of analysis as it is a "flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of the data" (p 578). Lyons and Coyle



(2016) explain that thematic analysis can be used to answer most types of research questions that are of interest to qualitative researchers, and these authors also see the primary strength of thematic analysis as its flexible nature, stating that there is no ideal data type for a thematic analysis study and no particular sampling requirements; it can be used for both smaller and larger data sets; can be used to capture surface or latent meanings; and can be used inductively or deductively. Thematic analysis was deemed appropriate for this study due to its flexible nature which suits: the breadth and high complexity of the data collected; the sampling method chosen (sampling was purposive but also convenience-based due to the supervisor's connections in the donor conception community, rather than the theoretical sampling involved in grounded theory for example); and because the purpose of this study was to understand and analyse the experiences of the participants, not to generate or consolidate a particular theory.

## Framework

Braun and Clarke (2006) believe that it is important to clarify the framework of a study from the outset. Schwandt (2001) describes a constructivist view as one that holds that people do not find or discover knowledge, so much as construct or make it; that individuals invent their own concepts, models and schemes to make sense of their experiences and continually test and modify these constructions in the light of new experience. This study follows a constructivist framework, coming from the perspective that conceptualisations of family and self are constructs which do not occur in isolation; they are shaped and constructed by one's experiences including family upbringing, social interactions (for example with peers, other donor-conceived individuals, the media, medical professionals etc.)

## Interview Questions

Interview questions were grouped around topics deemed to be relevant based on existing research and literature on donor conception, but themes were largely constructed from the participant's own words and experiences, not from pre-existing theories. However, in line with a constructivist framework, it is important to understand that thematic analysis is an interpretative act whereby the researcher's own experiences, beliefs and prior research inform her or his understanding of the participant's stories, thus though themes may be inductive they shouldn't really be seen to have "emerged" solely from the data; to some degree they will have been influenced by the aforementioned factors. As Macleod explains: "qualitative research is always to a greater or lesser extent a hermeneutic enterprise – where interpretation occurs, further competing interpretations are always possible" (2011, p45).

## Participant Recruitment

Participants were recruited by Ken Daniels (a supervisor of this thesis) because of his connections within the donor conception community due to his long-standing involvement in the area. One participant contacted the interviewer and supervisor directly as she had heard about the project word of mouth, and wished to be involved. Most participants, or their families, were known to Ken Daniels and were enthusiastic to be part of the project, both in terms of sharing their own experiences and learning of others' experiences. Many expressed a keen interest in reading the results of the study.

All participants gave informed written consent to participate in the study. The study was granted approval from the Human Ethics Committee of the University of Canterbury<sup>3</sup>

#### Participants

Participants were fifteen donor-conceived females and six donor-conceived males aged between 19 and 46 (mean=30). Five participants were aged 25 or younger, twelve participants were aged 26-35; the remaining four participants were 35 to 46 years of age. The range of ages means that the participants in this study have varying degrees of access to information about the donor; no information (records destroyed or not kept); some basic non-identifying information but no right to contact the donor (records concealed); or the right to request contact with the donor through the clinic, though the donor has the right to refuse.

Participants were all born in New Zealand, though two were conceived in Australia. Most participants were New Zealand European; one participant identified as Maori. Currently, fifteen reside in New Zealand; four in Australia and two in the United States. One participant was born to a single mother; the rest to heterosexual couples. Participants included one sibling-set of three individuals; and two sibling-sets of two individuals. Most were university educated. Participants came from a range of professions including a senior academic in a tertiary education institution; teacher; project manager; production manager; administration; child care worker; nurse; veterinary nurse; psychologist; military; IT professional, builder and retail assistant; others were currently studying.

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<sup>3</sup> HEC 2015/142; November 25.

## Interview Procedure

In-depth interviews took place over Skype or Phone, dependent on participant's preference. Thirteen of the interviews were Skype video calls, one was a Skype audio call, and seven were phone calls. Skype calls were recorded via Pamela for Skype software.<sup>4</sup> Phone calls were recorded via a mobile phone recorder, uploaded as audio files directly onto computer, then deleted from the phone, and Skype calls were also backed up in this manner.

The interview followed a semi-structured schedule (see appendix 2); this allowed for consistency, but enough flexibility to eliminate questions that were irrelevant to a participant or questions that had already been addressed in other responses, and to add questions that may expand on a particular detail from a participant's previous response. Participants did not know the questions in advance.

Interview times varied depending on the length of participant's responses, which in turn depended on such factors as how relevant they found each question to be to their experience, or how much thought they may have already given to a topic. The longest interview was 56 minutes long; the shortest was 16 minutes (mean=34 minutes). The recorded interviews were then transcribed, and transcriptions were e-mailed to participants to check for accuracy and to allow them to make any changes or add any thoughts that thought they may have occurred to them post-interview. Only one participant chose to make changes, expanding on a few of her previous responses.

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<sup>4</sup> (<http://www.pamela.biz/en/>)

Transcripts were then read and re-read for the purposes of data immersion, and coded using thematic analysis.

#### Interview Coding and Analysis

Analysis began with broad line by line coding, and was followed by more focussed coding during which constant comparisons were made within and between data sets (the transcriptions), and memos were taken to inform and enrich the coding, analysis, and theory building. These focussed codes were recorded as frequencies to help identify patterns in the data, and were grouped into relevant themes once theoretical saturation was thought to be reached, that is, when no new codes were identified within the data. This process follows the steps that Braun and Clarke outline as “six phases of the thematic analysis process” (p87): familiarisation with the data by reading and re-reading texts and noting down initial ideas; attending to interesting features of the data; searching for themes; reviewing themes; defining and naming themes; and producing the report.

#### Layout of Results Section

Participant's transcripts were given codes for confidentiality purposes. Participants were coded by gender and interview order; F1- F15 for the fifteen female participants, and M1-M6 for the six male participants. These codes will also be used to label the quotes, presented in the results section below.

As with the semi-structured interview schedule, the results section will focus first on participant's family-make up and a general overview of their family relationships. This

information was not organised into themes, but is presented as background to the participant's situations and experiences, which is important to providing a fuller picture of the diversity of the participant's family experiences. A table of themes and subthemes will then be presented, with the remainder of the results section following the layout of this table.

## Chapter Four: Results

### *Who Makes up Your Family?*

To gain an initial overview of each participant's upbringing and current family situation, participants were asked about their family make-up and how any siblings became members of their family. Their responses are presented in Table 1 below.

*Table 1: Family make-up*

Siblings	Genetic Relationship	Frequency
Only Child	N/A	2
One Sibling	Donor-conceived. Same donor.	4
One sibling	Donor-conceived. Different donor.	4
One sibling	Donor-conceived. May or may not share donor. *	2
One Sibling	Half sibling from mother's previous relationship	1
Two Siblings	One donor-conceived, same donor. One half sibling from mother's later relationship	1
Two Siblings	One donor-conceived, same donor. One adopted	1
Two Siblings	Both donor-conceived. One different donor, one same donor.	2
Two Siblings	Both donor-conceived. Different donor to both.	1
Two Siblings	One donor-conceived. One from father's previous relationship (no genetic link)	2
Two Siblings	One donor-conceived, different donor. One half-sibling from mother's later relationship	1

- Unclear due to lack of records

Additionally:

- Three participants mentioned step-parents and step-siblings
- Twelve participants are now married or cohabitating with a de-facto partner
- Five participants now have a child or children of their own, and one considers his partner's child his family

- One participant also has a foster family that she considers family to this day
- Some participants emphasised strong family relationships with extended family and/or in-laws; one explained that her relationships with her friends were more family-like than those with her family, and another who is in the military spoke of his defence family in addition to his immediate and extended family
- Some participants define their donor and/or donor siblings as family members, some as potential family members. This will be discussed at further length below.

Participants were also asked to describe their family and family relationships:

#### *Describe Your Family*

Adjectives ranged from normal/average (n=3); to close; tight-knit; happy; supportive; good; great (n=12); to the more enigmatic: complicated; not typical; disjointed; fragmented; messy; 'traumatised but loving'; interesting; evolving; and 'secrets and lies' (n=6).

#### *Describe Your Family Relationships*

Most participants spoke of their family relationships in positive to glowing terms and used one or more of the following adjectives: close; supportive; unique; strong; affectionate; loving; good; healthy or functional to describe some, most, or all, of their family relationships (n=20), while some (n=7) also described a mix of relationships, and spoke of circumstances which had caused strain, tension, or fragmenting within their family units. Three participants stated that their family was transitioning or evolving, and recognised they were at a certain point in time of their family story, but



that they were actively working together as a family (with those family members who were willing) to improve communication and cohesion.

## Themes and Subthemes

Results from the above three questions illustrate that families built with the help of donor conception are far from uniform, as are their family constructs. Nonetheless, it was possible to identify a number of recurring themes and sub-themes from these twenty-one interviews, which represent how donor-conceived people may experience, view, and construct family. These make up the remainder of this results section.

*Table 2: Table of themes*

	Themes	Subthemes
<b>Major Theme: Empowerment Verses Disempowerment</b>	<b>“Secrets and lies”</b> <b>verses</b> <b>“All out in the open”</b>	<b>Disclosure: early disclosure was experienced in a more positive or neutral way</b>  <b>Communication: open communication is important and ongoing</b>
	<b>Positioning the donor</b>	<b>Constructing Meaning</b>  Integrating donor conception into identity <ul style="list-style-type: none"> <li>• Something unique and special about me</li> <li>• Just who I am</li> </ul>

		<p><b>Conceptualising Family</b></p> <ul style="list-style-type: none"> <li>• Family is love, relationships and shared experiences</li> <li>• Genes matter too</li> </ul> <p><b>Locating the donor</b></p> <ul style="list-style-type: none"> <li>• Motivations/benefits of contact <ul style="list-style-type: none"> <li>➢ Gaining a fuller picture of the self</li> <li>➢ Demystifying the donor</li> <li>➢ Exploring/establishing new connections and relationships</li> </ul> </li> <li>• Reasons against pursuing or continuing contact: <ul style="list-style-type: none"> <li>➢ Nothing to be gained/general disinterest</li> <li>➢ Negotiating relationships</li> <li>➢ Fear of rejection/ respect donor's wishes</li> </ul> </li> </ul>
	<b>Thinking about family-building</b>	<ul style="list-style-type: none"> <li>• <b>Ethics of assisted reproduction</b></li> <li>• <b>Thoughts on own fertility and reproductive choices</b></li> </ul>

“Secrets and Lies” verses “All Out in the Open”

Secrecy verses openness was identified as a central theme in the experiences of donor-conceived people in this study, predominantly in their narratives around disclosure and communication. For some participants, donor conception was a secret or hidden aspect of their family lives, for others it was an open and comfortable topic.

## Disclosure: Early Disclosure was Experienced in a More Positive or Neutral way

The concept of disclosure refers to when and how the donor-conceived person is informed of their donor conception. While some donor-conceived people are unaware they are donor-conceived, for those who do know, when and how the fact of their donor conception is explained to them, and the way in which that fact is integrated into their family life, are experiences that are unique to their family structure, and can be expected to contribute to their developing family construct. Thus, participants were asked to describe their experiences around learning of their donor conception. The key finding was that early disclosure was experienced in a more positive or neutral way than later disclosure.

## Age at Disclosure

Ten participants in this study reported early disclosure of their donor conception, meaning that they couldn't specifically remember when they were first told ("always known" or "as long as I can remember"). The remaining eleven participants reported later disclosure; these participants were old enough that they can remember the experience of first being told. Of those who reported later disclosure, three participants were primary school aged, and eight were high school aged or older.

## Method and Impact of disclosure

The ten participants who experienced early disclosure, described scaffolding of information over time: dialogue was ongoing, and any questions they had were answered to the best of parents' knowledge. For example:

I think mum always had lots of information available to us, and she wrote us big letters, like I guess explaining her decision, that we always had when we were younger and then I think that had certain information about the clinic and stuff

as well, but yeah, it was never something that was awkward to talk about or anything like that, or never something that I felt like I couldn't ask questions about. F11

Some specifically recalled a book, "Where did I come from?" or similarly titled, which explained both reproduction in the traditional sense and donor conception

Certainly, I remember the book; I remember the style of drawing and what the pictures were of I suppose, so it was significant enough that I remember a reasonable amount of detail you know, twenty-five years later. From memory, the book actually had something about: 'when mummy and daddy love each other very much this is what normal conception looks like but that didn't work for them so they did this'. I remember that, and that's about it. I don't really have any other ... like I say, I just always knew. M3

For these ten participants, learning of their donor-conception around the same time as they learnt about conception in general meant there was no big or sudden impact; their donor conception was experienced as "just normal" or a neutral experience because they had never known any differently.

There was no sense of before or after, it's pretty much well "this is how I was or am or sort of how I came to be" and you know it really isn't until much, much later until you start to get that there is ah ... I don't know, that it's somehow different or has some meaning, right? ... cos as a kid everything's new and it's all kind of bizarre, right? You know, sex and reproduction is totally bizarre and new, so donor conception's just no different in its bizarreness. M1

The three participants who remembered learning of their donor-conception during their primary school years (aged 8-9 years), each recalled a special talk with their parents and siblings. One participant remembers her parents telling she and her sibling during a walk on a family holiday. Another was given the picture book called "Let me explain" outlining the process. When questioned on the impact of the news, these three participants related relatively neutral experiences, with moderate elements of surprise, confusion and/or sadness.

I don't really remember how I reacted. I don't think it was a very overt reaction. I think it's more kind of been like an internal processing that I've had over time. So, I don't think it was a second where I freaked out or anything, I think it was just something that I've just gradually tried to process as I've grown older, yeah. F4

I had a little bit of understanding. I suppose it was a little bit confusing at the time for a week or two, but my parents were very open to questions, 'as much as you want to talk about it' and stuff, but after that, life kind of went on as normal, so it wasn't really a big deal after that. F7

At the time, it wasn't like a negative thing necessarily. I suppose, maybe we didn't quite understand it. I don't remember the language they used to explain it to us. I remember feeling sad, but also kind of special in a strange way. We did go to school the next day and tell our friends, but after that it wasn't really brought up again for another couple of years. F10

The eight participants who experienced disclosure at high school age or older (15; 16; 18; 18; 18/21; 19; 22; 35), all spoke of a "big reveal" or "unveiling" for which they were unprepared, indubitably resulting in a stronger impact. Most of these disclosures also involved a family meeting of some description. The circumstances under which they took place were varied, and for some, very upsetting. In two of these cases, the father was deceased by the time the participants were told by their mothers, and in one case the death (by suicide) was directly tied into the fact of the donor conception itself. One participant was told at the age of fifteen, by her father on a family holiday, following an argument, and then instructed not to tell her mother that she knew. Four of the participant's parents were divorced at the time of the disclosure, one of these estranged from his father, and two (siblings) described a strained relationship with their father; all four were told of their donor conception by their mother. Just one participant of the eight who found out high school aged or older, was told by both her parents together.

"Shocked" and "upset" were the adjectives most frequently used by these participants when relating their initial reactions to the news. Only one participant (whose

relationship with his father had broken down prior) experienced the initial disclosure as a positive thing.

It was a good night. Like I didn't really expect it or think anything of it previous to that or notice anything like that. But yeah, I didn't mind it. M4

In describing their reactions to the news, and the impact it had on them, these participants consistently reported experiencing: disruption to identity; a sense of genetic discontinuity, and a sense of betrayal.

#### Disruption to Identity

Some participants described feeling as though their identity was shaken up; that they were different in some way to the person they had been before the disclosure. Some described strong psychological reactions with physiological and/or dissociative symptoms, whereby they no longer felt right inside their body, or felt as though they were no longer in their body at all. Such reactions indicate a highly stressful or threatening event has occurred.

There was actually a bit of a physical impact, um, I felt really strange in my body, and I felt like the person I thought I was, and my identity had kind of been tipped upside down. F2

I was quite aware of my physical ... like blood pumping through my body and being like 'Oh my god, I've got this person's DNA inside me who I don't even know' and this kind of weird physical gross feeling, like just initially when we first were told ... and quite freaked out about um, being made up, I guess, and having physical features and things, of someone that we didn't know. F5

So, when he told me, I felt like I was floating; like my identity had just been ripped out from under me... and then I was on lunch duty, and I was just making these sandwiches, and just feeling like I was not even present in my body F13

#### Genetic Discontinuity (Questioning Relationships and Connections)

Some participants spoke of questioning their relationships because they were now aware there was no genetic link, or (as in the case of genetic half-siblings) the genetic

link was more diluted than they once assumed it to be. For some this initially brought feelings of loss, sadness and hurt.

So, they just one day said, “we’ve got something to tell you” and they sat me down and told me that I was donor-conceived, because I just thought we were just a regular mum and dad and two girls, and then, kind of, it just blew me out of the water that my sister’s not my full sister, and my dad isn’t even linked to me biologically. And do you know what the thing I was most upset about was? That my grandmother who I was really close to wasn’t my biological grandmother either. That was actually the most upsetting thing. F3

My sister and I were pretty upset at first finding out that we weren’t related to Dad, and that we were half-sisters, that was pretty ... a lot to digest. F2

For one participant, this sense of genetic discontinuity was further complicated by his father’s death; the fact that his father’s family did not know of his donor conception; and the choice that had been made to respect his father’s wishes that they not find out.

When I discovered that I was donor-conceived it raised a whole lot of questions for me around my relationships, my very close relationships, with his side of the family. My grandmother and I had formed a very close relationship because of course she lost her son and I’d lost my father so we kind of spent a lot of time together and it was starting to dawn on me, well, I guess it just flagged a lot of questions around potentially ...yeah, I don’t like keeping truths from people I love either, so it was quite awkward in my later teenage years and particularly when my grandmother would say “that’s something your father would have done”, you know, like we were genetically related . M2

### Sense of Betrayal

Participants who described a sense of betrayal, spoke of having to adjust to the knowledge that people they once thought they could rely on for the truth had kept the truth about their origins from them.

