

A Study on the Effects of Donor Conception, Secrecy and Anonymity,

According to Donor-Conceived Adults

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2016

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I, Caitlin Macmillan, confirm that this work has not been submitted for a higher degree to any other university or institution. Cited within the thesis are all sources of information used and the extent to which the work of others has been utilised. I confirm that Ethics Approval was obtained from Human Research Ethics Committee (5201600165)

A handwritten signature in black ink, appearing to read 'Caitlin Macmillan', followed by a period.

Acknowledgements

First I wish to express my deepest gratitude to all the donor-conceived people who contributed to this research and shared their personal stories. Without their willingness to participate this project would not have been possible. Thank you for being so forthcoming. I would also like to thank all the organisations, groups and individuals who assisted in distributing information among the donor-conceived community.

Finally I must thank my family and friends who supported me through this project. They helped me remain focused and motivated. I would like to notably thank Dr Melissa Johnstone, Associate Professor Mark Stokes, and Tracy White. They helped me keep going when I almost didn't. It is because of their consistent support that this thesis is available to read.

I dedicate this project to my sisters.

Abstract

Donor conception has increasingly become an accepted method to conceive a child. Despite gaining popularity, little attention has been given to the long-term psychosocial implications of the clandestine practice. Previous research has relied on parent reports, young samples, or has other methodological limitations that restrict the generalisability of findings.

This study established the effects of donor conception, secrecy and anonymity by surveying 72 donor-conceived adults (9 male, 53 female, 9 unspecified) online. The study first investigated the demographic characteristics of the sample, circumstances of disclosure, and relationships with parents. This study then investigated what motivated donor-conceived people to seek information about, and contact with, their donor. Finally, quality of life, identity, genealogical bewilderment, feelings towards donor conception, and feelings towards information and disclosure, were investigated, including how demographic characteristics, circumstances around disclosure, and relationships impacted each using a series of logistic regressions.

The majority of donor-conceived people had sought information about their donor, while a smaller group had sought contact. The most common motivation for doing so was to obtain an accurate medical history. Meanwhile, having a positive relationship with the biological parent was associated with less genealogical bewilderment and positive feelings towards donor conception, while coming from a non-co-parented household was associated with feeling more positively towards disclosure and access to information.

The study informs the direction of future research, which can extend the existing findings and increase reliability and generalisability, particularly among

males, and persons born from egg and embryo donation. In addition, longitudinal research with donor-conceived people over the course of their lifespan will contribute to understanding the effects at various stages of development.

A Study on the Effects of Donor Conception, Secrecy and Anonymity,
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Overview

While it is the social norm to want to have children (Newport & Wilke, 2013; Nunez, 2015), some people require assistance. Over the past forty years donor conception has become an increasingly accepted way to assist people to conceive a child who are unable to do so naturally (Allan, 2012; Russell, 2015). Despite its popularity, secrecy has surrounded donor conception, and very little research has been conducted to investigate the long-term psychosocial implications the practice, and how nature of disclosure affects donor-conceived people. In particular, research on donor-conceived adults is limited. Research that is available largely focuses on parent reports and younger samples, or has other methodological limitations that restrict the generalisability of the findings.

The current study will address these research gaps by surveying donor-conceived adults living in Australia. Firstly, the study reviews the demographic characteristics of a sample of donor-conceived adults, as well as the circumstances in which they found out about their conception, and the relationship with their biological parent, and non-biological where applicable. Secondly, the study investigates the motivations of donor-conceived people to seek information, and/or contact with their donors. Finally, the research aims to investigate donor-conceived adults' quality of life (QoL), sense of identity, genealogical bewilderment, as well as feelings towards donor conception practices, and feelings towards information and disclosure according to their demographics and personal experiences.

Background

In today's society, many people have been raised to believe that without children they could not be complete, or thought to have succeeded in life (Nunez, 2015). Despite increasing environmental and financial challenges to parenting in the modern day, the narrative surrounding parenthood has continued to intensify (Wood, 2016). Statistics show that the desire to become a parent has remained stable for over a decade, with a mere five per cent of people in a national survey expressing that they do not want children (Newport & Wilke, 2013). This desire appears to present at an early age (Jones, 2005; Lamb, 2013; Virtala, Kunttu, Huttunen & Virjo, 2006).

However, the desire to have children is not correlated with the ability to conceive. While more than nine in 10 people express the desire to have a child (Van Blen & Trimbos-Kemper, 1995), one in four couples in the developed world are affected by infertility (World Health Organization, 2016). For many other people the desire to have children is complicated by the presence of disease, by wanting children outside of a heterosexual relationship, or menopause (Blyth & Frith, 2009). In such circumstances, donor conception, which involves non-sexually transferring donated egg and/or sperm, or embryo to a female with the intent to achieve pregnancy (Mitchell, 2012; Singler & Wells, 1984), may assist people to conceive a child.

History

Families formed using donor conception have been termed "modern families" (para. 1; Barraud, 2015), however this is a misconception as the procedure is not new. After being used to advance animal genetics in the 18th century (Spallanzani & Bonnet 1784), the first successful conception of a human using donated gametes reportedly occurred in 1884 under the illusion of a medical examination (Gregoire & Mayer, 1965). Numerous other reports have also indicated donor conception was already occurring in humans at such time (Mitchell, 2012).

Nevertheless, little open discussion of donor conception was had in its early days, including with the people who underwent treatment themselves. For example, one of the first publically reported recipients of donated gametes was not privy to what had occurred during what she believed was a routine examination (Daniels, 2007). Her husband, who was informed post hoc that his sedated wife had been inseminated with sperm, followed medical advice and did not disclose the conception to his wife or child; keeping the secret to himself. The donor, an observing student, remained anonymous. Such secrecy and anonymity became the foundations of donor conception and continue to shroud the industry today (Allan, 2012).

The reasoning for secrecy and anonymity may historically be explained by the fact that infertility carried with it social stigma (Baron & Pannor, 2008), and the use of donor sperm raised concerns about adultery (Allan, 2016a; Kirkman, 2005) and legal parentage (Nadraus, 2015). Secrecy and anonymity was therefore claimed to protect all parties involved (Marquardt, Glenn & Clark, 2010). However, despite changes in social attitudes over time (Beeson, Jennings & Kramer, 2013), secrecy and anonymity have remained.

While stigma and fear still play a part, it has also been said that as a multi-billion dollar industry has grown in the modern era (Lyons, 2011; Resnick, 2001), secrecy and anonymity may serve to prioritise and protect the profitability of the infertility industry and the professionals within it (Daniels, 2007; Kirkman, 2003; Rowland, 1985). This is highlighted by fertility clinics now floating on the stock market and increasing their value to AU\$1 billion annually (Medew & Baker, 2013), and each live birth costing up to AU\$200,000 (Alexander, 2016). The perception that removing secrecy and anonymity would “Kill Gamete Donation” (Pennings, 2012,

p.1) by for example, reducing the number of people willing to act as donors (Cohen, 2012), appears closely tied to a desire to protect profitability.

Changes in Policy and Practice: Anonymous, Open, and Known Donors

The issues of secrecy and anonymity remain. However, the role of secrecy and anonymity in donor conception has increasingly been questioned (e.g., Parliament of Victoria, Legislative Assembly, February 23, 2016; Rowland, 1985). Further, policies are beginning to favour prospective transparency and openness (Allan, 2016b; Blyth & Frith, 2009; Nordqvist, 2016). However, some recipients continue to remain resistant to this change in approach (as cited in Beeson, Jennings & Kramer, 2011; Inhorn, 2003; 2011), which appears particularly true among recipients of donated eggs (Hass, 2015).

As policies towards transparency develop, three types of donors have evolved: anonymous, open-identity, and direct (Persaud et al., 2016). An anonymous donor refers to a donor whose files are closed whereby neither the recipient nor persons born as a result can access identifying information (Pi, 2009). Clinics have been known to require recipients sign a mock-contract agreeing to this promise of anonymity before they can receive treatment (Rees, 2012). Historically, fertility clinics only supplied gametes from anonymous donors to recipients who agreed to anonymity (Baron & Pannor, 2008). Globally, this is the most common form of donation (Beeson, Jennings & Kramer, 2011; Hertz, Nelson & Kramer, 2013; Sawyer, Blyth, Kramer & Frith, 2013).

In many countries anonymous donations are no longer permitted, contributing to the emergence of the second type of donor, an open-identity donor. For instance, Austria, Australia, Croatia, Ireland, Finland, Norway, the Netherlands, New Zealand, Sweden, Switzerland, the United Kingdom, Uruguay, and Ireland, no longer permit

anonymous donations (Allan, 2016a; Blyth & Frith, 2009). Instead all donors must consent to the release of their identity upon the request of the donor-conceived person once matured. This open form of donation is a relatively new concept. In other locations, a choice remains between open and anonymous donation (Herrmann, 2013), with recipient preference being 50:50 (Sawyer, Blyth, Kramer & Frith, 2013)—although this may be influenced by the cost and wait for anonymous donations being less than open-identity donors in some locations (Dwyer, 2005).