She was always trying to bring us up honestly and she would say this, and say “I never tell lies. I always tell the truth and always try to be fair.” Well, actually you did tell lies for years; I guess more like an omission. And I remember her getting so uncomfortable when anything like this would come up. So, you know, I guess I’ve got a bit of cognitive dissonance going on there because I have this idea she’s not a dishonest person but at the same time she can hide something like that. Like I was seeing a health nurse at school and I went and donated

blood so I could find out my blood type and I was supposed to get the notification about my blood type in the mail and it just went missing; I never got it and I thought “oh I never got it, that’s really annoying, I won’t do that again for a while” and for such a long time I just didn’t know my blood type and I had a feeling I should know it. F12

Well, the biggest thing, I think, is your parents lied to you for the first fifteen years of your life by not telling you; even though that’s what they were advised to do and they were put in a difficult situation and maybe if they were given the chance again they would do things differently, so I try and have a lot of empathy and respect for the decisions that they made, but it probably didn’t make my adolescence and university years very easy. F13

For some, this sense of betrayal was heightened by the realisation that other relatives and family friends had been told that the participant was donor-conceived, whilst, it was hidden from the donor-conceived person themselves.

On my mum’s side of the family some people did know and this is probably what made me the most angry out of everything. So, my aunty and uncle and one cousin knew but I didn’t know and there could have been some reason like maybe because of her medical background that she found out, I don’t know, but it still makes me really angry when I think about it or when I talk about it. So, that’s my mum’s side of the family because you know, she just wanted to confide in people. Also, one of my mum’s friends knew and she actually advised her not to tell us ever; that makes me angry. It just seems so odd that all these people know something and you don’t know yourself, and I guess it’s still a little bit – maybe not triggering, maybe it’s not bad enough to say triggering - it just makes me feel like you don’t respect me as an adult – you don’t think that I have the capacity to deal with it or that I would be able to deal with it appropriately. F12

So, they [extended family] obviously knew and things were happening, which, yeah, bothers me as well, cos it’s like, the most intimate thing about you that you don’t even know, but other people know, is a weird kind of concept to think about. But they’re all people that love us and all awesome family people who, you know, there’s no malice or anything about it, they were all great supports to Mum and it was important that you know, her family knew what she was going through at that time as well, so I can understand how that happens and it’s kind of unavoidable really, for other people to know who were in her life. F5

Later Disclosure can be Disruptive but the Damage is not Irreparable

Participants who found out about their donor conception later in life frequently reported shock and upset, disruption to their identity, a sense of genetic discontinuity, and/or a



sense of betrayal. Additionally, when participants were asked if there was anything they wish or have wished might have been different in their life as a donor-conceived person, eight of the eleven who experienced later disclosure (two of whom were primary school aged at the time of disclosure, and six who were high school aged or older) said they wished their parents had told them earlier. Conversely, not a single participant said they regretted learning the truth or wished that they didn't know. However, most participants recalled that they did need time and space to recover from the initial shock and upset; time to process their own thoughts, re-examine their relationships and experiences, and to begin the process of redefining their identities and constructing meaning around this new information about themselves.

I wasn't angry at anybody. I remember I just needed some time for it to sink in really. I didn't want to get into talking in depth about it with Mum or Dad. Mum was pretty good with giving a basic explanation. I needed some time to digest it... M5

I didn't quite understand how it worked. Who knew, who didn't know all along, all those kind of things came into it. Just, um, a little bit overwhelmed I guess about the whole thing and it was probably later on when I started thinking about it more, that more questions came up but in the initial stage I was just like "oh my god, what does this mean?" Not really probably understanding and just being quite shocked. F5

It took a long time, I would say it took years to really get it through my head that that was what had happened ... for the first few years it was kind of like 'whoa', but it was all ... there wasn't really anything to do, it was just processing it ... I was fine with my parents you know, and they said it was like a weight on their shoulders for so long, but they were worried what I would think, but I totally understood. There were no arguments or anything like that. Yeah. F3

The length of time and space required, differed from person to person depending on their individual and family circumstances, and some are very much still in the process of redefining their identities, negotiating and exploring potential relationships, and

making meaning of their knowledge and experiences. Nonetheless, by the time of this interview, most participants felt they had successfully reconnected with their families.

Indeed, two participants stated that for them, there is now no sense of regret about having found out later, and that it may in fact have been beneficial in their cases because by the time they found out, close, loving relationships were already established, and lack of a genetic link was no threat to what they already had.

Finding out as an adult, although a massive shock at the time, I already had established what my feelings about family were, and knew what my family was, and I had a lot of history with those people so I think if I had found out when I was five or six years old then I might have grown differently and I could have had different feelings towards my father's side maybe, I don't know. M5

I think being told later in life has its advantages, because I'd gone so long thinking my dad was biologically my dad, it was easy not to change the way I thought about him. You know, he's my dad, he's always been my dad, that's not going to change... The relationship between me and my parents stayed the way it did easily ... I do wonder sometimes what it would have been like if I had of known as a child and perhaps that would have been better, but I don't know; what happened, happened, and you get on with it. F3

Others, who do regret the late timing of disclosure, nonetheless believe that the disclosure, when it did come, strengthened their family relationships, and brought them closer together:

I think it's made me think a bit more family-centric. I was always wanting to have a bit bigger of a family and everything, and now that I've found out that I do, it's kind of a bit better for me, I guess. It's made me think a lot more about my immediate family as well and how they're all going, and I think I've gotten a bit more in contact with my sister since then as well, so it's probably changed my view on family and how it's affected me. Yeah, I much prefer seeing and hanging out with family than I did previously that for sure. M4

If anything, it's probably brought Mum and me and [sister] closer together. I think that having that openness about the whole situation can't, you know, do anything but be a good thing, and we had a really strong foundation of a relationship with her before she told us anyway so I think whatever happened, we would always have come back together, and we would have always still been really close. So, I think if anything it's been really good and now we can all talk about it. F5

The impact for the three of us, cos we were all, we have always been really close, um has actually been bringing us closer together, and knowing what Mum went through and her being able to talk it through with us, probably for the first time, and feeling like she wasn't lying to us anymore and everything, that's actually a really positive thing overall for all of us. Yeah, I think Mum's really relieved, and we're happy for her that she's relieved and we'd much rather know than not know, so overall positive, but this is nearly ten years later, so maybe closer to the time I might have said something different. F2

These stories suggest that if there is a strong sense of cohesion to begin with, families can, and probably will, find a way back to each other. If the family has, or is committed to developing, open and honest communication, then all the better for working through any issues of confusion, mistrust, anger or betrayal, that may be present.

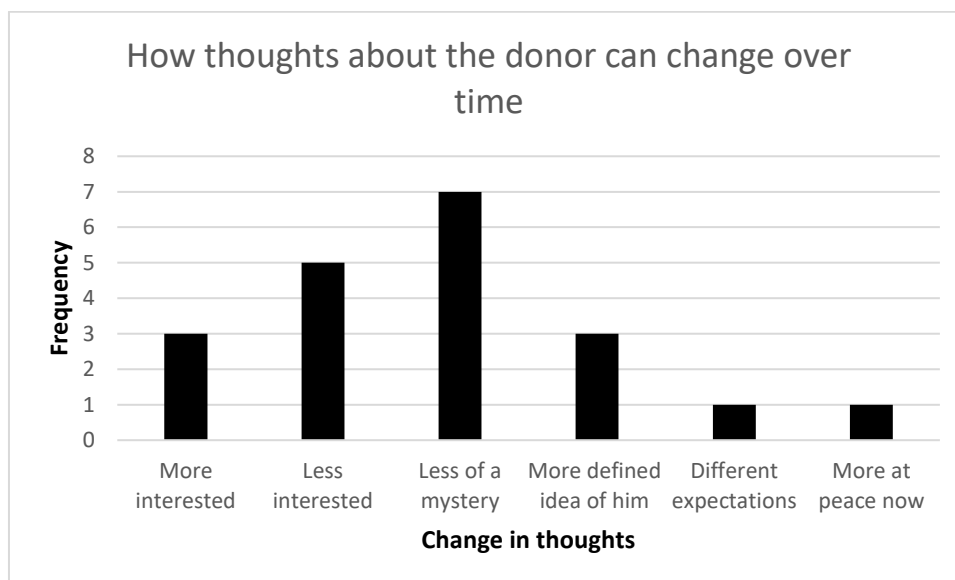
Communication: Open communication is Important and Ongoing

Whilst open and honest communication is a strengthening factor for families of all types and structures, and conversely, communication barriers can cause issues for families of all types and structures, for the family built by donor conception there are times when communication will need to centre specifically around the donor conception and/or the donor, presenting these families with a challenge that is unique to their family structure.

Disclosure is a central aspect of communication but not the only one. Another aspect of communication revolves around how parents choose to approach or acknowledge the biological link between the donor-conceived person and their donor; and the non-biological link between the donor-conceived person and their father. The parent's attitude, towards donor conception in general, and the donor himself, will be conveyed through such things as whether they are open to all questions their offspring may have; how they respond should their son or daughter express an interest in seeking or

contacting their donor; whether they disclose to extended family or wish for the information to stay hidden; and how they engage with the idea of difference.

It is almost certain that more discussion than one initial talk will be required. A person's interest in their donor and donor conception are mutable things and thoughts and interest levels may well oscillate over time. For example, in this study, most participants (n=15) stated that their thoughts about their donor had changed over time. The following histogram charts the ways in which their thoughts about their donor had changed (some participants gave more than one response).



*Figure 1: How thoughts about the donor can change over time*

Participants also spoke of key periods and moments in their lives in which they found themselves thinking about their donor more. These were: reaching adolescence and questioning one's identity; going to university or medical school and thinking about issues around genetics; dating or starting a new relationship (bringing up fears/anxiety around the possibility of inadvertent incest); planning to conceive and/or contemplating one's own fertility; and having children of their own.

## Disclosure and Communication

In this study, it does appear that early disclosure was also linked with better communication and a more positive attitude conveyed by parents towards donor conception and/or the donor. Nine of those who experienced later disclosure, compared to two who experienced early disclosure, described some awkwardness, discomfort, standoffishness, or silence on the topic (with at least one parent); Only three of those who experienced later disclosure felt that both parents (one parent in the case of the participant who only has one living parent) were now truly open to discussing donor conception. Two participants who experienced later disclosure felt that donor conception was still a closed or hidden topic in their families, with neither parent open to conversations around it. Most of those who experienced later disclosure, therefore, perceived some communication issues or difficulties around the topic with at least one parent.

Eight participants who experienced early disclosure and one who experienced later disclosure described a neutral, open, or grateful attitude towards the donor from both parents. All ten participants who experienced early disclosure said that one or both of their parents took an open approach to communication during their childhood, answering questions, and not avoiding the topic if it came up, though two participants felt one parent was more open to discussion around the topic than the other.

## Mixed Communication

While early disclosure may well pave the way for open communication, it does not in itself ensure ongoing communication. Two participants, both of whom have met their donors, spoke of mixed communication in their families with regards to their donor.

The first said that her mother was the one who had answered any questions when she was a child and her dad had avoided the subject, clarifying “that’s just Dad; he doesn’t talk about emotional things.” Overall though, she had never felt like it was a hidden thing in her household, just something her father wasn’t interested in discussing. However, she found that since she had contacted her donor, her mother’s attitude towards the subject had changed:

My mum used to ... she would answer all my questions, and stuff, and when I told her that I’d written to my donor in October she was like kind of excited about it, but then, since then, she’s kind of gone really awkward about it, and doesn’t want to talk about it. F1

As a result, this participant and her sister chose not to inform either of their parents when they first met with their donor.

I just kind of like wish we could be ‘let’s just talk about it’ and have it be open, but it’s all like secret- secret, can’t talk about it; gotta hide things; pretend. Like, she doesn’t know that me and my sister went to meet him last week, because my sister didn’t really want to tell them; she said she was going to her boyfriend’s house instead, and I would have preferred to just tell her, but then it’s also kind of like, you tell her and it becomes a big deal, and it’s awkward, so in some ways it is kind of easier. But she knows that I’m going down this weekend though, so, yeah, she doesn’t really want to talk about that so... F1

The second participant however, found that in her family, her father was the parent most open to communication around the donor:

Dad, I would say, was more all for it, like you know, “go meet him”, you know, “it’ll be really good for you” and he would always talk positively about him and stuff whereas my mum was more kind of quiet about it and we didn’t really talk about it too much. She was kind of just like, doesn’t want to have too much to do with it. But, either way they both supported my kind of idea towards it... He was the one who actually took me there to meet him and he just waited outside for me, but he was like really supportive and my mum was, you know, “good for you” but yeah, she didn’t have too much to do with it. My dad was really encouraging though. F8

Thus, for this participant, having one parent who was open and willing to talk about her wishes and experiences regarding the donor, somewhat alleviated the discomfort around having one parent who was less approachable (though not silent) on the topic.

These stories suggest that even in families where the child has known of their origins from the beginning, and where communication has seemingly been open, parents may let feelings or feelings of discomfort or awkwardness seep out, so that some donor-conceived individuals may feel that they should keep silent about experiences or feelings in relation to their donor or donor conception.

#### Closed Communication

When a person feels that they cannot discuss what is on their minds, it can be frustrating, isolating and emotionally painful, and can promote a culture of secrecy within the family. Two participants, for whom donor conception was not an open topic in their families, explained what this experience was, and is, like for them, emphasising that while they understood their parent’s choices and perspectives, there was still some sadness and isolation.

One spoke of the impact it had during her childhood:

It was if anything, quite a hidden thing. My mum is quite emotionally reactive and really didn’t really like to talk about it so yeah, whenever I brought it up which was only, if anything, a few occasions from probably 8 until 18, she would just sort of shut it down and just sort of tell me to be grateful and just don’t ask

those questions, and my dad was a little bit more open to it, but I really didn't want to upset him so I didn't feel comfortable talking about it because it's quite a sensitive thing for him so yeah, it wasn't really very talked about or open or anything at all. F4

Later she elaborated:

It [the lack of communication] was really hard growing up, like I was saying, I was really wanting answers and my mum would just shut it down, and um didn't really, I guess, react in the most appropriate way that could be ... you know, for my development - but it's obviously something that's really hard for parents to go through, so it's understandable in a sense that it is such a sensitive topic and that it's not pleasant to talk about ... I just wish my parent's reaction was more open when I was growing up and I wish that they allowed me at least to just talk about how I was feeling. Yeah. F4

The second participant who experienced closed communication with both parents, described how lack of communication impacts on her current relationship with her mother.

Well, it makes me feel that I can't connect with my mum on an emotional level and I've sort of accepted that and my friends are really my ... they're closer to me, much closer than my family is and I get a bit frustrated that my mum particularly won't open up but I've also just tried to accept that she's a product of her generation so if she doesn't want to talk about it, I don't want to make her feel uncomfortable, you know, because she's a lovely woman but yeah, I think I've come to accept that there's always going to be a limit there of how close we are. F13

Later this same participant observed that she is disappointed to see her sister passing the silence down through generations, knowing the negative impact that secrecy has had on their family.

I think my sister feels shame at some level of being a donor child because she's not told her children about it and she hasn't even told them that Dad exists because she doesn't talk to him and hasn't done for six or seven years, um she just doesn't refer to him at all, so she's sort of doing to her children what Mum and Dad to us and carrying that secrecy on and passing it on because if she didn't feel shame she would just be open about it. F13

This participant was not the only one to find that communication was not forthcoming with a sibling. Five participants spoke of tension with other donor-conceived siblings who did not wish to discuss donor-conception, thus these participants were unable to



share their thoughts and feelings around such things as tracking down their donor, establishing contact, or meeting with their donor, because the siblings closed off this line of communication. Lack of communication caused some tension in the sibling relationships to varying degrees, but most acknowledged the need to respect their sibling's wishes to avoid the topic.

My relationship with my sister is the closest family relationship that I have, although also strained in that I am actively looking for our donor and half-siblings. I'm also active in the DC community and have been for many years. My sister on the other hand shuts down any conversation if it has anything to do with DC. She wouldn't comfortably talk to either of our parents about being DC, and I know that she's told very few people. F10

Sometimes it's a bit difficult because I'll want to share my experiences, you know with my brother, and be like "you know, you should meet him" and stuff but I have to respect that he's not ready or he's not interested, so sometimes it's a little difficult when I want to share things but I have to always think about him as well. F8

#### Excluding Extended Family

For three participants, all of whom had experienced later disclosure, communication regarding their donor conception was closed off with extended family members from their father's side of the family because these family members had not been informed of the donor conception. One participant explained the reason secrecy had become such a factor within his family:

My father came from a "blood is thicker than water" kind of approach to family. Um, he was unable to tell his family that he was infertile, because he has been raised in a tradition of blood is first and foremost, and it's the strongest thing you can have. A confession like that was not something he wanted to participate in, so he came from very much a different camp which was probably similar to some of the themes of the day, which was take the baby home and forget about it, so Dad had that approach. To this day, the side of the family that brings me the most sense of connection, is actually the side that doesn't know, still doesn't know this, and we've decided to honour Dad's legacy in that respect. And that will change. In the next five or ten years, there will be another chapter to this. M2

These participants often felt compelled to censor their conversations to avoid upsetting the status quo in their families.

It's the whole censoring aspect. What can I talk about, who can I talk to about this, who doesn't know etc. For me, it's not about perpetuating the secrecy, because I'm definitely not advocating that, but it is an awkward conversation that I kind of need to be somewhat prepared for, and choose my moment. An example is my aunt (married to my mum's brother) was adopted and recently I had a really interesting conversation with her about her meeting her birth mother. Now this could have been my moment to tell my aunt and uncle that I'm DC, except that felt at the time like I would be stealing her moment. She was telling me about her experiences. No doubt I'll get the chance to tell them, and now that I've heard about her experiences maybe she will find my story just as interesting, possibly she may even relate to some of my experiences like I found myself doing when she told me about meeting her half-sisters and finding out about her birth mother. F10

Touching on the impact this secrecy has had on her relationship with extended family this participant explained:

I think I question my relationship with my dad's side of the family, because I know that they don't know. So, I feel kind of a distance to them. F10

A subsequent issue which had arisen for the three participants who could not yet tell their extended family members was dealing with the limitations that this closed communication places on their ability to express themselves in the public domain.