The final option is direct donor—also referred to as ‘known donor’ (Daniels & Douglass, 2008). This typically involves a recipient receiving donated gametes from a specific friend or family member (Weil, Cornet, Sibony, Mandelbaum & Salat-Baroux, 1994) and allows the donor-conceived person to know and form a relationship with the donor from an early age (Bos, 2013). Direct donations are the least common (Beeson et al., 2011; Hertz, Nelson & Kramer, 2013), likely to be in order to avoid interference (Dempsey, 2005; Goldberg, 2006; Sifris, 2014; Chabot & Ames, 2004). However heterosexual couples may also be deterred as other forms of donation allow them to avoid disclosing the need for donated gametes, and thus protect the narrative of a traditional family. In these instances, secrecy allows the recipient/s to maintain full control over their family (Dempsey, 2005), and to continue the narrative of a traditional family even after relationship dissolution (Brewaeys, 2005; Garner, 2008; Kirkman, 2004).

Prevalence

Even in countries where donor conception is legal there is difficulty obtaining true prevalence rates (Blyth, 2006). This is due to entrenched secrecy, poor record keeping, private donations (Nadraus, 2015), rising reproductive tourism (Inhorn, 2011; Inhorn & Patrizio, 2009; Marquardt, Glenn, & Clark, 2010; Yau, 2013), and the

increase in unregulated online gamete trading (Dwyer, 2005), including through social media (e.g., Free Sperm Donors UK, n.d.; Sperm Donation, n.d.; Sperm Donation UK, n.d.). In a calculation using reported births from donor conception conducted via clinics, Allan (2010) conservatively estimates that there are approximately 20 000 donor-conceived people in Australia. Media echoes a larger 60 000 (Barraud, 2015; Horler, 2015; Purtill, 2016) which has been estimated by support groups when taking into account private donations (Are You Donor Conceived?; RUDC, 2015a).

Current figures cannot be generalised beyond Australia as social norms, treatment costs, donor availability, and laws and regulation (Allan, in press; Blyth, 2006; Council on Human Reproductive Technology, 2013; Sembuya, 2010) heavily influence prevalence. For instance, as well as dictating recipient eligibility, laws and regulations also restrict the number of births allowed per donor (Council on Human Reproductive Technology, 2007; Hesketh, Lu & Xing, 2005; Zhu, Lu, & Hesketh, 2009); see figure 1 for more information. Hong Kong is currently the only country to enforce restrictions consistent with the recommended three births per donor (Baran & Pannor, 2008; Council on Human Reproductive Technology, 2013). In contrast, neither India nor the United States has existing regulation (Frith, 2001; Dwyer, 2005).

Donor conception practices are expanding rapidly (Allan, 2012; Levine, 2011), and figures are likely to be underestimates as recipients can import gametes, or travel overseas (Thijssen et al., 2014). This is neither uncommon nor difficult with some more lenient countries, such as Denmark, reportedly exporting 75% of supplies (Marquardt, Glenn & Clark, 2010). However, there is no international registry to document or measure the practice.

Even in Australia, donor conception practices are now the fastest growing health business (Medew & Baker, 2013).

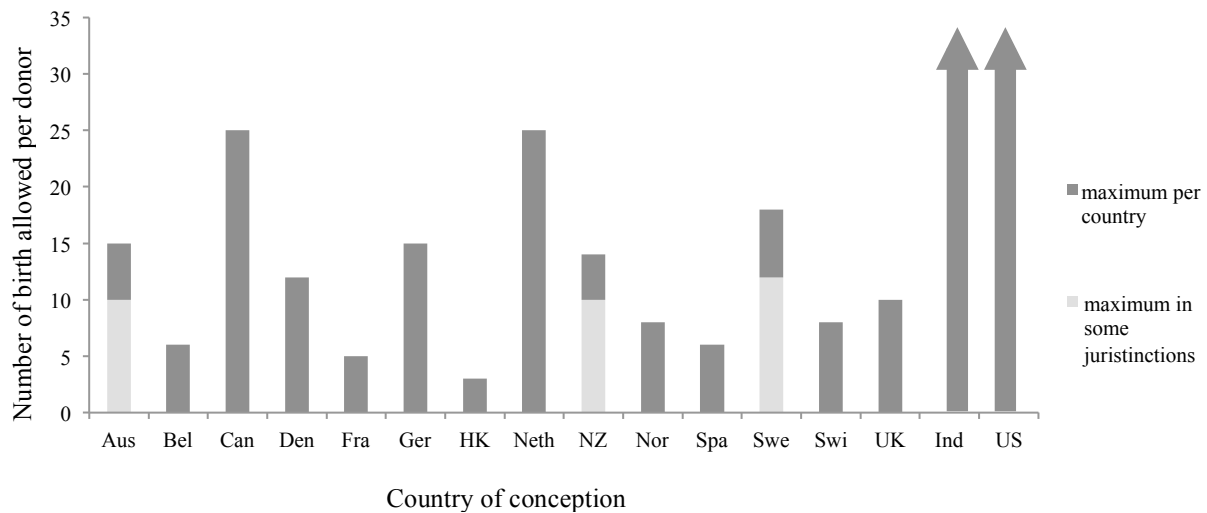


Figure 1. Number of births permitted per donor according to country of conception.

Aus, Australia; Bel, Belgium; Can, Canada; Den, Denmark; Ger, Germany; HK, Hong Kong; Neth, Netherlands; NZ, New Zealand; Nor, Norway; Spa, Spain; Swe, Sweden; Swi, Switzerland; UK, United Kingdom; Ind, India; US, United States.

References used to obtain data to create this figure are cited in text.

Disclosure

The current outlook is that disclosure is in line with the best interests of the child, provided it is planned and intentional (Marquardt, Glenn & Clark, 2010). Some people claim parents need to tell their children of their donor-conceived status at an early age in order for the child to develop donor conception into their identity, and to avoid later feelings of confusion or betrayal (Baran & Pannor, 2008; Narelle, 2005; Pascoe, 2016). Others claim that disclosure at an early age is hard for a donor-conceived person (Marquardt et al., 2010), while others advocate the popular idiom

‘what you don’t know can’t hurt you’ to justify non-disclosure (Hass, 2015; Leiblum & Aviv, 1997; Nachtigall, Becker, Quiroga & Tschann, 1998; Shenfield, 1997; Walker & Broderick, 1999). If, or when, disclosure should occur and how this may affect the donor-conceived person is debated, but ultimately unknown. While there is expert advice, supportive research is limited to young children (e.g., Golombok et al., 2011) and has several methodological limitations.

Historically, disclosure has been extremely low (Brewaeys, 1996; Clayton & Kovacs, 1982; Gottlieb, Lolas & Lindblad, 2000; Lycett, Daniels, Curson & Golombok, 2005; Nachtigall, Becker, Quiroga & Tschann, 1998). More recently it appears to have increased in some locations, and situations. For example, after the Ethics Committee of the American Society of Reproductive Medicine (ASRM) revised its anti-disclosure recommendation in 2004 (ASRM, 2004) disclosure rates steadily increased. However this appears predominately among new recipients (Baccino, Salvadores & Hernández, 2014; Blyth, 2006; Rumball & Adair, 1999; Sawyer, Blyth, Kramer & Frith, 2013; Söderström-Anttila, Sälevaara & Suikkari, 2010), as recipients with adult children appear to have resisted the trend (Hertz, Nelson & Kramer, 2013). Nevertheless, donor-conceived adults are presenting in larger numbers, and from diverse backgrounds. While previous research has tended to group families into pro-disclosure, non-disclosure or undecided (e.g., Colpin & Soenen, 2002), it appears that increased numbers of recipient parents changed their position towards disclosure (e.g., Gordon, 2015). While the reason is largely unknown, increased media attention, changes in public understanding about what constitutes a family, and legislation may have contributed.

Some parents admit that keeping the secret was too difficult, generally forfeiting the secret and the pressure after the death of a spouse (Cordray, 2012;

Dingle, 2014; Kirkman, 2003; Stevens, 2012). Other donor-conceived people have found out unintentionally, where increased lay understanding of genetics and the commercialisation of genetic testing may have contributed. Others report being aware of a secret, and finding out the truth after investigating their suspicions (Baron & Pannor, 2008), or finding out from someone other than their parent/s (e.g., Kirkman, Rosenthal & Johnson, 2007).

Irrespective of parents' disclosure preference, it is common for them to disclose donor conception to friends and other family members. Of parents who indicated they were not going to disclose donor conception to their children, more than half disclosed the nature of their child's conception with friends and family (Gibbard, 2012). This is not a new occurrence as previous research has repeatedly found disclosure to another person outside of the nuclear family above 80% (Cook, Golombok, Bish & Murray, 1995; Braverman, Boxer, Corson, Coutifariz, & Hendrix, 1998; Leiblum & Aviv, 1997). As such the likelihood of donor-conceived people finding out the true history of their conception from another person is high. As a result some parents may be unaware that their child knows they are donor conceived. It is also possible that a donor-conceived person has been contacted by their previously anonymous donor, which is legal in New Zealand (*Human Assisted Reproductive Technology Act 2004*) and Victoria, Australia (*Assisted Reproductive Treatment Act 2008* [Vic, s. 59]), and does not require parent consent.

Donor-Conceived People and the Impact of Donor Conception

Physical and mental development. Limited research exists on the physical and mental development of donor-conceived people. In one early study both were found equal to naturally-conceived children (Iizuka, Swada, Nishina & Ohi, 1967). However, mental development was limited to consideration of intelligence. In

addition, measurements were made using a modified intelligence measure, on children aged 2 to 11 years. For children aged younger than 2 years ($n=14$), intelligence was not measured but instead inferred based on recipient-parent intelligence, which was again inferred based upon parental occupation. This has been found unreliable (Hauser, 2002). In their follow-up study, Izuka and colleagues (1967) investigated a small sample of nine. Such a limited sample dramatically decreased statistical power, reliability, and may have created a biased sample reducing generalisability (Field, 2013). Commonly referred to as a ‘winning effect’, the small sample size likely exaggerated effect (Button et al., 2013).