My dad's family don't know ... well, probably don't know. Eighty percent, don't know. Yeah, I feel like they've been looking at me a little bit sideways my whole life, going "where did she come from?" but my mum asked me not to tell them because she thinks that they would be upset because it's relatively recent that my dad died. It is a little bit annoying because I'd just like to have it out in the open but I just thought maybe it's something I don't need to deal with immediately because I just don't see them that often and it's not like it's something I would need to say to them. I think if I was seeing that biological side of my family more and it became necessary for me to tell people, to explain why, then of course I'd tell them and it's better to tell them than for them to find out some other way. I was looking at talking to media because some people have done that to find the DC part of their family so I just mentioned it to my mum and she got really, really upset and she was like "no, family can't find out

like that" (laughs) Well, you could have told them! But maybe you couldn't; you know, it's not really my place to judge that. F12

It's just a bit weird, because I've become quite involved in donor advocacy and it means that people don't know so I have to be careful about how I talk about things and if I go public with it like how I deal with those reactions. F10

I'm just really conscious of the level of privacy; I could never go public for example today. M2

Another participant spoke of how hard it was for his grandmother to find out he was donor-conceived so many years after the fact, but clarified that it did not impact on his relationship with her:

I've got one grandparent left, that's my dad's mum, she does know, and she was pretty devastated I think when she found out, because she only found out at the same time that I was told and 'cos my dad's an only child, that was sort of like the end of the bloodline, she felt. So, she was devastated but not in a negative way towards me and my brother. She was upset that she never knew until quite late, but I've still got a really good relationship with her. M5

These stories suggest an important factor in creating a climate of openness is making sure that extended family members, specifically those from the father's side of the family, are also aware. This way extended family will have time to process the information, and the onus won't be on the donor-conceived person themselves to decide whether to reveal or hide the fact of their donor-conception from those family members with whom they do not share a genetic link.

#### Open communication

Compared to those who experienced mixed or closed communication within their families, participants who had experienced open communication generally spoke with more contentment about the natural and comfortable way in which conversation

around the donor and/or donor conception had been integrated into their lives so that they came to view it as a unique and interesting shared chapter in their family story.

I'm very open about it; I love the fact that it gives me a bit of a unique sort of distinguishing factor from every other ... well the majority of people you meet. All through my childhood if conversations steered anywhere near genetics or family traits or anything, when people say I look like my father, I go: "well, funny you should say that. Did you know ...?" and I'll just tell them everything; it's never been an issue and in fact it's the opposite, I almost brag about it a little, I guess. I've loved it, absolutely loved it. F15

Some saw the donor conception itself as less of a defining feature of their family than the strong communication and sense of cohesion that developed around the sharing and living of their story.

I think it's quite a special and unique quality and makes for a great story and yeah, it's been something positive for our family in the sense of from an early age having to build those communications and just being able to be comfortable to talk about it, so there was I suppose in that sense, a lot of trust. F6

One participant, when speaking of how grateful he was to his parents for taking the open approach, expressed that he wished all donor-conceived people could have this same experience.

I think for the most part I just want the things that I had and the opportunities I had and the early sharing and the knowledge that I had to be universal. I think my parents absolutely nailed it, especially given the context of, you know, three different kids across the time where there were three different policies around notification of donors and legislation and that kind of thing so I think they did an exceptional job and I wouldn't change a thing about it. M3

For other participants, although open communication was encouraged in their household to the extent that they knew they could ask any questions they had and did not have to hide their thoughts or feelings, it was nonetheless, something that was

rarely broached, something they felt their families took a more neutral approach to and therefore something they rarely gave much thought to themselves.

We don't really approach it. Like if we've got any questions we can feel free to ask Mum and Dad. It's open and everyone knows. Or everyone that needs to know, knows. F14

It's definitely not ... I never got the feeling the conversation was off limits, if that makes sense. Just something I didn't really care too much about; they'd told me about it, and then we talked a little bit about it over the years. Yeah, the conversation was never off limits but there's not much to say really. M6

Likewise, other participants stated:

It's just not really a big focus in my life F7

It never really seemed like a big part of my life, it's never something that's been massive, there's other stuff in my life that's more important than that ...I never had like a big unveiling of when I got told, cos I've just always known. It's always been just that - a part of my life. F1

Including Extended Family

Most participants from homes characterised by open communication reported that the topic of their donor origins had never come up with extended family but that they assumed extended family knew as it was never treated as a hidden or secret thing.

For these participants, there was no sense that they needed to avoid the topic; they just hadn't felt it to be relevant to their day to day interactions or conversations.

They knew and they've always been very accepting of me... Yeah, there's definitely no stark comments or gestures or anything I can think of that suggest anything other than acceptance really. That's predominantly my dad's side, we've got more to do with them than on Mum's side, but same again on that side. I think everyone's just like "oh, okay" and then just carry on. F15

As far as I'm aware my parents took the same approach with them. Everyone always knew from the start, and they all knew we all knew from the start, so I guess that prevented any sort of big moments of realisation at some awkward family meeting for them or for us to go through as well, which I think was an excellent choice by my very, very clever parents. Yeah, again, never came up, my cousins they all know, I guess they all knew from day dot as well and we all knew, there was never anything there that made it seem different - it was just another way. M3

One participant, who had grown up with both early disclosure and open communication, explained how she had a moment of insight into what it must be like to grow up in a family characterised by secrecy, when she and her mother realised her father's family had never been told by her father (whom had since passed away) and that she and her mother would have to reveal this information to them so long after the fact:

It certainly wasn't a secret, like all my closest family and friends all knew; it was on a kind of need to know basis I guess. I never had any sense that it was a secret, put it that way. It didn't come up that much because, you know, it kind of doesn't, but it wasn't that it couldn't be talked about, there wasn't any discomfort in talking about it. The only thing that happened years and years and years later was that I realised, and Mum realised - and I think that we both thought that Dad had mentioned it to them – the other side of his family in Australia didn't in fact know; they had thought that I was Dad's biological child and so ... the only kind of awkward moment in the entirety of my interaction with all of this was when I started making a documentary about searching for my biological father, and we're like "shoot, maybe they don't know, this is going to come out on television in New Zealand and they're bound to hear about it - we better just check that they know" and as it turned out it was fantastic. I was totally nervous about it. I used to spend weekends over with my aunt and uncle and cousins and I felt for the first time "oh, maybe I was sort of an imposter", things that probably most donor-conceived kids that are not growing up in open circumstance feel all the time. I had my first kind of sense of what that might be like. And we told them and it was just not even an issue, it was totally fine. F9

### Engaging with Difference

Some parents may hold back from discussing donor conception with their children because they have concerns that their children will feel different to other children or perceive their family as different to other families, or they may fear that people outside of the family will view or treat their children differently if they know that their family was not formed in the conventional way. When asked if they saw their family as different to other families, over two thirds of the participants said that they did.

Yeah, I do. I do to be honest now. I mean because it is different. It's a strange kind of way of putting a family together, for want of a better word. It's not how everybody else is naturally conceived and so is odd. I kind of do think it's weird, and I kind of, in a way, don't actually like that that's how I was conceived. It is a bit strange. Just 'cos it's not natural and it's not how I know it to be usually or how it is for most people. F5

Yeah, well, it's a big deal. Especially when you thought for nineteen years you were just a regular nuclear family, although you still are, but the way it formed I suppose. Um yeah, thinking about my friends, you know it's just ... because I never thought that, you know, my parents would divorce or I'd have stepsisters or brothers like lots of other people's families do, and then I find out that actually my family isn't the 'normal family' either, and that there are other things happening. F3

Some added that they felt different regarding other more visible things such as having divorced parents (some participants also mentioned that they felt the strain of keeping secrets may have impacted on their parent's relationship); the death of a parent; needing foster care (due to mother's serious health condition); coming from a single parent family; having a twin; having large age gaps in their family; or having an older parent than their peers.

Yeah. I was different on many other metrics than that! F9

I already kind of did - just growing up with separated parents, none of my friends had separated parents, and then they were both remarried when I was twelve, and my sister's in a wheelchair and I always thought we were quite different anyway, so finding that out was just kinda like, oh yeah, here's another thing and ... but I like different anyway. F2

Some people can be a bit funny about um: "oh she's only your half-sister" or not having a direct genetic link. Do you get what I mean? Just sort of ask questions, because she's older than me; she's quite a bit older - she's about fourteen or fifteen years older. I tell people I've got an older sister and they go "oh yeah" and then I say, "she's quite a bit older than me" and they look at you strangely again... sort of amused I suppose. F14

For one participant, the fact that she was from a single parent family when there were few single parent families amongst her social circle, meant peers were more likely to notice the structural difference between her family and theirs, and therefore ask

questions outright without her initiating the topic, which for this participant meant that even though open communication was encouraged at home, she was more reticent in her responses to peers, due perhaps to feeling forced to discuss an issue which for those from two parent families was generally visible only to those who were in the know. However, with time she found she had become less guarded, and more open about sharing with other people.

I think maybe when I was younger I was like ... I don't know if embarrassed is the right word but I didn't really share it with many people so maybe I was like, quite guarded about it but now I think I've learned to be like "whatever", like I'll tell people, I'll know them reasonably well and if they ask me then I'll be reasonably open about it but I wouldn't when I was younger, I would skirt around the subject and so I think even some of my really close friends from high school or like my friend group don't really know or wouldn't have asked me or I haven't talked about it with them, but then people that I've met more recently, like say I have less history with um or especially at [university]– I find that I've been quite open with them about it. So, I think maybe when I was younger I was particularly guarded F11

These stories indicate that parents may be right in thinking that their children will feel different from those who are not donor-conceived, especially if there are other factors that might cause them to stand out. However, as the participant's stories below reflect, effective communication can help frame difference as a positive thing to be shared by the whole family, or something they can take pride in.

It's always been like a topic that both parents were willing to talk about, and that my dad was willing to talk about it made it okay, and didn't make it like a segregation or a separation, or that it was not okay to ask about it because somehow, he was different. It was just a case of "this is how it is -what more would you like to know? Is there anything else I can tell you?" And really just a case of "I love you" and like he loved me, and so it was that simple, I suppose. Yeah. F6

For as long as I can remember I have known and been very proud of it actually. Yeah, I'm very proud of it because I think it's such a wonderful gift and opportunity which has been given to my parents when they were trying for fifteen years without success and I think it's the greatest thing ever really. F15



Many expressed an appreciation of what their parents went through to conceive, and a sense that, in turn, their parents had appreciated having children more than they perhaps would have, had they not had to go through so much to conceive. Some participants felt that if their families did differ in any noticeable way, it was only in the level of positive interactions they had and the amount of togetherness time they enjoyed. For example:

I suppose compared to my friends we were so functional, like our parents were so grateful to have been able to have children, I guess they made a lot more time for us than my friends' parents, there was a big focus on family time like holidays together, weekends, yeah, my dad was a very attentive father, and so I think that's the only way that we'd really be different. F7

Thus, the above stories indicate that time, effective communication, and shared experiences can help turn difference into a positive thing. Perceiving difference as a positive aspect of one's family story may also serve as a buffer should the donor-conceived person encounter any negativity as it is true that there will always be people who think traditional is best and a traditional assumption of family is that family members are linked by genetics. However, despite traditional views, family is changing, diversity is on the rise, and people are becoming more accepting of diversity. This fact was noted by participants themselves.

It's changed because you know, same sex marriage is now, and is so much more accepted and I think children see things that it would ... it's probably going to be even more accepted, quickly I think, and I think it won't be as important anymore because it's just becoming more common that families aren't all one hundred percent biologically 'that family.' A lot of friends I know come from all different people and groups. No, I think in New Zealand, I think in general, people are becoming a lot more open. It's not as important - you know you're not going to be sent to Hell if your father's not your real father or biological father. F3

Additionally, most participants said that they had only ever received positive or interested responses when they chose to share the news of their donor conception with others.

Well, I always tell them in quite a bouncy tune because I'm very proud of it and they're like "wow; wow really?" and it usually comes back with questions like "so can you meet the biological father?" and things like that, and I'll explain "probably one day, but we'll both have to want to" and just explain how it goes and after that there's no negativity or anything. It's usually fascination that I'm met with; it's almost like they want to reach out and touch me like "oh it's real" (laughs). But I haven't had any negative exposure or experience with telling people at all. People are very interested because it's not too common. When I was little some kids might have been a bit confused but other than that, no. F15

Thus, the growing acceptance of diversity means that difference can be both openly acknowledged and appreciated, now more than ever. One participant reflected on how different things may have been for his family, had they taken the open approach that is recommended in New Zealand (and other countries with similar legislation) today:

Reading Ken's [Daniels] book comes to mind; he sent a copy last year and I, at the end of it, first of all I was very sad because I thought if this book existed forty years earlier, then my dad could still be alive you know, they would have taken a different approach to the whole notion of secrecy, because you know, the power of secrets can be life threatening ... I loved reading in Ken's book the way that people had introduced things when children were very small, and obviously introduced them in appropriate ways, but the child would start discovering that their family was unique, you know, and so it didn't have a negative or strange energy attached to it, so I'm very supportive of those kinds of things. For me that's the preference for sure. M2

#### Parental attitudes and communication

In order to build effective communication, parents may find they have issues they need to work through, issues that may stem from their own feelings of insecurity or shame around not being able to conceive naturally and having to instead access donor insemination. Though parents may think they are keeping these feelings to

themselves, the experiences of a several participants suggest it is likely that such attitudes are conveyed through the way the parent chooses to communicate, or conversely not to communicate, with their donor-conceived children.

In the words of one participant:

It seems that when people don't tell their kids early on, those are where most of the issues arise, both for parents and kids. It seems like that arises out of the parents' fear of the meanings of what it's all going to be and this kind of conception of "is it different?" Even these questions that you ask, which are very normal and kind of a natural kind of inquiry for people, sort of come from this slight point of view of how is this thing which is different – does this make a difference? And I guess, it seems to me, that this makes much less of a difference, and in fact an imperceptible or unseeable difference, but yet if we treat it as if it does, so you don't tell your kids, when you do it's a big secret, that sort of stuff, then it does; it's a sort of self-fulfilling prophecy right. ... I think in most cases, kid's attitudes are probably reflective of you know, the way their parents framed it and if Mum and Dad were kind of touchy and upset about it then they probably think it's something bad. So, it's almost like the best thing you can do for your kid is kind of get over your own issues about it. As a society, we do have this probably quite natural association of blood, and like this being somehow secondary, inferior or different – it obviously is different - but like sort of somehow worse, which, I don't think in any meaningful way it is. And so, it's probably just helpful that if someone isn't involved and have a donor kid then like its fine right, you can sort of hold whatever opinion you want, but I think if you are going to go ahead and have a donor kid then I think it's probably helpful if you actually kind of deal with your own stuff around it and not perpetuate this sort of negative attitude towards the situation, because you think of all the stuff around this, it actually has been created purely by the concerns of doctors and parents who were involved and I don't know, I've never run across many kids who have been told or brought up with it that think it's a potentially big issue.  
M1

### Positioning the donor

This theme refers to the very complex and ongoing process in which donor conception and the donor are positioned or integrated into the donor-conceived person's identity and family construct.

## Constructing meaning: self-constructs and family-constructs

In psychology, meaning-making refers to the process of how people make sense of life events and experiences, relationships, and the self. Making meaning of our lives and our family and cultural experiences is something that we all do, regardless of our family structure. Donor conception provides a challenge for the individual, the family, and society with regards to defining and conceptualising family because notions of family and kinship are continuously redefined by those families who sit outside traditional frameworks and assumptions. For the donor-conceived person there is the additional challenge of determining where being donor-conceived fits into his or her self-construct.

## Something unique and special about me vs Just who I am

In response to the question “what does being donor-conceived mean to you now?”, participants’ typically expressed that it was something unique or interesting about them, and/or a big part of their identity (unique identifier); something that had opened up new relationships or experiences for them, made existing relationships stronger and/or made them think about how grateful they were to be here (special); something that was slightly different or interesting about them but not really a big part of their identity (ambivalent), or something that they rarely gave thought to (“just who I am”/neutral feeling) Thus, responses were divided into two categories: unique/special (n= 14; 66%); and ambivalent/neutral (n=7; 33%).

Unique/special

Two thirds of participants view their donor-conception as something that sets them apart from others, often in a positively distinctive way, and adds an extra layer to their identity and experiences:

It's part of me that I think is special, and I really like. Something I share with close friends, people when I feel close to them, and it's actually something I really like about myself. ... It's something ... something unique and cool about me that I like F2

I like it. I like that I'm a bit ... you know, it's something different compared to other people I think, that makes me "me". F8

For many, being donor-conceived was viewed as a special thing that meant reflecting on such things as:

1. The happiness that donor conception brought to their families

I suppose ... probably the happiness that it brings. I mean, my mum, from what she had explained to me, she was really wanting to have kids at one stage and when both her and her husband at the time found out that they couldn't conceive they went through the donor conception and yeah, she believes that it's been the happiest period of her life, that she's had us and yeah, I guess that's what it kind of means to me, the fact that it can bring happiness, I mean depending on who's viewing it I guess, but the fact that it can bring happiness to families who aren't able to experience possibly the joy of natural conception. M4

2. Their gratitude to the donor

It means that someone has been generous enough to give my parents the greatest gift of all – the ability to have a family. And that meant a lot especially to my mum who wanted many children and was devastated when she found out she couldn't with Dad ... So, for them having tried for fifteen years without success and to then have me as a result, I think it's such a wonderful gesture, it's a gift, and we're all extremely grateful for it. F15

### 3. Their appreciation for their parents

I guess more recently it's the identity that I have ... I don't know I guess it felt good, and I feel a pretty strong affinity and almost proud of it partly because of how rare it was in the early and the mid-80s, I guess. Part of it is that, and the other part of it is how much it reflects ... how much you must know that your parents want you, that they go through all that in order to have you and that's absolutely not the case for all parents. Yeah, I mean it says a lot about Mum and Dad and what they were willing to go through to have kids, and their commitment to us from before we were born let alone from when we were. M3

### 4. The wonder of their conception

I think it's interesting that if you were born at any other time, you know forty or so years earlier, it wouldn't have been possible. So, that is interesting to think about. I guess I feel a bit more ... lucky, in a way, maybe. M5

For those participants who had tried unsuccessfully to locate their donor, donor conception was a big and unique part of their identity in the sense that something important was missing from their lives. These participants spoke of how the meaning of being donor-conceived has changed for them, and how it continues to change, with time and circumstances.