Parent-child relationships. Current understanding is that the quality of parent-child relationships is equal (Casey, Jadv, Blake & Golombok, 2013), if not superior (Blake, Casey, Jadv & Golombok, 2014; Golombok et al., 2002; 2011), when donor conception has been used by a family. However again, methodological flaws make some such findings questionable. Younger samples have been the hallmark of research conducted in the previous decades, with few including children over the age of 12 years (e.g., Clayton & Kovacs, 1982; Brewaeys, 1996; Casey et al., 2002; Golombok, 2002; 2011). Inclusion of only pre-pubescent participants in these investigations may have skewed results for many of the variables of interest, such as; parent-child relationship, relationship development, and discipline. For example it was concluded by Golombok (2002) that parents with donor-conceived children experience significantly greater parenthood enjoyment, are more emotionally involved, more protective, and more lenient on discipline. Had the study focused beyond pre-pubescent offspring, results may have been different.

Only focusing on pre-pubescent participants does not provide any data on psychological outcomes of those who have undergone significant development

through adolescent years and may have reflected more fully on their life and background. In particular, attitudes towards, and experiences of, donor conception change distinctly at three different stages of development: in childhood, adolescence, and adulthood (Hewitt, 2002; Scheib, Riordan & Rubin, 2005; Vanfraussen, Ponjaert-Kristoffersen & Brewaeys, 2001). For example, in one study, Hewitt (2002) reported that before the age of 12 she misunderstood the concept of donor conception, that during adolescence she felt anxiety and uncertainty, and then resolute in early adulthood. This is consistent with theories pertaining to the development of abstract thought (Belsky, 2010), which are discussed below.

In addition, research on parent-child relationships with young children invariably fails to make allowances for individuation and parent-child conflict that are expected to manifest in adolescence (Belsky, 2010). Research generally shows parent satisfaction deteriorates from the time the child turns 12 years of age, with the parent-child relationship undergoing significant changes thereafter (Summers, Hoffman, Marquis, Turnbull & Poston, 2005). It could also be suggested that the inclusion of offspring aged two years may inflate positive results as parents have expressed elevated satisfaction when their child is at that age (Pollmann-Schult, 2014). Focusing on such a narrow sample has the potential to leverage the data, essentially elevating and distorting the overall outcome; meaning a lack of in-depth understanding of the parent-child relationships, experiences and wellbeing of donor-conceived adolescents and adults.

In addition, focusing on younger donor-conceived children further compromises generalisability and ecological validity in two prominent ways. First the population that is under investigation has been conceived within a different system as donor conception is developing and changing for each generation (Allan, 2016c).

Therefore the impact of donor conception may be different, so too the experiences and coping mechanisms of such individuals. Secondly, pre-pubescent participants do not possess abstract thinking (Belsky, 2010). Abstract thinking is required for deep reflection, and continues to develop over time through reinforcement as various life challenges present (Sharp, 2009).

Further methodological limitations in such studies include low inter-rater reliability (Casey, Jadv, Blake & Golombok, 2013), and an overreliance on parental reports (Casey et al., 2013; Golombok et al., 2011; Golombok, Murray, Brinsden & Abdalla, 1999; Scheib, Riordan & Rubin, 2003). This is problematic as parent reports have found to be culturally biased (Page, 2012), comparisons are have often been between unmatched groups, particularly relating to ages (Golombok et al., 2002), and thus an understanding of the experiences and thoughts of donor-conceived people themselves is not obtained.

Families within the literature have generally been divided into two categories, those with, and those without, a male parent (Baccino, Salvadores & Hernández, 2014; Beeson, Jennings & Kramer, 2011). However, investigations into information and disclosure, separating and comparing heterosexual, same-sex and single-recipient families, found same-sex families presented similarly to heterosexual families, both of which presented distinctly different to single-recipient families (Sawyer, Blyth, Kramer & Frith, 2013; Scheib, Riordan & Rubin, 2005). It appears therefore that differences in feelings towards information and disclosure are more likely attributed to the presence, or absence, of a (male or female) co-parent, rather than the presence of a male parent.