I go through phases of how I feel about being donor-conceived. It's like a cycle. Phases can last years, months, weeks, or just hours, but something I have noticed is how my feelings about it constantly change. Sometimes I'm kind of okay with being DC. Other times it depresses me and I feel an enormous weight of unknowns and unanswered questions. I also go through periods of being angry and frustrated about the 'industry', the doctor, and even the donor's lack of foresight. How could he do that for money? How come he hasn't checked in to see how many children he has? How we're doing? Why is he so hard to find? Does he not want to be found? Why? When I was younger I felt it all so much more deeply than I do now. I think I've just accepted it as something I may never have answers for. That doesn't mean I'll stop looking, but it's more of a curiosity now - perhaps sadder in some ways. I guess being donor-conceived is about loss in ways that I'm unsure that I have words to explain. F10

It's a very healthy thing in my heart now ... Right now, I feel really balanced with it. It's been a definite factor and issue for me in the past and its involved itself in pretty much all of my family relationships, apart from the one with my wife obviously, so it's been a journey, but right now ... [I'm] looking to create a

support network now in New Zealand for donor-conceived people, so it's just sort of going from strength to strength in terms of how I feel about it. So, yeah, I'm pleased we didn't have this interview about twenty years ago. I'm pleased to come from a much more balanced perspective on this. M2

Just who I am – ambivalent/neutral

A third of participants were either ambivalent or neutral about the fact that they were donor-conceived. The ambivalent were less certain about the role donor conception had in their life.

I'm quite pragmatic so as soon as I found out about him, I knew I couldn't find out who he was ever, so I've just sort of gone "well I can't find out about him ever, so that's that ". I actually don't think about it very much, although I have done a little bit more lately because as I mentioned I'm single and looking at using it as a means to have a baby. But I guess it makes me feel a bit different to other people ... I do look at other people and think I wish that I had the relationship with my dad that they have with theirs because they share a lot more things in common with their dads, like share a sense of humour, and they're on the same wavelength and I don't really have that with my dad ... Um, yeah, so I don't know what it means to me, I just accept it ... F13

Some took the approach that it was a little bit interesting but not something that they really considered a particularly unique identifier or something that they generally had much to say about when the topic did come up:

I totally tell people when it comes up but it's not like I'd proffer the information. I don't kind of see it like a big part of my identity like 'M1 - Donor Child', you know, any more than like 'M1- A Type Blood', like it's not tied up in my identity, or anything like that, it's just sort of a quirk of my background. You know much like having a middle toe, that's kind of longer than your big toe. You know it's kind of funny, but it doesn't really impact your life in any meaningful way apart from skiing and being a donor child doesn't make it difficult to ski, so ... M1

Those who were neutral about being donor-conceived rarely engaged with it as a topic of conversation, had little to no interest in their donor, and did not see the fact as a particularly interesting part of their identity:

I've always kind of viewed it as um, like a medical transaction or something, like he's a number, I don't think of him as a person really at all. Probably because it's not as if him and Mum had a relationship and she knew him or anything, it was like this medical transaction where she went in and almost like got a blood transfusion or something, got help from this person who is faceless really. So, I don't really think of it at all on that level. I've never had any desire to find him or reach out or have any kind of connection, and I don't know if that's an avoidance thing or me being in denial or something. I really don't think it is, I just generally do not care about it in that way. F5

It doesn't mean anything. I haven't really thought about if I'd want to know. It's not something I'd seek out; I never think about it, but if I was offered any information about him, I'd probably take it, because it might answer a few questions that I've had, not big meaningful questions, just like "why do I play sports when the rest of my family don't?" and things like that... I've never thought of him as anything remotely special and I've only ever sort of questioned those little physical traits that I have. M6

I'm not really worried about it at all really. I'm not curious or anything; I'm not too worried. F14

Constructing Family: Family is about love, relationships, and shared experiences

When it comes to making meaning of family, donor-conceived people are no different to those who are not donor-conceived in that, for them, the concept of family is primarily based on feelings, rather than genetic connection, and feelings can be hard to sum up with words. One participant's response to the question: *Do you sometimes struggle to find the right words to describe your family relationships?* articulates this nicely:

Probably yes for that one, just because I don't think too much on how to express it; I just know that I do. I just feel that I do love them quite a lot and I don't think there's really too many words that could be probably eloquent enough to explain my feelings for them. M4

Though family experiences were diverse, and some participants had experienced more tension, communication issues, difficulties, or trauma within their family environments than others, invariably participants spoke lovingly of their families and



family members throughout the interviews, regardless of whether they shared a genetic connection. For example:

My family is my family and there's no other way that I view us; even though technically my eldest brother is only my half-brother and technically my dad is not my biological father, it doesn't make any difference to the way I feel about them. I would do absolutely anything in the world for them, so I suppose that construct of family for me is all about relationships and maybe a little bit more willing to look beyond just genetics bond in terms of what family means 'cos there's a sense for me that obviously extends beyond just my dad, like my aunties on that side and my grandmother on that side, it's all of those things, so it impacts that and it also has a roll-on effect on a lot of things like that history and that heritage and those other relationships, and they're all family to me. F6

Some participants reflected on the fact that the members of the family that they feel especially close to are those with whom they share no genetic link at all:

I think it's interesting because I've always been a lot closer to my dad, and like, there are so many similarities between us ... my dad's just always been the one who's really listened to me and understood me, he's the one that I sort of talk to, and I find that really interesting, because you know, we're not blood related, but we're just so similar and he's the one that I would go to, you know, if there was anything wrong, if I was wanting advice if I was upset or even if I was just happy, sharing good news. It's just quite an interesting dynamic. ... I think it's almost kind of special because um, we've got this bond, but we're not you know, biologically related. F4

You know, the interesting thing for me is that my sense of family comes from how I feel with the people, and how they treat me, and that strangely came from the side of my family that I'm not actually related to, you know, so whilst my mother's side were splintering and arguing and not getting on together and things, obviously with the level of trauma that I was experiencing I really needed a safe place to go and that came from my father's side. M2

Time and time again, participants emphasised that what made their particular family a family was the experiences they had together, and the love that they felt for each other.

My concept and understanding of family is that it is more centred around nurture and association through interaction and how you understand one another, and how you choose to think, and the things that are either encouraged or discouraged, and the development of your own moral code or fibre is more indicative of family than a genetic trait. So, I know that I have a broader view of

what constitutes family than I probably would have otherwise had because family for me hasn't needed to mean necessarily that you're genetically related at all or through any percentage. Family is the people you choose to spend your time with and the people who love you and raise you, who you have that family obligation to, which is more a feeling and less tangible than genetic traits. M3

Mum, Dad, and I are family. The fact that I was created through a donor is just a nice wee add-on I guess, um, it's still Mum, Dad and I and, not to sound dismissive of the donor or anything like that because we are truly grateful, but he hasn't been involved in bringing me up or anything like that, and not to say I'd be in the same boat as an adopted child but I can imagine that it would be that sort of element of it. F15

#### Open-mindedness: Family is What You Make It

Several participants expressed that being donor-conceived has given them insight into the world of infertility and family building, and/or a better understanding of and empathy towards the different kinds of family structures that exist.

I guess I'm very open in terms of how families are formed. I've got my own family which is a very unique story and my sense of family ... so when I read a book about the fact that there's lesbian couples having a child or something like that, that's not strange for me at all you know, because I've got a story that's strange; if you wanna get strange about something then you know ... (laughs). So, I'm very open and to me it is the sense of family and how that's derived. M2

All participants shared the sentiment that family is what you make it, and it does not have to follow a traditional nuclear structure to be a functioning family. You can belong to any type of family and turn out "as good as the next person"; it is the quality of care and relationships that matters. The quotations below represent the general shared feeling on family:

I guess I still feel that despite how our family was made and how I came about, that all of that doesn't really matter at the end of the day. I still feel the same about my family as before I knew and that's based on our relationships, our experiences together, our memories, the support system that we've got for each other, and that kind of stuff has got nothing to do with the biology of how it all came about. If anything, it's just reiterated that to me and made our connections stronger because you're like, well despite all that we still are family, and what

is a family? Like, whatever I thought it was before is obviously not what it was and the whole donor world, which before I had no idea about what that was or you know any concept of how that kind of world existed, it's totally opened me up to all these other different kinds of families, and I've met other people that have been conceived in different ways and um, it's also given me a real appreciation for Mum and knowing that she just really, really wanted a child and so you were born and made because you were really, really wanted and that's cool, that's really cool. F5

I guess I'm very lucky in that most of my friends come from, you know, nuclear families and standard sixties picture book conceptions of families. My experience would suggest that creating family, having an expansive family- which I do think is super important to people - is much less about who the people are, whether it's like your grandmother or aunty or your uncle, or whatever's happening, and you know the relationships that you choose to form with people... I would say that it's possible to kind of create that feeling of family in some ways, wherever you are. M1

I think especially these days - well I think always - family has been able to be anything that you make it, it doesn't have to be a nuclear family or whatever you think a traditional family is, but also I think these days people are a lot more open minded as to what family is, and I think culture is a huge part of it as well, and I think being donor-conceived has taught me that family is more about who you grow up with and who you learn from and it doesn't have to be necessarily a mum, a dad and siblings, its whoever is around to raise you and that's who your mum and dad are, or just your mum, and you can turn out just as good as the next person with just a mum or two dads or anything. And genetics doesn't make someone a dad to me F2

## Dad vs Donor

Of the twenty participants from dual-parent families, most were also adamant that in their minds there exists a very clear distinction between their donor and their dad. Many expressed feelings of protectiveness towards their father, and some explained how the language they use, (and the language they dislike) is reflective of these thoughts and feelings.

There was some video that was made with these two little girls and they were sort of talking about their donor as like their real dad, and I remember having like this really strong reaction to that, like, I don't know, as being, not disrespectful but maybe kind of hurtful to their father. I would draw a really strong line between, you know, biological paternity and a father or dad and I

think there is no question in my mind around my dad/father/whatever is and so I think that's kind of what drives that kind of ambivalence towards a biological donor. Also, to me it would be important that Dad in no way felt slighted or maligned by that. M1

I'm really hot on dialogue for my own reasons. Obviously, part of preserving my relationship with my father is that he is very much my father so any dialogue that I would use around this topic would be that the person is the donor, and I do find it quite confronting when donors say that they're the donor-father even, they start to sort of blend the two. Yeah, there was a donor panel at the conference [on donor conception] and you could see across the panel through six people, they all had very different perceptions but some were from my view, and probably because of my history and my story, you know, some of them were well and truly crossing the line, going to the whole long-lost relative side of it which for me doesn't protect or preserve the nature of the exchange in the early days and the family that's formed around that person since. So, for me, I might be a little bit stronger about dialogue than some other people are. M2

Some participants spoke of frustration with regards to the question that friends have posed to them: "what about your real dad?"

I think that some of my friends have said "your dad's not your dad" and I'm "No, no, he is my dad! He raised me!" and they can't get their heads around it because they haven't been in that situation but when you're in that situation, it's just well, your dad is your dad and your donor is your donor and that's it. F13

One explained that such conversations are the reason she avoids disclosing that she is donor-conceived to other people:

I certainly haven't told a lot of people that I'm donor-conceived. I kind of worry about confusion or reaction so very few if any people know. I think ... a couple of my closest friends. I don't even know if my husband's parents know... There's a bit of confusion. Like a bit of "what's that?" and "what do you mean?" And then like "what about your real dad?" and I'm like "well, my dad's my real dad". I think having to go through those sort of things isn't very pleasant. F4

Despite unanimous agreement that a family is formed through love and experiences, and a strong sense that 'Dad' and 'Donor' are two different things, many participants also wished to clarify that the value they place on relationships, love, and shared experiences, does not rule out an interest in genetics, nor do positive feelings towards the family they have grown up with change simply because they may be interested in their genetic connections. As one participant explained:

DNA's not really important; it's who actually raised you, and who was there for you that are the people in your family, not who is biologically related to you. But then it's also like the biological relationship is still kind of important to me, but I don't think I would consider those people to be family as such. I think a family is more like the people who are around you, the people that you love or who you know. I don't really have a word for all the people who are like biologically related to me who aren't part of my family. F1

When asked what the biological link between them and their donors meant to them; more than half of the participants (n=13) said they currently felt the biological link between them and the donor was an important or special link, though some emphasised it was not an emotional link. Nine participants stated that this link had little or no meaning in their lives currently, but four of these had considered the link an important one at other times in their lives.

Participants generally agreed that while genes are not an essential feature of family, biology is nonetheless important too, and some expressed that the donor-conceived person's right to know more about their genetic connections and maybe even form relationships with their donor and/or other offspring from the same donor shouldn't be denied.

This is a product of, I think, of Mum and Dad telling me early, and the wonderful relationship with Dad – I'm a very strong believer that family is the people that you love and care for; my foster family is very much my family also, even though they have no biological relationship to me, um, so yes just a very, kind of a sense of that, that a family is not defined by biology. That is not to say though, and I have to kind of quickly follow this on without taking a breath when I say this to people because the take away often in people's minds is "oh well then, it must be fine that you're donor-conceived if you think that it doesn't, you know ... if family's all about those social bonds then surely it doesn't matter to you that you don't know what your blood connection is." Um, that's not true. I think that knowing your biology is vitally important. F9

This participant also explained that she uses the term biological father to describe her donor, a term which other participants also used in passing during their interviews. The terms "father", "real father" and "donor dad" were also used in certain contexts, demonstrating that donor-conceived people vary on what terms they are comfortable and willing to use, and highlighting the complexities of language in general.

#### Societal Attitudes/ Bionormativism

Some participants stated that society does place a strong emphasis on the importance of the genetic connection, and that this is reflected in day to day interactions and conversations, including a big focus on shared resemblances. For some, this became more obvious after they had their own children:

I feel like if you're asked a question like that people probably tend to downplay it and say, you know, "family are the people that love you and care about you" and I think that's very true, but that said, people spend so much time saying "he has your eyes" or "he takes after you" or "he does that because of that reason" you know and I really think that looking back on my childhood and all the awkwardness, I just think of the awkwardness that was there, especially when people would talk about my brother's red hair, you know "oh, where did that come from?" Well, who knows really, but she always said it was my great-grandmother had that same hair. Don't know if that's true (laughs). Yeah. But people do really spend a lot of time thinking and talking about biology whether they realise it or not, so I think it really is important. F12

I do struggle sometimes, when people are talking about, you know, people who don't know might mention "oh he looks a bit like your dad, I wonder if he's gonna

have your dad's colour eyes". So, those sort of things. Or when we were growing up my sister used to get a lot, you know, that she looks like Dad. F7

Some participants also noted that while society is becoming more open to the idea of assisted reproduction and assisted reproductive technologies, and that people are often very supportive of the recipients of these procedures, there is sometimes judgement and misunderstanding about donor offspring; a misconception that the donor-conceived person is ungrateful towards their parents if they want to know about the person who helped conceive them and with whom, as a result, they share genetic material.

I guess people just don't really understand, like they don't really know what it is. A lot of people think "why would you want to know who your donor is; why would you want to know them - it doesn't mean anything; it's not your dad. Like your dad is the person who raised you not your donor, why would you even want to contact them?" Like a lot of people don't really understand why you would want to have contact at all and why you would want to know who they were. F1

People are generally superficially aware of what sperm donation is. Or their awareness is to do with say a lesbian couple needing a donor to conceive. So, in my experience people see it as a positive thing, but without going any deeper than that to understand the process let alone the actual child born and the nuances of being DC. F10

One participant addressed the notion that it is a contradiction to value genetic links to the donor while at the same time perceiving family as the people you love and share experiences with, by emphasising that it is in her view, a contradiction for a person to value and strive for a genetic link between parent and child, while intending to cut the resulting child off from one set of his or her own genetic ties:

The reason that people kind of go with donor conception is because they value a biological link, like if my mum hadn't valued having a biological link with her wanted-for child then she could have adopted. And she chose not to adopt and to use donor conception instead because she wanted a biological link, so there's an incredible hypocrisy, and I certainly don't mean that towards my mum

in a pejorative way, but there's a core hypocrisy in it, to then not have that biological relationship available for the child. To say that a biological relationship really matters enough that you're going to go for donor conception instead of adoption, says that it matters to an adult that there's a biological link. You can't at the same time as you pursue that, say it's okay to sever it for a child. F9

Most participants in this study expressed gratitude both to their parents for having and loving them, and to the donor for his role in their conception, demonstrating that these positions do not have to be in conflict. Many participants mentioned concern for their father, and a wish to not hurt his feelings, or make him feel uncomfortable or rejected. But for some the desire to avoid hurting other people's feelings can lead to a sense of isolation from being unable to express one's own feelings, and the experience of disenfranchised grief, (loss that one is expected to keep hidden or unexpressed).

#### Locating the donor

The above themes on family and genes logically lead to such questions as: What is the motivation behind seeking one's donor? What could be gained from contact? What is this loss some speak of, and why does it matter so much to some but not others? Is the donor family? What of other donor offspring- are genetic half-siblings from the same donor family? Can there be a social relationship as well as a genetic one? The answers to these questions may help us to better understand how donors and donor siblings fit into the family constructs of the donor-conceived, and what it means for someone born through third party reproduction to grow up without knowledge of their donor, and without the presence of the donor in their lives.

In an attempt to answer questions like the ones above, participants in this study were asked to speak of their thoughts and feelings regarding the donor, including: motivations for seeking contact; benefits of establishing contact if they have been able



to; what, if any, benefits they envision if they haven't; and alternatively, reasons for not seeking contact. Most participants had not made contact with their donor. Only three had actually met with their donor at the time of their interview. The table below illustrates the varying levels of contact participants have made with their donors, and the different levels of information sought and obtained.

Table 3: Levels of contact and information held

<b>Level of contact/information</b>	<b>No. of participants</b>
Met donor/currently in contact	2
Met donor/not currently in contact	1
Contact established / currently in contact/intend to meet	2
Contact established /currently in contact/open to the possibility of meeting	1
Contact established /no intention of meeting or further contact at this stage	2
Attempted to locate donor but unsuccessful/ no information at all or basic identifying information from clinic only	3
No contact sought/ has some basic non-identifying information from clinic or snippets of information from elsewhere	5
No contact sought/ no information	5

### Motivations for Contact

The following were identified as motivations for, and (actual and potential) benefits of, seeking information or contact: gaining a fuller picture of oneself; demystifying the donor; and establishing new connections and relationships.

## Gaining a Fuller Picture of Oneself

There's a bunch of concrete things but what is much more significant to me is much harder to articulate which is just ... the knowledge of myself, and I think particularly as you're growing up, just a sense of ... it's not that your biology defines you but it gives you a kind of roadmap that would be nice to have the choice to either follow or not follow. I don't know, it's weird, I'm a [senior person in occupation] now. I got a full scholarship to [university], I did all these kinds of things that are totally crazy from the perspective of my mum who - well actually like her I left school when I was fifteen - and it would have been nice to have some kind of roadmap of what the possibilities were, even if I hadn't been defined by it or followed it, but just to have a baseline. Right now, it's just a huge gaping hole. It means a lot to me ... I'm very, very different from my mum, we, in some respects, you know we look familiar, but there is a lot that's left to be explained and the frustration with the not-knowing is if you have two parents that you can look at, then, you can figure out what is uniquely you, but without that there's always those questions. Now, with my own kids, I see how much comes from each of me and my husband and to not have that for myself is a consistent point of frustration. F9

As the above quote illustrates, being donor-conceived can have important implications for a person's sense of identity and self-construct. All twenty-one participants, even those who had little to no interest in their donor, expressed that either: having more information on their donor; establishing contact; or meeting the donor, is or could be, beneficial for the donor-conceived person, to gain a fuller picture or better understanding of his or her self, in at least one of the following three ways: Identifying shared traits; genetic medical history; cultural lineage.

### Identifying Shared Traits (n = 17)

Many participants expressed that one of the key motivations in seeking their donor would be to satisfy curiosity about the donor's appearance and other traits, and more specifically to identify similarities between themselves and the donor.

For some, being donor-conceived has raised questions about their identity, including where they fit in relation to their family. Every family has individual differences between

family members but a donor-conceived person may wonder how much of this difference is due to the fact that they were donor-conceived.

I know that I'm not like genetically related to my dad so it makes you be like "oh well, that's why I'm not like that, that's why I'm different from my dad, I don't have as much things in common", it makes you wonder what you would be like if you were genetically related, like how different you'd be. So, I think it does affect how you think about your relationship but it hasn't really ... I don't think it's affected how close I am to my dad. F1

When you talk about you know, the type of hair you've got or your body features or whatever, then you've kind of got no reference on that side of the family so that's ... I mean I know a lot of people in that situation whether they're donor-conceived or not, but that can be a little bit frustrating, because before being told about it, I did think that I knew that side of the family. I knew who I see as my dad now, I always tried to connect his grandparents and that to myself to explain whatever, like why I was into art or whatever, you know? M5

One participant described how establishing contact with her donor helped her to understand herself a little better, and gave her a sense of belonging that she felt had been missing from her life before:

I always felt like I was a little bit out of place in my family; a little bit weird, but I know a lot of people feel like that and they are the biological children of their parents, so I don't know if I can fully say this is why but, well, my donor is a quite academically minded, you know he's an academic with published papers. I've just always felt like I was the academically minded one in my family and my dad was not like that at all and yeah, I'm different to my brother and I'm different to anyone and I always felt like I was different ... but now I look at it and I do feel like it's explained and you know, when I talk to him I feel like we are really similar, just like he's quite weird and quirky and obviously a massive nerd like I am so I just think "oh that's really nice" it's nice to have that information ... I feel like right now it explains things for me and I really want to meet him. F1

Similarly, the following participants explained how contacting and meeting their donors respectively, had provided answers to questions they held about themselves in relation to their donor.

I don't think he'll ever be like a father figure to me, but I guess like a self-satisfaction maybe, or answering self-curiosity, so I think like even as soon as I made contact with him and saw pictures and talked about like what he did and

stuff then it became less urgent to meet him because there was already like certain things had been answered and I'd made certain connections and seen similarities and stuff like that. F11

I think it's a good idea, I guess, if anyone knows that they have a donor, that they should definitely go and meet them, you know cos you never know what to expect and sometimes, like when I met him, you just feel like a whole other side of you is complete and I think it's more positive than it's going to be negative. I don't know ... it just makes you feel complete I guess. It's like finding out the other half of you. You know what I mean? It's kind of like connecting all the dots together and kind of understanding the other side of your background. F8

#### Genetic Medical History (n=11)

Being donor-conceived also has obvious biomedical implications. Inheritable diseases and genetic disabilities can be passed on through donor gametes. Around half the participants desired access to medical information about their donor and many of those who had made contact with their donors found this to be one of the most beneficial aspects. Others, who held little to no interest in their donors, felt that medical history was something that they may be interested in obtaining to ascertain how at risk they may be for certain diseases or whether they were likely to experience premature balding.

It would be nice to know medical history stuff of heart attack and cancer and things. You know you go to the doctor, they're like "have you got a family history of like blah?" it's like "well..." and it's funny cos I'll go "oh like my granddad died of cancer - oh actually, that's not relevant because he's not biologically related to me". I sort of forget, right? Um, yeah, that would be helpful. That is probably the only thing. M1

One participant explained that having children led to a mild interest in her donor as it suddenly dawned on her that she did not have access to their whole genetic medical history, while another began a quest to find the donor to whom she had previously

given little thought, when she experienced some medical issues that suddenly made having this genetic information pertinent.

Two participants below gave their perspectives on why medical history from their donors could be interesting or useful for them:

I have a genetic disease; part of how it comes about is both your parents have to have the degenerative gene, so there is an element there that interests me because obviously the donor has the defective gene as well, and the only thing I've ever thought about wanting to know would be that kind of medical side of things and maybe finding out about how that came about, maybe some more information about how they screen donors now or how they did back then, or if there is some kind of family history on that side. Um, yeah, but never as a personal thing or a personal connection to him. F5

My husband, for example, in his family has the BRCA 1 gene and that's something because of his family history he could document, he was able to get testing on and insurance for and we found out that he has it. That's not something that's available to me and I don't know, maybe my biological father's family does have the BRCA gene, but I don't know and as a result, I can't get insurance coverage to just test that. F9

#### Cultural Lineage (n = 6)

Some participants were curious about their ancestral roots, and experienced a sense of frustration from being cut off from that knowledge. For instance:

It's a bit frustrating not knowing on one side of the family that lineage or sort of cultural history - I don't know any of that on one side of the family. Apart from a little bit of information about the donor that he, the donor, obviously filled out when he made the donation, which said something like English and Scottish descent or something, so not knowing that is a little bit frustrating. M5

For one participant who had since discovered her donor's nationality, there was a sense that something was stolen from her; that she should have been given the opportunity to learn about her ancestral heritage and language from a younger age and to share that knowledge with her partner before they had children together.

I think that I do think more about biology, you know, and the genetic inheritance that she [daughter] is getting. I almost feel like I married my husband and had a baby under false pretences; he didn't know what he was getting. Also, my donor is Czech, so it turns out that I'm half Czech which really makes me think about things in a different way. Like, why did I waste my time learning Japanese; I should have been learning you know, my bi-ancestral language or something. F12

## Demystifying the Donor

Demystifying the donor was identified as another motivation for, and benefit of, seeking contact. While the wish to demystify the donor is also partly about quenching curiosity, this motivation runs deeper than an interest in appearance and shared traits. Just over half of the participants expressed discomfort or unease at not knowing the identity of their donor. For these participants, there was an unpleasantness associated with knowing that fifty percent of their DNA could come from a random passer-by on the street and they wouldn't know. For others, there was a sense that there was a "missing piece to the puzzle", a "gaping hole", or a "grey area on the family tree". Some described a sense of mystery around what it would feel like to meet with the donor; what sort of connection, if any, there would be. For some, at times, the need to demystify the donor can become intense and obsessive.

One participant found it difficult to describe what the biological link between he and his donor means to him, as a result of not having any information on his donor whose identity is sealed:

You sort of try to do a bit of guesswork to what he might be like ... I don't know what it means to me. It would only be at times that I really sort of think about it briefly but then I just end up getting a little bit frustrated because you know there's no answers to your questions, so it just leaves a little bit of a grey area on the family tree really. M5

Another described what it would mean to her to have that information available to her, and preferably to be able to meet him.

I don't like the word, but closure, in a way. Yeah, um, just the opportunity to meet him I think would be I suppose healing... The missing puzzle pieces. I can also stop imagining who he is and what his life has been like. It can take up a lot of my energy trying to work out who he is. I'd like to think knowing would be a kind of freeing experience. F10

Contacting or meeting the donor and having a general understanding of who he is can remove that mystery. All participants who had met with their donor expressed that their curiosity was at least partly satisfied and they felt reassured or more at peace with the situation once they knew what he looked like, or where he was living and what he did for a career. Two of the participants felt this meeting brought them closer to their donor, or made them more interested in getting to know him better.

Now that I'm kind of getting to know him, it's like, I think, I feel like it's going to be more important in the future than what it has been for me in the past. Before I didn't really know very much and stuff, and it was just like 'donor' was this abstract figure and now it's a real person so it probably means a lot more now than it did before ... Now it's like he's actually a concrete person ... whereas before it was like it could be anybody. He could be dead, he could be overseas. F1

When I didn't know him I was just like "oh what is he like?" and then when I finally met him it's like "wow", I guess I can see a bigger picture now since I've met him kind of thing, it was always like a curiosity feeling towards him until I met him and now it's like I understand, that kind of aspect, yeah. F8

The third participant who had met with her donor described how meeting him meant demystifying not only who her donor was but also her connection to him and what that connection meant, so that eventually her mind was freed from thinking about him.

It's ... well ... it was all a big mystery, it felt like this missing piece, and a missing part of my body and identity before I met him. And it was kind of like a big blurry, hazy area that I really wanted to fill, like a puzzle and then ... when I met him, it was just really ... trying to look at his face and see myself in him and yeah, it

was more physical than anything, really, that link. And then now ...it's kind of ... it's hard to describe ... it's just a physical link that I have with him that is related to how I look, and whether I'll be at risk of disease, and really kind of a medical thing for me. Um, it's not a fatherly link at all... I remember when I found out about it, picturing him and wanting to put a face on the idea of it, he was just an idea to me and it was very mysterious and felt a bit strange, and then I was working in this local café, and um I think we'd exchanged letters and I knew his occupation and I knew that his workplace was probably quite, just over the road from where the café was, so every time I made a coffee for a male around his age I thought it was him, and I'd be walking down the street and I'd think "It could be him. It could be him" and I didn't like that at all, and part of my reason for wanting to meet him was to kind of fulfil that need of just putting a face to a name. And it was nice to get to know him a bit and see that he's a good guy and see similarities in both of us and over time I slowly stopped really thinking about him at all. F2

Likewise, some participants who had made contact with their donor, but had chosen not to meet him, expressed similar feelings of reassurance and clarity.

That mystery isn't there anymore. Like "is he a millionaire or is he in prison?" or you know, to kind of know where he's at. Yeah, just reassuring... I think that I'm really happy I could gain a sense of who he was through his letters. We talked a bit about who we were, our interests, um he talked about his family. He talked about any health conditions which was quite reassuring to know, because you know when you go to the doctor and ask if there's any family history, half of that was a mystery so you know that was really reassuring. And it was really nice to see a photo of him, we look quite similar so that was quite funny, um, and I'm just, I'm really happy with that, and I think at this stage I'm happy not to meet him. F4

I suppose when I hadn't had contact with him, you're imagining all this stuff and wondering "do I look like him?", "am I like him in character?" you know, "what did I get from my donor?" and the not knowing ... was probably the actual time when it bothered me the most. Um, yeah just imagining. But once I actually had contact with him, um, at first you realise, like it's a stranger. it's ... I was able to get a full medical history, ask any questions I wanted which was really helpful, um, but in getting that information I definitely realised you know, this person's not my father, I have a dad, I have a family, you know, it's easy to be more impartial about it. F7



Exploring/establishing new connections and/or relationships

I think I just view my family as just being larger now. Like, I always wanted to have a bit more family. M4

Some participants spoke of the potential for establishing connections and relationships with the donor and donor siblings, although not necessarily what they would consider family relationships. Eight participants said that they do view the donor and/or donor siblings as family, but of those eight, most clarified that donor and donor siblings are biological or genetic family, not social family, and therefore whilst there is a connection, they do not consider them the same level of family as the family they grew up with. Some clarified that any relationships formed would need to stand on their own merits based on more than genetic connection alone.

Illustrating the point that family is more about relationships than genes, one participant spoke differently of her perceptions of the donor she had exchanged e-mails with but was yet to meet, and the donor sibling she had built a social relationship with.

I don't see him as part of my family. No, because I think family is more than just, you know, it's more than blood, and you've got to have relationship. You don't ... I wouldn't say that we've got a relationship. I guess we do in some way but, there's nothing set in concrete with him I suppose. F3

I do count her as my family. I ended up being her bridesmaid six months after I met her, because she lost touch with all of her side of the family. So, I went over, I flew over to see her, and she was like "oh, be my bridesmaid", so she only had a tiny little wedding but it was still really nice ... yeah, we clicked pretty well, and everyone kept saying "you look alike" and all of those things and yeah, I count her as family, I care about what's going on in her life. F3

Conversely, another participant who had met her donor, but was yet to make contact with any donor siblings (though was interested in the prospect) had this to say of her donor:

I see him as my family, but I would never call him, like Dad or anything, he's always going to be my donor dad, but I definitely see him as family. F8

But felt differently about her donor siblings:

I'd need to build a relationship with them, it's a bit strange calling someone, a stranger, your family. F8

Almost half of the participants reported that they were more interested in genetic half-siblings than in the donor himself, and participants spoke more often of the potential for developing relationships with donor siblings than they did of the donor, perhaps assuming donor-siblings would be more open to the possibility of kinship than the donor.

I guess by extension I would [consider them family], not so much as how I feel about my close family, but I feel that because they've gone through the same thing that my family has, they'd probably be quite open to welcoming me into their family as well; at least I hope they'd be open to it. But yeah, by extension I would probably say so, but not so much as my immediate family means to me. M4

Five participants had met one of their donor siblings, and a further nine said they would like to. Some were on a voluntary donor registry, but as none of their donor-siblings were on this same registry, they were yet to make contact. Some added that they wouldn't seek contact themselves but would be open to meeting if they were approached. Curiosity regarding shared traits was cited as the main point of interest in donor siblings.

The thing I find most curious is probably like on the little sheet it said that he had three children, so the thing I find really interesting specifically is less about the donor and more about having half-blood siblings and I find that really curious as to genetically what they look like and what they do and who they are. F6

For those who had met a donor-sibling, identifying similarities was something they found both enjoyable and rewarding.

Sitting opposite him, I kept staring at his features, seeing myself in a way. It was strange, but also kind of comforting because I always felt like I looked different to my family. We talked for about an hour and the conversation flowed fairly naturally. F10

It was quite funny cos we really looked like each other and we kind of laughed when we saw each other and she's two months younger than me, so we just kind of fizzed over how similar we were with lots of different things. We both like yoga and we both like running and we both cook and things like that but then in lots of ways we were very different as well. F2

For some the possibility of establishing ongoing relationships was a definite factor in wishing to connect with donor-siblings.

Hopefully I get to meet my extended family and then we have these kind of huge family gatherings that I've heard some donor kids get up to. I heard about one family who get together once every year, but there are heaps of them, I can't remember and I think I only have like six, well seven, I don't know if that's enough. It'll be a start though. F12

Others, however, had no desire to establish such relationships, and one participant explained how different expectations between she and the donor-sibling she met created an uncomfortable situation for them both.

In some ways, the meeting was not ideal because I felt that she was really looking for something more and she had reached out to the donor and not heard back and I don't think she has to this day, and I had met him, so it was a bit unequal and unbalanced and I wasn't exactly allowed to divulge too much stuff about him, um so that was a bit unfair on both of us really, it was kind of an elephant in the room, a little bit. And as it turned out she is estranged from the rest of her family, she's got broken down relationships with them so I really felt like she wanted a sister... I've got my sister and I don't want her to think that I'm replacing her ... It was nice to meet my donor once, and I haven't pursued that any further and it was nice to meet her once, but I'm not really looking for anything more than that one meeting. F2

Some participants spoke of discomfort with the possibility that someone they encounter, or even form an intimate relationship with, may in fact be their genetic sibling, and they wouldn't know.

One of the most important things has been the sibling thing. Like having half siblings cos I only have one sister, so it's like knowing that I have six others who I don't know has always been frustrating, and something that I've wanted to know about. And now that I know that I have - my donor has three children - and I can't get in contact with them, it's really frustrating. But it's also like, the thing that people like never really think about, it's like every time I get into a relationship with anybody the first question you have to ask is "I know this is a weird question but are you donor-conceived or is someone in your family?" Because you could end up dating your brother or sister. I found out that one of my donor's children, he went to the same university as me and studied almost the same things, and at the same time, so I possibly have encountered him at some point but I'm not really sure. I could have easily become friends with him or something because we have five mutual friends on Facebook and stuff. I think that has always been one of the most important things for me, is the sibling thing. F1

Recently I had a really weird thing, 'cos I'm in a new relationship with a guy, we've been together for six months, and it came up for me and I got really freaked out and convinced myself that he could be my donor sibling (laughs) and I went home at Christmas and I went through my letter from my donor, which, he'd given me a photo of himself when we met, and I got the photo out and studied it and convinced myself that it looked like my boyfriend and so I had to talk to him about it and he had to kind of remind me that I was being crazy and that he was naturally conceived by his parents and things, but yeah, it just came up for me hugely and it consumed me for a couple of weeks F2

Some participants has given little or no thought to the possibility of donor-siblings:

I haven't really thought about that actually. But I don't know, how many brothers and sisters do you need? I don't think knowing or anything would make a lot of difference for me. F14

Yeah, that's a weird one too. I've actually never even considered that angle of it. That's crazy. That would be a little more interesting [than meeting the donor] I think. But um... yeah. That would be a little more interesting but I think also too, like it kind of ... does it create a weird family thing that you don't necessarily want to get into? M1

I'd be freaked out by that to be honest. And if someone approached me, like I don't know if I'd want to meet them. F5

A participant whose donor was unknown, explained why he prefers not to think of potential donor-siblings at all.