Further, parents appear to seek the approval of researchers and strive to be the unsurpassable family (Heritage, 2016), and may have more positive perceptions of

their children's experiences than is the case. For instance in a review of literature investigating QoL, parents were found to overestimate their child's QoL (Upton, Lawford, & Eiser, 2008). Even highly confident parents have been found to deviate from the reports of their child (Jokovic, Locker & Guyatt, 2004; Jokovic, Locker, Stephens & Guyatt, 2003). Parent reports have been found least reliable when relating to their child's activities, relationships and experiences outside of the home, and become increasingly inaccurate as their children age (Jokovic et al., 2004). It appears parents report their own perceptions, which are affected by the level of information shared by their child while also protecting the family's reputation (Adams & Lorbach, 2012; Scheib, Riordan & Rubin, 2003).

Also confounding the use of parent reports to understand their children's experience of donor conception is that recipient mothers are more defensive and more likely to perceive negative stigma (Page, 2012). In turn, such reports are biased towards the socially desirable responses, and indicate parent-child enmeshment (Golombok et al., 2002). This is an important finding to consider when interpreting the results of parent reports as enmeshed parents lack the ability to differentiate their child's emotions and experiences from their own, and instead reflect, and therefore perceive, and report on, their own (Chase, 2015).

Not only are the majority of investigations into donor conception based on parent reports, of the more recent investigations the majority of parents are same-sex or single-recipient parents (Sawyer, Blyth, Kramer & Frith, 2013; Scheib, Riordan & Rubin, 2005). This is not unexpected as parent participation among heterosexual couples is low, and further decreases as their children age (McWhinnie, 2001). This may be due to heterosexual recipients' non-disclosure preference and their ability to easily hide donor conception. Furthermore, a sizeable body of research of parents out

of a Cambridge University unit appears to be producing research using the same sample. Again, according to parent reports, donor conception has no effect on offspring wellbeing, functioning, psychological health or relationships (Casey, Jadva, Blake & Golombok, 2002; Golombok et al., 1996; Golombok, Cook, Bish, Murray, 1995; Golombok, Murray, Brinsden & Abdalla, 1999). In each study participant demographics and sample sizes remains constant; thus it appears that the same parents are being used resulting in literature that appears more substantial than it is.

Together these patterns make it increasingly difficult to rely on parent reports, particularly for investigating the long-term effects of donor conception. The solution would be to directly question donor-conceived people. Vanfraussen, Ponjaert-Kristofferson and Brewaeys (2001) previously claimed “because of the secretive attitude of heterosexual couples, only children born into lesbian...families can be questioned about their experiences as donor offspring” (p. 2019). Such a statement facilitates naïve understanding of what it means to be donor-conceived and overlooks the increasing availability of donor-conceived people.

Impact of secrecy and anonymity upon family relationships. As information accumulates, it appears that that secrecy accustomed to donor conception can cause adverse effects on those born as a result, and on family relationships (Marquardt, Glenn & Clark, 2010). Effects have been found within the donor-conceived person’s relationship with their non-biological parent, as well as their biological parent (Gibbard, 2012), and siblings (Cordray, 2012). One donor-conceived person has described being aware of his parents withholding information and believed it poisoned relationships between all family members (Cordray, 2012), another described the effect as “corrosive” (p. 33; Stevens, 2012).

Without being aware of their donor-conceived status, people have reported feeling as though they did not belong in their family (Benward, 2012), deducing that they were adopted (J.S., 2012), or that their mother had had an extramarital affair (Cordray, 2012) or was a rape victim (Marquardt, Glenn & Clark, 2010). In each scenario a profound impact on both the biological parent- and non-biological parent-child relationship was reported. Even after disclosure, secrecy has been found to have lingering negative effects within families (Benward, 2012), while the effects of anonymity have been found to effect donor-conceived individuals, and their families, throughout life course (Marquardt et al., 2010). This may be due to the permanency of anonymity.

Interestingly, parents who have not disclosed donor conception to their child have stated that their motivation is to in fact protect the parent-child relationship, particularly between non-biological parent and child (Clayton & Kovacs, 1982; Cook, Golombok, Bish & Murray, 1995). This has persisted (Golombok et al., 2002) despite research finding an enhanced non-biological parent-child relationship post disclosure (Marquardt, Glenn & Clark, 2010; Turner & Coyle, 2000), also supported anecdotally (Stevens, 2012). Furthermore, it appears recipients have not been privy to the longstanding principle that transparency of information, no matter how intolerable, enhances, rather than worsens family relationships (Green, 2002).

Genealogical Bewilderment

Genealogical bewilderment was termed in the mid-20th century to describe the confusion and uncertainty felt by adoptees who lacked genetic information (Sants, 1964). It was found to compromise one's mental health and development of self-security. The term has now been applied to people raised in foster care, residential care, step-families, and to people who are donor-conceived or born illegitimately of a

married woman, who each report similar experiences (Walker, Broderick & Correia, 2007).