That is simply something that I will never know, so it's not something I need to spend a lot of time with you know, otherwise It makes you sad; there's no happiness in it. M2

Reasons for not contacting or meeting the donor

The fact that the right to information differs across eras, means that in some families, information is available for one or more siblings, but not others. One participant described how within his family of three donor-conceived siblings, each was born in a different era, meaning the right to information differed for each sibling:

My thing is I'm not able to, so: brother - no information collected on the donor basically, or at least not that he is able to have access to. My era, a little more information; I know height, eye colour, hair colour and a single hobby, but no more information as a conscious choice that they couldn't let me track down through their occupation or anything like that. And then my sister I believe had full access to talk to them if they wish which is what makes it weird with me that she could and I can't. M3

Because M3 shares a donor with his sister, the idea that she legally has the right to approach her donor through the clinic at which she was conceived, whereas he does not, was a circumstance he found weird. However, he went on to explain, that for him, having no right to obtain this has never been a big issue, as he has no interest in contacting his donor:

Never came up for me, as something even when my sister was looking at you know, wondering whether she would want to meet him or not, um, yeah, Dad's Dad. Like I say, I'm grateful to the other guy but that's where the connection ends. M3

Eight participants who had not contacted or attempted to contact the donor or donor siblings said they currently have no interest in doing so, though some have given it thought in the past, and some acknowledge they may have a desire to do so in the

future. Participants who currently had no real or hypothetical interest in seeking or meeting with their donor, or who have chosen to have no further contact with their donor after initial contact, gave reasons that fit under three categories or sub-themes: Nothing missing, nothing to be gained (general lack of interest); negotiating relationships; and fear of rejection or impinging upon the wishes of the donor.

Nothing Missing; Nothing to be Gained (General lack of Interest)

The most common reason given for hesitation around seeking contact with the donor, was that there is nothing missing from their lives and therefore nothing to be gained.

I've never really felt like I've been missing out on anything in terms of a family kind of connection, or you know a want for more. I don't have anything [information on donor] and I've never really sought it. My understanding is that I, because of the timing, probably wouldn't get anything, but I've never tried. I've never been motivated to push for it. I just don't know what good that would do or what I would get out of it - why I'd be wanting to do it. It would probably make it a wee bit more real then I wanted it to be. If I had any kind of information that would start creating a picture of the person. F5

I've always liked having the knowledge that if I wanted to I could, but I haven't felt a burning desire to so far because I've always felt a father role in my life. I don't feel like I've missed out on anything and if I did want to meet him it would be to (a) say a tremendous thank you and (b) just out of pure curiosity to see if I look like him actually. F15

Negotiating Relationships

Some participants felt that making contact with their donor could "open up a can of worms" that they were not wanting to deal with, specifically in regard to building new relationships and figuring out what these new relationships would mean, and how they would fit into their existing family constructs.

I don't know what that relationship would be. I kind of don't know. Would you kind of like hug the person? I guess, but like you don't really know them from a bar of soap. You know, would you sort of be a kid? Not really. Yeah, I don't know. It's sort of a strange thing I think ... I think if the person sought me out I

would be like obviously open to having that conversation but I don't... Yeah, I just don't kind of quite conceive of how that would fit in, you know. M1

For me - happy family, no itching, burning current desire to find the donor but when he steps into the picture if he wants to - then I can't see him having too much involvement. It probably depends on how well we get on actually, when we do meet, whether it's just a sit-down, cup of coffee, "thank you very much, see you later, it was lovely to meet you." Or, whether it's a call once a year to see how he's going, type thing, who knows, but without a doubt it will add something into it. F15

For some there is concern that the donor will want a familial relationship, while the participant is adamant that this is not what he or she wants.

I got a bit frightened with the idea of it, mainly when I was doing second year at uni ... and had a lecture on donors and there was some research somewhere that mentioned something about how a particular cohort or group of donors that had met their corresponding successful outcome wanted a parent-child relationship like seventy percent of those wanted a parent-child relationship and that was definitely not something that I was wanting to engage with so ... I had my parents, I love my parents and I didn't want to engage in that sort of relationship at all. F6

Many worried about how meeting the donor will impact on existing relationships and, especially, how it might affect their fathers.

I, on the one hand, don't want to stir up too much emotion where I already have such a close relationship with my dad, I don't want to hurt my dad, and I'm just happy with my dad, and I'm happy with how much I know. F4

Thus, negotiating relationships is part of the process for those who choose to meet with donors/donor offspring, and how these relationships are negotiated will often depend, at least partially, on the perceived impact on existing relationships. Knowing this beforehand, some donor-conceived people will decide that contacting their donors is not worth the risk.

The impact is much wider than myself so I was always conscious around how my dad would feel about that specifically and how my middle brother would feel about that seeing it's his donor as well and how my oldest brother would feel

since he can't meet his donor for reasons that happened along that path um so it was never ... it was always a sense of curiosity but never ever something that I was willing to put my relationships with my family in jeopardy for although of course it's completely unknown and it might have been wonderful at the time but it wasn't something that I was willing to risk. F6

#### Fear of Rejection or Impinging Upon the Wishes of the Donor

Lastly, some participants alluded to a fear of rejection from the donor, while others were concerned about impinging upon his wishes by breaking the initial agreement around privacy, and seeking further information.

I think eventually I would like to try but I mean, I'd completely understand and respect his wishes if he didn't want to... yeah I guess I respect his wishes that I don't think he particularly um, wants to be met with at the moment, from what I'd read [e-mails between donor and donor sibling] he wasn't too into it; he was fine with sending emails and letters and stuff but with the meeting I don't know what his true feelings would've been on that. M4

Because of the timeframe and the laws or legislation there's all these things when we were initially conceived where they don't have to agree to make contact so how would I process that sense of rejection if they said no? F6

I know the nature in which he donated in wanting to be anonymous, I think that that for me is sort of like a statement to say that it's not a ... he's not looking for a family out of it, do you get what I mean? ... [but] it would have been nice to know more about the donor rather than the brief information that I was given on their little sheet of what the doctors filled out as a private donation. It would be nice to know more about that, and it would be nice to meet him. M5

#### Views on Family Building

Most participants expressed that they had given some thought to the ethical and practical considerations of donor conception, some in relation to their own fertility, as they began their own journeys to conceive.



Some participants stated while they were grateful to be here, and were open-minded about family structure and what constitutes a family, that didn't mean they were in full support of making a family by whatever cost. Some participants worried that the measures some people go to, in order to have a child genetically related to one or both of his/her parents, are sometimes unethical, and that potential parents may be valuing genetic offspring at the expense of the wellbeing of any future children and/or themselves.

Cutting children off from their genetic ties via donor anonymity or lack of disclosure was a core issue raised; the general consensus being that anonymity is not in the best interests of the donor-conceived person.

To grow up armed with all the knowledge that belongs to you - who you are, where you come from, your medical history, and who your biological relations are – is important for so many reasons. Here's where I might add that I'm not sure I agree with donor conception. I'm quite conflicted about this, but I do know that I'm against any form of anonymous donation. To be honest the whole thing feels icky to me. The overemphasis on the 'consumer' model of baby-making frightens the hell out of me. Babies grow up. The sooner the clinics and 'consumers' realise this, the sooner we can sit down and work out how to reconcile these two very different objectives to family. No one should be deliberately created with the intention to cut those family ties. F10

I feel strongly that everybody should have at least the opportunity to create a social bond with their biological parent if at all possible. There are plenty of circumstances in the world where that's not possible, and we can think of many of them, but donor conception is not one of them. F9

When we first enquired, we were told that our records had been destroyed which is quite a common experience and it just sounded so dramatic that at the time I just laughed at it, but then I hadn't been searching for years and years and I hadn't been told all these different things like other people had been. So, for us, I think it was relatively straightforward, but also kind of traumatic. I'm glad that they weren't destroyed but it just seems so weird that the doctors and clinics that have gone to all this trouble would decide what people can know and what they can't know, when it is literally who they are and I'm really glad that we have DNA testing now so that they can't hide it – it is your genetic make-up, so yay for that. And I really hope that people can find out this kind of thing

at an early stage and I'm glad the law tends to support that now. I know they also have some issues with a lot of stuff going on like this like parental surrogacy and 'free sperm donors' (makes quote marks in the air) so that kind of disturbs me a little bit but I think people are slowly catching up, though it seems that they haven't really caught up to the same level as adoptees rights, but I think we're getting there. I have hope for the future. F12

One participant discussed ethical issues with her own donor conception in relation to the over-utilisation of donor sperm:

Like of course I'm very thankful to be here and without donor conception I wouldn't be here but then ... like one of my friends recently was like "well obviously you're pro-donor conception because that's how you were born" but I don't know, I guess it's also like other aspects of medicine as well it's like, how much should we be taking control of nature and evolution and stuff like that and maybe, like sure donor conception is great and it brings lots of people happiness, but then also there are lots of ethical issues and also maybe its life's way of population control, I guess. I think also because especially with the clinic that mum went through there were heaps of ethical things that came up that I found out later that maybe tainted my experience of it. They were like meant to use the same donor for just five families and like I grew up knowing that and knowing like family 1,2,3,4 and how many offspring and there were about maybe nine, but then when I was about twenty-two I joined the register or something, somehow, I found out they'd used the same donor for lots more families and that there were nineteen offspring so, which is like ... I'm glad they're a person, but it's not really natural and safe. Yeah. F11

Another participant reflected on his preference for donor conception over Intracytoplasmic Sperm Injection or ICSI, a method of assisted reproduction that does not involve a third-party, by which a single fertile sperm injected into an egg.

I think when people say like the whole thing about having kids, or donor kids or ah, adopting or whatever I think I'm much more open to that or I think that many people have this thing they want a kid that's sort of "mine", you know in a kind of biological sense, I think I'm less like that, you know, I would say I don't think that particularly matters much, you know obviously I'm fairly biased but you know, I think that kind of factors into that sort of stuff, and strangely I would say, I think as a result, techniques like, I think it's called ICSI or whatever, where they can kind of do more, with like fertilising your own sperm and eggs, when otherwise they couldn't, um, you know, when you start to talk about some of those things that have some kind of ethical implications of passing down

hereditary infertility and some of that kind of stuff, I think as a matter of policy I'd be more inclined to say "look, you know, it's kind of just a bad idea and please don't get hung up on biology in actual fact, and not pass down some of these hereditary things and just have a donor kid or adopt kids" so you know on those kind of things I tend to come out much more and just place not particularly much weight on biology, I think more so than most people right, and I think of these commentaries "ah but you know it's blood" kind of piece, and I just largely don't kind of put much credence in that, you know, myself. So, I think like that's a direct result of having been a donor child. M1

Thus, while none of the participants stated that they were opposed to assisted reproductive technologies in themselves, and many recognised the great potential these methods have for creating families and bringing happiness to those who cannot conceive in other ways, there was concern that people who are supplying the services aren't necessarily doing so in the best interests of those involved, and that the recipients of such services aren't always thinking about the implications for any offspring that result.

Several participants felt that resources were lacking in the field of donor conception in terms of both education and counselling. Some believed that the counselling their parents had received at the time of their conception was inadequate (particularly that which advocated secrecy); others felt that it would have been a positive or helpful thing for either their family or themselves to have been offered counselling during their childhood; and some thought there should be more support groups available for them now as adults.

If my parents gave me the opportunity to talk to someone about it and, you know - because it was so hard for them to talk about it - so if they gave the option of someone else being able, then that would have been hugely beneficial I think. But, it was very much an alone feeling. F4

There are no support groups in New Zealand for donor-conceived people. There's lots and lots if you want to have a child by donor conception, but there's none actually for people who were donor-conceived as of yet. Apparently,

there's one being formed... Most of the [donor-conceived] people I know are just from the internet, from talking online and stuff. F1

A few participants, who were born in the era of donor anonymity, were disheartened by the lack of support and empathy shown to them by certain fertility professionals during their search for information on their donor and/or donor siblings.

There's been issues with the clinic, being reluctant to kind of try and find him. It's to do with the doctor and his hesitation, I guess, like he's not ... he always brings up the fact of the ethics of he made a contract with the donor and he's not willing to go back on that. It could be to do with the year that I was born, or the era more specifically, although I know of other people conceived at the same clinic only two or three years after I was, and they've been able to contact the clinic and be put in touch with their donor. Sometimes I wonder if it's the way I approached the doctor. I was seventeen years old when I wrote a letter to him to ask for information on my donor. His reply complained of the lack of signature at the end of my letter (I had identified myself by writing my full name though), before telling me he couldn't tell me anything because the donor was anonymous. Over the last fourteen years I've had a trickle of information. If I've persisted, and many times this has taken several attempts, then I might eventually get a little piece of new information. The first time I asked whether I had siblings was in that letter I wrote when I was seventeen years old. It took until I was in my mid-twenties to find out that I have four half-siblings (not including my twin sister). I've met one half-brother and I'm still waiting to find out what sex and what year the other three were born. F10

One participant described her emotional journey attempting to locate her donor via a television documentary, after her attempts to locate him through the fertility clinic proved unfruitful.

I think growing up ... there had sort of been a working assumption in the back of my mind that surely when I'd grown up there'll be like ... I'll be able to find out this information, like I knew he was anonymous but it didn't, I don't know, it wasn't real for me until I started asking questions of "well where's the records?" and the fact that there literally was no records, then it just started to become clearer and clearer that this was not information that was ever going to just come to me and I asked everyone that I could, who had been involved [in the fertility program]. I just felt sure that somebody must know something. Anyway, it just wasn't panning out. And so, I figured that the only that I was going to be able to find a donor was not going to be directly from doctor [in charge of the program]- he was not going to say anything - was to go public and put out a call to find men who had donated sperm [at this particular fertility clinic] and so I met up with a film-maker who was interested in the topic and started building

up this documentary where we advertised for donors. Amazingly, a handful came forward and it was a fascinating process because you learned through that that even though they too had contributed under the circumstances of anonymity and they had not questioned at the time, they had subsequently watched their own kids grow up and had questions in the back of their minds about “well I wonder what happened to the results of my donation” so there was equal curiosity on their side. Um, so that was a really interesting process and you know, as it turned out none of them were mine but it was nice to just see the donor’s perspective or a potential donor’s perspective. It was also gruelling to, you know, the time that you wait between doing the DNA tests and actually getting the results, your mind goes to “well, maybe he is really mine” and then you find all the ways that you can think of to imagine the way that he does look like me or you look at photos of his kids and you’re like “oh that could have been me when I was a kid” and you recreate a whole life narrative around this person being the man that’s given you half your DNA, and then you know, it turns out not, but I just had no other way of trying to find out, and in particular, so this was ... before genetic testing had become so widely available and I think there are sort of easier options to be pursuing maybe now, but that was sort of out of my desperation at that point... After the documentary screened, I got very involved in the HART legislation. Um and I think that it was nice to be able to keep that positive in a way, that at least ... I hadn’t found my donor, but at least we could ensure that identifying information going forward. F9

Although ultimately F9 found meaning and purpose through this experience, clearly much stress could have been avoided if the information on her genetic origins had been made available to her, and/or staff at the fertility clinic were willing to work with her in an open and empathetic manner.

Some participants had reached out to other donor-conceived people for support via social media and others had attended conferences on the subject, which had provided them with the opportunity to meet other donor-conceived people and to discuss issues they found those who were not donor-conceived had difficulty understanding. Two participants were working to address the gap in support services by co-founding their own donor conception advocacy group.

I believe this group that I’ve co-founded will do good things. New Zealand may not really know what donor conception is just yet, but they will. Give us five years and the landscape will have changed -we will be talking about DC without hushed tones and we will be sitting confidently at the table. F10

Thoughts on fertility and participant's own reproductive choices

A few participants spoke of how being donor-conceived has given them pause for thought with regards to their own fertility.

It means I relate to things that I wouldn't necessarily relate to like the fertility world; I like having conversations with people about fertility and feel like our family's been through some things that lots of people go through and I can relate to them more, and I, I've never tried to have kids yet, but I feel like I'd be more in the know about that sort of stuff if I ever do struggle to have kids. F2

I guess when we were starting to get pregnant and starting to try, there are questions in the back of your mind, "am I", you know, "are we going to have problems getting pregnant? What if we did? Would I want, you know, to use a donor?" And things like that. F7

One participant spoke of the impact she thinks being donor-conceived has had on her reproductive choices.

I think my background of being donor-conceived has definitely had quite an influence on how I've chosen to look after my own health and fertility. Comparatively, to a lot of my friends, I think I think about it much more in terms of the long-term effects of certain contraceptives or whatever that may look like and for my own personal fertility I think I always tried to be as natural and supportive of that process as possible... Not that I'd be concerned if I ended up in the same process as Mum and Dad have. F6

Another, who is thinking of trying to conceive, spoke of the way in which she thinks being donor-conceived may have impacted on her thoughts and emotions regarding the process.

It's really interesting because I'm actually coming into the phase where I'm ... where my husband and I are thinking of starting a family soon and you know there's a lot of emotion around that on its own and um, yeah I don't know if this is related but I've always had a bit of a thing at the back of my mind that I won't be able to conceive myself, and I find it really interesting because with donor conception, that's the father's side that there was a problem with the infertility,

yeah, but for me I've just always thought "oh I'm either not going to be able to have a baby or there's going to be huge complications and something's gonna go really, really wrong". I don't know if it's a sort of a subconscious thing, which has resulted from being donor-conceived. Yeah, it's interesting. But I'm really open, if we aren't, we're really open to adoption or donor conception or in-vitro fertilisation. I don't think it will impact on the family that we hopefully have in the future, but we would really love to have our own in saying that. F4

Overall, most participants expressed or implied that they are supportive of donor conception as an alternative way to build families in the event of infertility, and that they are or were open to it themselves when considering issues of fertility and infertility. One participant, currently considering donor conception to build her own single-parent family, described her thought processes about the situation and how her personal preferences and ethics are coloured by with her own experience of being donor-conceived.

I have struggled with the idea of having an unknown donor to conceive and this is maybe quite telling, I would actually prefer – my heart would prefer- having a donor that I know, and I asked a friend recently and he said no, so now I'm actually having to get used to the idea that the only personal donor option that I really had is probably a definite no and I'm really going to have to look at the serious option of an unknown donor. I've actually been looking at a site in Denmark because they have a really large sperm bank and the Danes are really altruistic and they have a personal statement or the clinic staff have written their perception of each donor, and often they'll say "X wants to donate because he thinks it's the right thing to do" or "he thinks it's his civic duty" or "he's of altruistic nature" and they all just seem so loving! So that makes me want to go there rather than South Africa or America where they are paid more, because in Denmark ... it basically compensates their time, but it's not revenue-generating, not to the same extent as South Africa or America, but there is ... of the five hundred there, online, it says open or anonymous, and instinctively I only clicked on three open ones who would want to be contacted, so I was thinking about that, going why do I only click on the open ones? My first instinct wasn't to go anonymous so I think that tells me that if given the choice, I would want my child to have the chance to know who their father was or is, even if they don't meet, but just to have an identity. F13

Thus, for this participant, who has no information at all on her donor, the preference for her own child was one of openness, rather than to cut the child entirely from his or

her genetic ties, and subsequently her hope is for a donor who is willing to be contacted should any offspring so desire, and who donates for moral reasons over material ones. This participant then went on to speak of the challenge she faces in letting go of a family construct based on traditional assumptions.