Anecdotal accounts suggest that genealogical bewilderment is common within donor conception (Cahn, 2009; Leighton, 2012; Williams, 2012). Further, the effects of lacking genetic information may be exacerbated for donor-conceived people due to the lack of record keeping, purposeful record destruction (Allan, in press) and record alteration (Dingle, 2014; Hewitt, 2002; Needham, 2016; New South Wales Government, 2015; Rowland, 1985). There is some anecdotal evidence from donor-conceived people who have publically described their feelings, that genealogical bewilderment may be particularly acute for people who discover they are donor conceived later in life (Allan, 2012). It also appears to escalate as donor-conceived people age, possibly due to the development of abstract thinking and the ability to think more deeply.

Others argue that genealogical bewilderment could not impact donor-conceived people (Leighton, 2012; Walker & Broderick, 1999). However, the evidence-base upon which Walker and Broderick (1999) make this argument is that 20% of the entire population are assumed to be unknowingly unrelated to one parent, but 20% of the population does not report genealogical bewilderment. They claim that reports of genealogical bewilderment among donor-conceived people are insufficient and believe it a concoction to coerce recipients into disclosing donor conception to their child, which they argue is denying parental rights.

It is possible that anecdotal accounts are biased, and only people who are experiencing distress articulate their feelings. On the other hand, as Allan (in press) notes, genealogical bewilderment may not exist for all donor-conceived people, but it does not discount that it may exist for some. Among people who do report it,

symptoms of genealogical bewilderment appear to be exacerbated when attempts to obtain information are unsuccessful (Adams & Allan, 2013). Thus, it is clear that further research is required in order to comprehensively understand the extent to which genealogical bewilderment affects donor-conceived people.

Thus far, genealogical bewilderment appears to be affected by family structure and dynamics. Donor-conceived children with same-sex parents report less genealogical bewilderment compared to heterosexual and single-recipient parents (Marquardt, Glenn & Clark, 2010; Scheib, Riordan & Rubin, 2005). However, upon separating, male offspring with lesbian parents are more likely to seek information about a donor, and at an earlier age, compared to female offspring within the same family (Vanfraussen, Ponjaert-Kristofferson & Brewaeys, 2001). Whether donor-conceived children with same-sex parents truly have less interest is further obscured as this group has been found to express significantly less interest in an attempt to protect their co-parent (Scheib, Riordan & Rubin, 2005; Vanfraussen, 2003). In comparison, donor-conceived people with single-recipient parents have been found to experience more distress (Marquardt et al., 2010). They have also been found open to discussing donor-conception with non-family members (Scheib et al., 2005). Therefore differences in genealogical bewilderment symptom recounts may be closely related to differences in communication between family types, rather than experiences of it. Further research would be required in order to understand the effects of family type on genealogical bewilderment more comprehensively.

Identity

As well as reporting symptoms of genealogical bewilderment, donor-conceived individuals also report feeling profound loss related to perceived gaps in their sense of identity (Shanner, 2012; Williams, 2012). Personal identity refers to the

innate lifelong journey one engages evaluating who they are as an individual and how they ‘fit’ into the world (Benward, 2012).

Identity comprises four salient principles: self-efficacy, distinctiveness, self-esteem, and continuity (Belsky, 2010; Vignoles, Chryssochoou, Breakwell, 2002). Self-efficacy refers to the belief one holds about their perceived ability to succeed, and plays a major role how goals, tasks, and challenges are approached (Stets & Cast, 2007). Distinctiveness is the internal motivation individuals have to strive to differentiate themselves and be a unique being. Self-esteem refers to an individual's perceived worth (Orth, Maes & Schmitt, 2015), while continuity refers to innate motivation to keep past, present and future connected (Wang & Xu, 2015).

Generally, issues with identity first become apparent during the primary school years (Belsky, 2010), are heightened during adolescence (Orth, Maes & Schmitt, 2015), and do not change after one reaches 30 years (Huang, 2010). However, donor-conceived individuals report experiencing difficulties throughout life (Stevens, 2012) and may not experience identity formation according to standard trajectories (e.g., Trzesniewski, Donnellan & Robins, 2013). It appears that some donor-conceived people are unable to understand who they are, and how they ‘fit’ into the world as they are missing information relating to their past, and as a consequence their present and future (Benward, 2012; Carty, 2007; Turner & Coyle, 2000), all of which are utilised to build identity.

While the relationship between identity and donor conception has not been directly investigated, effects can be inferred from personal recounts. In a study by Turner and Coyle (2000) one participant stated: “I was faced with an immediate reappraisal of my own identity” (p. 2044) after losing all familiar parameters. Another stated that learning her father was not genetically related “changed my view of my

identity” (p.2045). In a recent news article one donor-conceived person described her identity experience as “excruciatingly painful” (para. 3), while another remembers being traumatised by no longer recognising himself (Gordon, 2015). Each statement reflects Breakwell’s (2015) theory of continuity in identity building, or rather discontinuity.