I think I'm struggling a little bit with the decision to get an unknown donor because in my heart of hearts I grew up wanting to fall in love and have a family with the person I met before and I've got this romantic notion I think of the genes of two people who love each other making a new life and the fact that I didn't come from that ... oh, I came from love, but the love created the behaviour that made me, but it wasn't the genes that made me, you know what I mean? It wasn't the genes of my parents that made me. So, I'm having to let go of that romantic notion now in facing the likelihood that I'll have to get a clinic donor.  
F13

Tellingly, this reflects how deeply the idea of the bionormative nuclear family is enshrined in our collective minds so that even those whose families did not fit into the "norm" may grapple with the idea of what that means and whether they themselves wish to establish a family unit that sits outside traditional conventions.

#### Conceptual Integration: Empowerment vs Disempowerment

Empowerment verses disempowerment was identified as the central theme underlying and connecting each of the aforementioned themes and subthemes. Participants who experienced early disclosure and open communication were empowered with knowledge that allowed them to integrate their donor conception into their concepts of self and family from a younger age. Donor identifiability was also associated with empowerment; contacting and meeting one's donor allowed some participants to "connect the dots" by providing answers to their questions, and empowered them to comfortably position the donor within or outside their self and family constructs (at any given point in time, since thoughts and feelings about the donor are malleable).



Conversely, those who wished to have contact with their donor but were unable to locate or contact him, lived with a sense of being denied something that should rightfully be theirs. Many participants had felt disempowered by professionals, donors, and parents who had dismissed or devalued their opinions or feelings, and failed to support them in their quest for genetic information. Later disclosure and closed communication were also experienced as disempowering and isolating; secrecy placed strain on relationships, both within the nuclear family and extended family, and in some cases this secrecy caused great damage. Participants' views on assisted reproduction reflect a wish for professionals, donors, and recipients of donor gametes to recognise the rights of donor offspring to knowledge of their genetic origins.

## Chapter Five: Discussion

I will begin this discussion by highlighting some key findings of the present study: love matters most but genes are important too; information sharing is pivotal; and donor conception can broaden one's family construct. This will be followed by some discussion of the needs of the family built through donor conception in the context of existing models of family, and therapeutic implications. Next, I will address some concerns that families may have around disclosure and open communication in relation to the following findings of this study: a donor is not a dad; and donor conception as a positively distinctive feature of the self and family construct. I will then review the implications of this study before discussing its limitations and future directions.

### Conceptualising Family - Love Matters Most but Genes are Important Too

Most participants in this study viewed their families positively. One key finding is that participants unanimously expressed that love, shared experiences, and relationships are the defining features of a family, and that the connections that arise out of love and shared experiences do mean more than connections that are based solely on shared genes. Although family experiences varied, and some participants reported greater levels of conflict than others, invariably participants spoke lovingly of their families and family members, regardless of whether they shared a genetic connection. Some participants reflected on the fact that the members of the family that they feel especially close to are those with whom they share no genetic link at all.

This study also found that genes do matter for many donor-conceived people. Consistent with recent studies (e.g. Blyth, 2012; Blyth et al, 2012; Jadvá et al, 2009; Persaud et al, 2017) which have found that donor-conceived people value both genetic

and non-genetic connectedness, this study found that many participants do value the biological link between themselves and their donor, with more than half of participants stating it was an important link. Most participants, however, were clear that the link between them and their donor was not a familial one; most stated that they did not consider him family.

While some participants reported that they were interested in the opportunity to establish ongoing contact or a relationship with the donor, more were interested in other offspring from the same donor. Recent research has found that forming relationships with donor siblings can be a positive and enriching experience and is an experience that can have a positive outcome for identity development (Blyth, 2012; Persaud et al, 2017). Participants in this study, who had met with their donor or donor siblings, reported positive or neutral experiences of the meetings although, as was noted by Persaud and colleagues (2017), such meetings could also be complex, particularly with donor siblings, as such meetings may come with an expectation that there will be an instant bond or connection upon meeting, or that a social relationship will ensue. Nonetheless, several participants expressed an interest in their donor siblings and some felt frustrated that they were denied access to information about them.

Of those participants who said they did include their donor in their family construct, most did so in a conceptual sense, such as those who would never be able to meet him due to the timeframe in which he donated and the policies of secrecy prevalent at that time, but who nonetheless highly value the genetic connection and consider his absence a significant gap in their lives. One considered her donor family in a practical sense as she had established an ongoing relationship with him. Others were in the process of getting to know him.

Thus, when considering the family built through donor-conception, a layered view of connectedness is necessary, one that recognises that socioemotional connections are paramount for most but that for some genetic connections matter too, certainly on a different level than the former, yet still enough to conceptualise people with whom they share these links as family. For these people, Naomi Cahn's (2013) model of kinship whereby she divides the family into two forms - the immediate or primary family and the donor-conceived family community or donor kin network- may be a helpful representation of their circumstances

Where and how one's donor and/or donor siblings are positioned within their family constructs will depend largely on the value and meaning each individual ascribes to the genetic link, and this is something that can change overtime. What is important for donors and recipients to realise is that donor offspring may attach different value and meaning to the genetic link than the donors or recipients do, thus while the donor and/or recipients may be willing to sever any link between donor and donor offspring, donor offspring themselves may resent such a choice being made on their behalf.

For those who wish to establish connections and relationships with their donor or other donor offspring, and who are given the opportunity to do so, questions may arise around negotiating relationships, such as how much contact to have, in what form (e.g. face to face or just e-mail), and how to best protect the feelings of those with whom they have existing relationships, particularly parents and siblings. For some participants in this study this has meant sheltering their parents from the knowledge that they have made contact with or met their donor, in order to protect their feelings or to avoid tension and conflict.

## Information Sharing is Pivotal

A second key finding of this study is that all participants were in favour of information sharing. Participants expressed a strong preference for early disclosure, open communication, and donor identifiability, all of which were experienced as empowering. Parents that practiced early disclosure and open communication were praised by their offspring for their choices, and these participants emphasised that early disclosure and open communication were positive aspects of their family upbringing.

Participants' access to genetic information varied depending on the era in which they were born. Just as Blyth and colleague's (2012) meta-analysis of the literature found that most donor offspring had a strong interest in their genetic information, and that desires for social, familial, and medical history were routinely expressed across the studies, all twenty-one participants in this study expressed that some information about their donor was, or would be, helpful in gaining a fuller picture of themselves.

Gaining information about such things as one's medical background and ancestral heritage, and discovering similarities between one's self and donor/donor siblings, were empowering and affirming experiences for many participants who had been able to contact their donors. Those participants who had met with their donor described relief at having answers to their questions about such things as where certain physical or behavioural traits had "come from" and spoke of "filling in the missing pieces" and "connecting the dots". Consistent with Persaud and colleagues (2017) and Blyth (2012), participants in this study who had met with donor siblings reported enjoying seeing similarities between themselves and their donor siblings. This seemed to be

especially the case for those who felt quite different in appearance to their family members.

Demystifying the donor was found to run deeper than a quest for knowledge about the donor in relation to the self. Some participants reported that the mystery surrounding their donor regarding his identity, location, and what, if anything, the genetic connection would mean for them should they meet, can be very encompassing and consuming, and can impact on their wellbeing and their relationships in multiple ways. Some described intense discomfort around the fact that “he could be anyone”.

Many participants described building up narratives around who their donor might be and what kind of relationship they might have if they were to meet. One participant described how, when attempting to locate her donor via a documentary, she created a “life narrative” in her head around each potential donor, as she waited for DNA results to come in. Another described how when working at a café she would inwardly question if any of the men she was serving were her donor. Others wondered if he were alive or dead; if he was a millionaire or if he was in prison. One participant described it as a lot of guesswork, several expressed that the imagining and guessing is (or was) for them the most frustrating part of being donor-conceived. This is similar to the “recourse to fantasy” observed by Turner and Coyle (2000) in many of the accounts of their donor-conceived participants. Turner and Coyle suggest that this recourse to fantasy may be a coping mechanism for “blocking the threat to their identity by providing a form of temporary escape through wishful thinking or speculation” (p 2046).

Participants in the current study, who met or made contact with their donor, described a sense of relief and calm that came with the knowledge of his identity, and of no

longer having to wonder if he was that passer-by on the street or the man they served in the café. Some explained how that contact helped them to define, clarify, or even sever, the link between themselves and their donor; shifted their donor from an abstract concept to a concrete person; and freed their mind from the constant wondering. Thus, what might seem like a small thing to some - a photo, a letter, a phone call, or a single meeting – can be a very big and important thing to donor offspring.

Those participants who had sought information on their donors and had been blocked from receiving it, experienced a deep sense of grief and loss that is difficult for those who are not donor-conceived to understand. Searching for information on one's own genetic history and being obstructed at every turn was experienced as disempowering by those who have a deep desire for this information. Again, this is consistent with findings by Turner and Coyle (2000) who noted that a common theme in their study was the experience of "perceived and temporary loss of positive agency or self-efficacy in the face of obstruction" (p 2407). Participants in the current study who had no support in the search for their genetic information described a sense of isolation and of being misunderstood by others. Likewise, participants in Turner and Coyle's study also lamented the lack of support and spoke of frustration at the refusal of others, including professionals, to acknowledge their need.

#### Donor Conception Can Broaden One's Family Construct

A third key finding of this study was that being donor-conceived can broaden one's construct of family.

Family is continuously defined and re-defined across cultures and generations. The bionormative ideal (Witt, 2009) still pervades Western society, but this is now just one

type of family among many. Legal definitions of the family, while more inclusive of different family structures than they once were (e.g. Henaghan & Atkin, 2013) are still restrictive and vigilant for obvious reasons. It would not be ideal for anyone to be able to consent to take custody of a child, turn off a person's life support, or claim an inheritance based on a tenuous connection, genetic or otherwise, therefore any changes to definitions must be given careful consideration in light of socio-legal implications. Individual and social constructs, however, can differ immensely from legal constructs, and here there is more room for movement, and for acceptance of all kinds of family types. Therefore, extended family situations, such as the donor-conceived family community, described by Cahn (2013), can be recognised for the significance they bring to those who experience them.

This study found that being donor-conceived does not just broaden one's family construct in relation to their own family, but also how they conceptualise family in general. Many participants stated that being donor-conceived has given them insight and empathy towards the different kinds of family structures that exist. Just as Appleby and Karnein (2014) maintain that families built through donor conception are cause for celebration due to the doors they open for diverse family types and structures, many of the participants in this study expressed that because of their donor-conception they were open to different ideas of what constitutes a family, and that they were grateful for that trait. Several spoke of how they enjoy seeing the growing diversity in society today. In the words of one participant: "there's all kinds of crazy things happening and everybody's family's got some kind of dysfunction or you know ... what is normal? So, everybody's got things that are going on. So, at the end of the day it's probably just another thing that someone's like "oh yeah, okay, that's just different for your family, my family's got this going on, you know?" While this participant's use of the words



crazy and dysfunctional reflect deeply embedded ideas of 'normal', and other participants were observed to use similar terminology throughout their interviews, the premise of this quotation represents the general view of participants - that the growth of "modern families" is a positive thing as it means that people are no longer so pigeon-holed and expected to be the same, or to live up to traditional assumptions and outdated ideas of what is and isn't a healthy family.

All twenty-one participants shared the sentiment that family is what you make it and does not have to follow a traditional nuclear structure to constitute a happy, functioning family, many citing their own family as an example of a positive family experience. Others, whose family situations were more complex or troubled, viewed the core issue in their family as secrecy or silence around the topic of donor conception, not the donor conception itself, a matter that will be discussed in more detail below. This finding is consistent with studies such as that of Brown-Smith (1998), which identified a number of negative consequences of secrecy for the family.

#### Understanding the Needs of the Family Built through Donor Conception via Existing Models

Existing models of family that allow for flexibility in structure, such as family-strength models and family-systems models, are as applicable to families built through donor conception as those built through natural conception.

#### Family Strengths

Communication, cohesion, and flexibility, are strengthening factors in all families, but they are factors that take on an extra element or layer specific to donor-conceived families in relation to how the family approaches the (covert or overt) presence of the donor.

Participants who experienced open communication, early disclosure, inclusion of extended family, and a positive attitude towards difference, perceived that being donor-conceived had become a strengthening factor for their family by increasing feelings of connectedness and cohesion. Most participants who experienced later disclosure reported initial experiences of shock, upset, disruption to identity, genetic discontinuity, and betrayal. This is consistent with other research such as Blyth (2012) and Turner and Coyle (2000). Meta-analyses by Blyth and colleagues (2012) and van den Akker (2006) reveal that many such studies have identified numerous negative consequences associated with late disclosure. As Blyth and Colleagues state: “in most studies, participants who were told later in life or who discovered their donor origins in other ways than through planned parental disclosure, often reported the information coming as an unwelcome shock that challenged a previously-held sense of personal identity, resulting in a sense of genetic discontinuity, and difficulty in assimilating their new identity as being donor-conceived” (p782).

It is important to note that in the current study, the majority of those who experienced later disclosure, described how existing cohesion within their families allowed them to individually process the news in their own way and their own time, and then to come back together as a family, with most participants describing relationships within their family as either much the same or better than before. Thus, cohesion, flexibility, and communication allowed participants and their families to come back together and work through issues that had arisen from the “big reveal”. Some participants stated that their family was still in a state of transition, and some spoke of the lead that the donor-conceived person themselves had to take in facilitating communication. Others chose to limit conversation about the donor conception or donor to protect their parents’ feelings on the matter.

This knowledge is important because parents of older donor-conceived children, adolescents, or adults, who are yet to be informed of their origins, may question whether it is too late to disclose, and these results may help provide reassurance that any damage or disruption to family relationships caused by late disclosure is not necessarily irreparable. Likewise, while many participants expressed regret that they hadn't known of their donor conception sooner, no participants regretted learning of their donor conception, suggesting later disclosure is preferable to no disclosure.

### Family Systems

The choice to withhold information, and the impact of doing so on the family, can be viewed from a family systems lens, such as the biopsychosocial lens discussed by Daniels (2006). This model recognises the interplay of biological, psychosocial and social factors on the family unit.

In the case of donor conception, the meanings that society has attached to infertility and the practice of donor conception has led medical professionals to advocate a culture of secrecy (Daniels & Taylor, 1993; Haimes, 1993; Haimes, 1988; Rao, 1996; Richards 2015;). Such professional advice serves to reinforce the sense of shame and stigma that many men experience in relation to being infertile and having to access donor sperm (Daniels, 2004; Fisher & Hammarberg, 2012; Readings et al, 2011). Attempts to present the DI family as a traditional family of mum, dad, and their biological children may then help embed the traditional assumption that "blood is thicker than water" (Daniels, 2006) more deeply into social constructs of family, rather than openly challenging such assumptions so that those families who sit outside traditional assumptions and standard definitions of family can feel accepted. Living with secrecy, shame, and the fear of stigma, then places strain and tension on the

family unit (Brown-Smith, 1998; Daniels, 2004; van den Akker, 2006), while later disclosure, weak communication, and secrecy can lead donor offspring to feel as if the nature of their conception is something to be ashamed of.

Defining a family secret as “any information that directly affects or concerns one but is either withheld or differentially shared between or among family members (p 23)”, Brown-Smith explains that family secrets create boundaries or barriers between those who are aware and those who are unaware, as the ‘awares’ are forced to derive and implement strategies for withholding the information from the ‘unawares’. Some participants in this study were put in a position of withholding information about their genetic origins from their extended family on their father’s side. This was because of their parents’ concerns that sharing this information with others might bring about negative consequences, such as a lack of acceptance of the donor-conceived person as family. These participants, who were asked specifically not to discuss their donor conception with extended family members, experienced strained relationships with extended family members, resentment towards those who asked them to keep the secret, and/or a sense of guilt around being one of the ‘awares’. For others, learning of their donor conception later in life and discovering that they were one of the ‘unawares’ while other family members, who were less directly affected by the fact of the donor-conception, had been made into ‘awares’ added to their sense of betrayal, confusion, and/or anger around the situation.

A systems approach to therapy for families built through donor conception means that just as infertility treatment should focus on the couple not the infertile individual alone, therapy around DI should explore implications for the whole family, including the implications of concealing the truth from any future offspring. Up until recently such therapy has found to be lacking even in open-policy societies such as New Zealand.

For instance, Hargreaves and Daniels (2007) found that parents of children conceived through donor gametes, who had not yet disclosed, were more likely to have received no formal counselling in the fertility clinic about information sharing, including child development models or scripts for telling. Additionally, these families were more likely to be secretive with others, have difficulties communicating with spouses or other close family members and hold conflicting views about secrecy and disclosure. This has changed however, as New Zealand legislation now supports a systems model of donor conception, recognising for example, that holistic counselling is an extremely important part of family building through donor conception. Counselling on such things as the importance of telling offspring about the nature of their conception is mandatory for fertility providers throughout New Zealand (Human Assisted Reproductive Technology Act, 2004), and as Goedeke and Payne (2010) explain in their qualitative study of New Zealand fertility counselling in embryo donation, “Counsellors are encouraged to have an holistic, psychosocial approach to their practice, and to consider issues beyond the individual client's experiences, such as how the infertility and its treatment affects the couple's networks and relationships, the implications for the child born as a result of treatment and for his or her siblings and wider family and also the impact on a societal level.” However, recognition of the important role that holistic counselling has for families built through gamete donation is by no means universal, as one meta-analysis of twenty international studies reporting on counselling and donor conception found: “Twelve studies stated that counselling was offered. The reported studies reflected no consensus about when and how counselling in gamete donation should be offered and no theoretical background of the disclosure/ secrecy issue. About 50% of the parents expressed the need for guidance and support of a counsellor. Special concerns were the disclosure issue and the future contact with the donor. Parents did

not receive the guidance and support they needed in the disclosure process after treatment.” (Visser et al. 2012, p159)

The scaffolding of information through such means as age-appropriate explanations, books, letters, creating an open family atmosphere encouraging conversation around the topic, and demonstrating a positive attitude towards the donor and his role in the conception, were all methods that participants in this study who experienced early disclosure stated were helpful in forming an understanding of their family’s origins, and subsequently in forming their family constructs. Arming parents with this type of information may help them to be more confident about disclosing their family’s origins to their children. Mandatory counselling from a holistic, biopsychosocial approach, is clearly one way of getting such important information to parents and future parents of donor offspring.

A Donor is not a Dad

While some parents worry that disclosure will harm the relationship between father and child (Daniels, 2004), this research highlighted that awareness of the sperm donor need not be a threat to the father-child relationship at all. As with Blythe’s (2012) study, almost all participants in this study reported that they made a clear distinction between “dad” and “donor”. Participants were also very sensitive of their dad’s feelings when considering such things as whether to seek information or contact their donor, or whether to meet with their donor or donor-siblings. While some participants did view the donor and/or offspring from the same donor as family, they were quick to point out that this was “on a different level” to the family with whom they shared love, relationships, and shared experiences.

## Donor Conception as a Positively Distinctive Feature of the Self and Family Construct

Some parents worry that disclosure may lead to the child being marginalised for being different (Hargreaves & Daniels, 2007; Readings et al, 2011). Results from this study revealed two thirds of participants viewed donor conception as a positively distinctive feature of their identities, not necessarily a defining feature of their family, but nevertheless something special or unique about them and their families. These participants reflected on such things as the fact that it gave them something interesting to talk about with their peers, that it made existing relationships more special because, for example, they knew their parents must have really wanted them, or it made them appreciate the closeness between themselves and their father even more. Others, who had been able to contact their donor and/or donor siblings, said that they liked the way it had extended their family. Most participants reported that they had only ever had positive reactions when sharing the nature of their conception with others, although some were more reticent to speak of it than others. A third of participants were more ambivalent or neutral about the meaning of donor conception in their lives, but generally did not view it as a negative thing, though some aspects of it did not sit comfortably with them.

Most of those participants who had grown up with the knowledge that they were donor-conceived had learnt to view donor conception as an interesting shared chapter in their family story, perceiving it as either something a bit different about their family unit but not in a significant way, or something to be celebrated and grateful for. Some participants took great pride in their family and perceived the donor as a giver of a great gift, (but not necessarily a member of their family or family construct). Likewise, when Daniels (2004) interviewed parents on their experience of disclosing their young children's origins, these parents described positive and loving reactions from their

children, such as thanking their parents for having them, and wanting to buy their donor a gift in return.

Others, whose families had taken a more neutral approach of disclosing early but rarely broaching the topic, appeared more neutral on the subject themselves; they explained they were generally comfortable with it but felt no need to engage with it and did not consider it a particularly interesting part of their identity. This is in line with research by Persaud and colleagues (2017) who, exploring the identities of donor-conceived adolescents that had grown up with the knowledge they were donor-conceived, found that, “most described feeling that their donor conception was a part of who they were and that fundamentally they did not differ from other families” (p18).

All but one of the participants who had experienced later disclosure, reported an initial period of shock and disruption to their identity; however, after taking the time to process their thoughts they too came to integrate the donor conception into their sense of self in either a positive, neutral or ambivalent way. This is consistent with Turner and Coyle’s finding that “although disclosure brought almost universal shock and a reappraisal of identity, it also sometimes led to positive adjustment (p 2044)”

This finding demonstrates that parents need not view difference as something that will have negative implications for their family, but rather as something that if not treated as hidden or shameful, can be in fact be a positive feature of their children’s self and family constructs.

#### Implications

This research sought to identify how donor-conceived people experience and perceive family and to understand how their experiences shape their family constructs. Donor-conceived people are the experts on what it is like to grow up in a family built through



donor conception. As such their voices are an essential part of any dialogue around donor conception. Yet, for many years, their voices have been absent because of the silence and secrecy that has surrounded the process, and the fact that for a long time most donor-conceived people did not know of their origins (see Adair & Purdy, 1996; Cahn, 2013; Daniels & Taylor 1993; Daniels, 2004; Freeman et al, 2014; Haines, 1988; Haines 1993; Kramer, 2016; Rao, 1996; Readings et al, 2011; Richards 2014). Because of this gap in our knowledge, there is international interest in research exploring the experiences of donor-conceived persons, particularly those who have grown up in societies whose policies encourage openness around the matter of donor conception. Furthermore, to the best of this author's knowledge this is the first study of this particular age group (19-46), further enhancing its contribution to the current body of knowledge.

The findings of this study therefore have much to contribute to our knowledge of donor conception and the family, and may be an important part of shifting parental and professional attitudes on donor conception, improving our understanding of such things as: what being donor-conceived means to those who are; the impact of secrecy and disclosure on the family; and what it means for a donor-conceived person to grow up without any knowledge of, or involvement from the third party. Research on families built through alternative methods of family making may also help to broaden societal understanding of what makes a family, thereby facilitating greater acceptance of changing family forms. This and future research may also have an influence on legislation, as many countries around the world continue to debate the issue of donor anonymity.

The results of this study have important implications for the donor conception community. The voices of the donor-conceived participants in this study add weight to

the mounting evidence that honesty is the best policy – the donor-conceived should know their family history preferably from the time they are very young, and information on the donor should be available to any resulting offspring, as it currently is in New Zealand.

#### Limitations and Future Directions

One important methodological limitation of this study is that some calls were Skype visual calls, while others took place via Skype audio or telephone. Clearly, the dynamic is different in a video call to a phone call or audio call because interviewer and interviewee are aware of the other's body language and nuances on both sides can be missed without non-verbal cues. Video calls allow for a more open and relaxed interview between interviewer and interviewee and can increase rapport. In fact, the briefest interviews in this study were phone interviews; most phone/audio calls were shorter than the mean interview time of thirty-four minutes. This suggests that video calls or face to face interviews are preferable for qualitative research if the researcher is hoping to obtain information-rich data. However, in this case, the geographical spread of participants, combined with the fact that some participants do not have or use Skype technology, meant that the choice was necessary. The interviewer was satisfied that all interviews were informative and added much to the final analysis, so, under these circumstances, it was not felt that this limitation impacted the outcome of the research in a substantial way.

The sampling method for this study may also be considered a limitation. The fact that participants in this study or their parents were previously known to the second supervisor due to his involvement in the donor conception community means that these participants were selected from among those who are or have been overtly

involved the DC community in some way. It could be expected that such a sample may identify more with their donor origins or may have more interest in locating their donor than those who are not overtly a part of the donor conception community.

However, it is a fact that any study on donor conception will be limited by those it can reach. The secrecy that has surrounded this topic for so many years, and the fact that there are still many who do not know they are donor-conceived, instantly precludes many donor-conceived people from speaking about their experiences as a donor-conceived person. Another obvious limitation of this research is that it took place as part of a Masters dissertation. Therefore, constraints on time and word count, limited both the time that could be spent locating potential participants, and the number of participants that could be included in this study. Thus, the convenience sampling method worked well for the nature and purpose of this research.

Another possible limitation of this study is that all but one participant came from dual-parent heterosexual-led families, and therefore the experiences and thoughts expressed by these participants may differ from those donor-conceived people who come from different types of families such as single parent families or lesbian-led families. However, prior to 1996 in New Zealand, clinics could choose to accept only heterosexual married couples, thus in this demographic this is to be expected. Research exploring adolescent or children's views is therefore more likely to represent a wider range of family types, (e.g. Jadvá et al, 2009; 2010., Persaud et al, 2017 Slutsky et al, 2016) and in the future as donor offspring from single parent families and lesbian led families grow into adulthood, research on donor-conceived adults will likely be inclusive of different family types also.

Most participants were university educated and/or professionals in some capacity, and NZ European, therefore are not necessarily representative of all donor-conceived New Zealanders. Maori voices were particularly lacking in this New Zealand study (one participant identified as Maori). Future research could seek to amend this gap by consulting local iwi to locate Maori who may have accessed, or have considered accessing donor sperm; Maori who may have been conceived through donor sperm; and for Maori perspectives on donor conception in general, including those who may have discounted it as an option. Such research would be of relevance to those Maori who are currently on the waiting list for sperm but have long waits due to a shortage of Maori donors, and to potential Maori donors themselves. For instance, New Zealand Fertility Associates reported in May 2016 that they are currently desperate for Maori sperm donors, and at that time had none on their books. As Dr Olivia Stewart from Fertility Associates explained, “We see it as very important to have Māori donors in order to be able to continue their whakapapa and genealogy origins throughout their whānau and for their future whānau” (Treacher, 2016, para 3). Likewise, in an increasingly global and multicultural society it would be helpful to have views from other ethnic groups represented.

Nonetheless, although participants in this study could be said to represent a homogenous sample of donor offspring and therefore may impact upon the study’s generalisability or transferability, it is encouraging that the views and experiences of the participants in this study showed the type of variability that one might expect to see in a general population, and that the results of this study align with recent research (e.g. Blyth et al, 2012; Blyth, 2012; Jadvā et al, 2009; Persaud et al, 2017; Slutsky et al, 2016; Turner & Coyle, 2000; van den Akker, 2006). Furthermore, the almost-even divide between those participants who were disclosed to early and those who were

not, made this sample particularly interesting for comparisons such as the impact of early and late disclosure and the relationship between disclosure and communication patterns.

Future research could broaden the focus on family to include parents and/or extended family in the discussion; either individually or in focus groups. Future researchers could also advertise more widely for donor-conceived participants, reaching out into the public to perhaps include people who had no previous involvement with the donor conception community. Similar studies in other countries with similar legislation to New Zealand will also extend our understanding.

## Conclusion

The results of this study suggest that families built through donor conception are like any other family in that the quality of relationships and communications between family members are experiences that shape one's construct of self and family. Nevertheless, the family built through donor conception does differ from other families, if only in the fact that a third party was involved in the creation of these families in a very significant way. Therefore, it is important to gain understanding of what it means for donor offspring to grow up without the involvement of that third party.

Loving relationships, shared experiences, and open communication were highly valued by the participants in this study. The absence of the third party in the lives of these participants was not experienced as problematic by most, though lack of information sharing and open communication was. Problems arose within families of participants who tried to keep the information secret and within families where conversation about the donor or donor conception was actively discouraged by parents. Problems also arose for those participants who were denied information

about their donors due to policies enforcing or supporting donor anonymity when they were conceived and this is an ongoing issue for some participants.

Thus, genetic connectedness while not viewed as a necessary component of family by any of the participants, was still considered a very important component of one's identity by many of the participants. Most participants experienced their donor conception as a positively distinctive feature of their identity. Awareness of the donor from a young age was in no way perceived as a threat to participant's relationships with either of their parents, siblings or extended family; though later disclosure did lead to a temporary sense of discontinuity for some participants as they questioned what the lack of genetic connectedness meant for them.

Ultimately, all these participants concluded that love, not blood, makes a family, and many expressed appreciation for the fact that their construct of family is broader than it may have been, had they not been donor-conceived. For those who do consider their donor and/or donor siblings family, this appears to add to their experience and construct of family rather than undoing it in any way. These results should be encouraging for those wishing to access assisted reproduction via third party gametes in order to build their family, and for those who already have.

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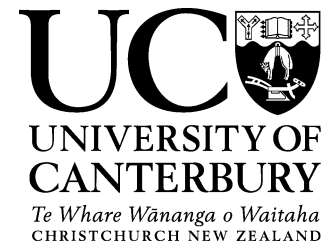
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## Appendix 1: Information and Consent Form



Title:

**Donor conception and its impact on family constructs – the views and experiences of donor-conceived persons**

Information Sheet for research participants

Hello, my name is Angela Mostyn and I am a Masters of Arts student in Psychology, studying at the University of Canterbury. The purpose of this research is to interview donor-conceived persons about their experiences of family, and look at what family has come to mean to each of these interviewees; that is, to explore their individual family constructs.

If you choose to take part in this study, your involvement in this project will be to take place in an interview that will take one-two hours, over Skype or telephone. You will be asked to share some of your experiences and perceptions of family.

In the course of this interview there is the risk of issues arising that could cause distress or discomfort, due to the sensitive nature of the topics discussed. Ken Daniels will be available to discuss any such issues with you post-interview and can also arrange for you to speak to someone other than himself, at no cost to you.

I will provide you with a copy of the written transcript of our interview and you will have the opportunity to make changes to this if you would like to do so.

Participation is voluntary and you have the right to withdraw at any stage without penalty. You may ask for your raw data to be returned to you or destroyed at any point. If you withdraw, I will remove information relating to you. However, once

analysis of raw data starts it will become increasingly difficult to remove the influence of your data on the results.

I will provide you with a copy of the written transcript of our interview and you will have the opportunity to make changes to this if you would like to do so.

The results of the project may be published, but you may be assured of the confidentiality of data gathered in this investigation: your identity will not be made public without your prior consent. To ensure anonymity and confidentiality, only Ken Daniels and I will have access to raw data (which I will transcribe), and your identity will be coded by Ken before data analysis takes place. Recorded interviews will be password protected by me on my own personal computer, and any information put on a USB stick for transportation or transcription purposes will be kept in a locked filing cabinet. After transcription has taken place, your raw data will be kept solely by Ken, in a locked filing cabinet and will be destroyed after five years as is the standard procedure for material collected as part of the Masters Thesis process. A thesis is a public document and will be available through the UC Library.

Please indicate on the consent form if you would like to receive a copy of the summary of results of the project.

The project is being carried out [as a requirement for an MA] by Angela Mostyn, under the supervision of Ken Daniels who can be contacted at [ken.daniels@canterbury.ac.nz](mailto:ken.daniels@canterbury.ac.nz), and Neville Blampied who can be contacted at [neville.blampied@canterbury.ac.nz](mailto:neville.blampied@canterbury.ac.nz). They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)).

**If you agree to participate in the study, you are asked to please complete the following section and return it to Ken Daniels or Angela Mostyn**

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## **Donor conception and its impact on family constructs – the views and experiences of donor-conceived persons**

### **Consent Form**

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
  
- ☐ I understand what is required of me if I agree to take part in the research.
  
- ☐ I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
  
- ☐ I understand that any information or opinions I provide will be kept confidential to the researcher and supervisor and that any published or reported results will not identify the participants
- ☐ I understand that a thesis is a public document and will be available through the UC Library
  
- ☐ I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.
  
- ☐ I understand the risks associated with taking part and how they will be managed.
  
- ☐ I understand that I am able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

## Appendix 2: Donor conception and its impact on family constructs. Interview Schedule.

### **Preparation**

1. Go over the Information Sheet. In particular
  - You will have received a copy of the information sheet and know what the study is about (address any questions with regards to this)
  - You understand that your participation is voluntary and you are entitled to withdraw from the study at any time but after the data analysis has started (give approximate date), it becomes increasingly difficult to remove your information.
  - Your identity is confidential and any quotations will be coded
  - If at any point during the interview you feel the need to pause or take a break for any reason, that's perfectly okay, just let me know. Feel free to pass on any questions you don't want to answer.

### **Demographic questions**

What is your age?

What is your highest level of education?

What is your occupation?

Your current location?

### **Background questions regarding the family**

Who makes up your family?

- How would you describe your family?
- Can you describe relationships in your family?

### **Questions related to donor conception**

- Can you tell me about when you first found out you were donor-conceived?
- (How old were you? – ask if not answered in above question)
- Do you recall how you reacted to this news?
- What impact has learning you were donor-conceived had on you?
- What does being donor-conceived mean to you now?
- Was your donor conception a significant factor for you or your parents in your family?
- Did you see your family as being different from other families? If yes, in what ways?
- (If yes) In what ways - ask if not answered in above question

### **Questions related to present family relationships**

- Can you describe your current relationship with your parent/s?

- Does your donor conception impact on those/this relationship/s?
- How does your family approach the non-biological link to your father?
- What are your reactions to that (or what is that like for you?) If not already covered in last answer.
- If you have siblings in your family can you describe your relationship with them?
- How did they become members of your family? (if not already covered)
- Could you tell me about your extended family and in particular do they know of your donor conception, and if so any thoughts or reactions from them regarding your donor conception?

#### **Questions about the donor**

- What does the biological link between you and your donor mean to you?
- Have you made contact with your donor or have you met?
- (if yes to meeting): Could you tell me a bit about what the experience of meeting your donor was like for you? (if no) Do you want to meet him or have you attempted to meet him? Can you tell me about your thoughts regarding this?
- If you haven't met him or made contact with your donor do you have any information about him? If yes, what does having that information mean for you?
- What if any, have been/would have been/or would be the benefits, of having contact with your donor? (if hasn't already been covered in previous answers)
- Do you see your donor as part of your family? (or if this has already been answered in the above question then clarify i.e. so you do/don't see the donor as part of your family)
- Do you know of any others who have the same donor as you?
- If so, have you made or attempted to make contact with any of them? If yes, what was that like? If no, would you like to?
- Do you view them as part of your family? (If no,) what do you consider your relationship to be?
- (If participant has met donor-siblings) How did your parents react to this/these meetings?
- Have they met them also? If yes, can you describe this experience?
- (if the participant has children) Has having a child/children impacted on your view of being donor conceived and of what family means?
- Have your views about your donor changed over time? If yes, what are some examples of this?
- In terms of language, do you sometimes struggle to find the right words to describe your family relationships? If yes, could you give me some examples of where this has been an issue for you?
- Do you have any additional comments on how being donor-conceived has shaped your concept of family, what makes a family and/or how a family should be built?

#### **Questions related to social and professional attitudes**

- Do you have any thoughts about the way in which biological connection in families is viewed in NZ society?
- Now as an adult, how do people generally react if you choose to tell them about your donor conception?
- Have you encountered negative attitudes towards you or your family because of your donor conception?

- Have you ever attended any counselling sessions or support groups in relation to donor conception?
- If yes, can you tell me a bit about what this experience was like for you?
- If no, do you think this is something you would have found helpful?

#### Final Questions

\*Looking back on your life as a donor-conceived person are there things that you wish or have wished, might what were these?

\* Is there anything that hasn't been raised in this interview that you feel should have been addressed, anything that you feel is important that we haven't touched upon?

\*If there are any additional things that occur to me later, down the track that I feel could have been important would you be willing for me to get back in contact with you?

Thank you so much for your time.