Effects are especially prevalent among donor-conceived people who are required to reevaluate their identity after finding out about their conception later in life (e.g., Cordray, 2012; Carty, 2007; Gordon, 2015). As the information about the past is rendered inaccurate, continuity is broken causing one’s identity to become ambiguous, which causes uncertainty, instability, and further discontinuity (Campbell & Lavalley, 1993; Dennison, 2007). This appears to invoke more negative feelings in donor-conceived people who find out later in life (Cordray, 2012; Harris & Shanner, 2012), compared to those who report being told by their parents at an early age (Pratten, 2012), although feelings do appear to neutralise over time (Marquardt, Glenn & Clark, 2010; Stevens, 2012).

Such findings mirror those found among adoptees - in particular those who find out in adolescence and where discussions about biological relatives were avoided, and fostered people who are placed within a family at an older age (Triseliotis, 1983). They too report experiencing greater discontinuity, lower self-efficacy, appear to have lower self-esteem, and struggle with identity building (Triseliotis, 1983; Turner & Coyle, 2000).

However it is important to note that identity, particularly self-esteem, naturally fluctuates over the lifespan; dropping in adolescence, peaking in early adulthood, and declining with age (Trzesniewski, Donnellan & Robins, 2013). Therefore there is a possibility that the self-scrutiny of one’s identity during adulthood may not be

exclusively related to age of disclosure, although it appears to exacerbate it. Further research is required that can separate the attitudes of donor-conceived people based on the age they learned of their conception, whilst controlling for the effects of development on identity building.

For some donor-conceived people difficulties with identity building are further compounded by the lingering effects of secrecy (Benward, 2012; Turner & Coyle, 2000). Donor-conceived people report that despite the truth of their conception being shared with them family members often remain in denial, or become highly avoidant (Benward, 2012; RUDC, 2015b; Turner & Coyle, 2000). This is counterproductive, as donor-conceived adults need to consult with their parents in order to accurately construct their identity and successfully incorporate their donor conception (Kirkman, 2003). However, consistent with findings among adoptees (Baran & Pannor, 2008), donor-conceived people continue the secrecy by keeping their experiences private as they have learned their conception is not a topic open to discussion (Marquardt, Glenn & Clark, 2010). This further demonstrates why parent reports are not an appropriate measure to evaluate the effects of donor conception on those born as a result.

Identity development influences both mental and physical health. It is a cornerstone criterion of many mental health disorders and personality disorders (*Diagnostic and Statistical Manual of Mental Disorders* [5th ed; *DSM-5*]; American Psychiatric Association [APA], 2013). Losses in identity have been associated with depression, self-harm, suicide, disordered eating, poor immune health, and premature death (Breakwell, 2015; O'Leary, 1985). Thus, it is important to obtain an accurate understanding of the identity of donor-conceived individuals and the factors that influence it.

Research into Genealogical Bewilderment and Identity

To date, much of the evidence of genealogical bewilderment, identity, and health among donor-conceived people is anecdotal and the sources of the information should be recognised. For instance *Anonymous Us*, an online blog and edited book, publishes anonymous stories by donor-conceived people reporting on their experiences (Newman, 2013).

The stance and ideology of these sources should also be noted. For instance, *Anonymous Us* appears to emphasise negative experiences and highlights stories consistent with the views of anti-donor conception, pro-heterosexual family funders (Children Deserve to Know Where They Come From, 2011). A further example can be found in Sheller (2011) who reports that more than half of donor conceived people are clinically “disturbed” (para. 3). The reliability of such a statement is questioned when based on presentations to a church-run counselling service that does not support third party reproduction or same-sex parenting (Center for Marriage and Family Counseling, 2016; Dalzell, 2000). It is also recognised that data collection from a counselling setting is biased as pathological presentations are not unexpected as only those who are experiencing distress or impairment, and who require therapeutic intervention, would be expected in a counselling setting (Waydenfeld & Waydenfeld, 1980). In order to understand mental health in donor-conceived people investigations must be conducted among a representative sample.

Negative reports of the effects of donor conception are juxtaposed by reports that donor-conceived people who are unaware of their conception are happier adults (Kovacs, Mushin, Kane & Baker, McWhinnie, 2001), brought up with superior parenting (Golombok et al., 1996; Golombok, Cook, Bish & Murray, 1995). This makes it difficult to definitively understand the true effect of donor conception, secrecy, and anonymity. However research supporting the notion that donor-

conceived people have elevated self-esteem and wellbeing during adulthood (as cited in McWhinnie, 2001), do not appear to acknowledge that such positive outcomes are extrapolated from prepubescent samples. Nor that they are also based parent reports.

Motivation to Seek Information and Make Contact with Donors

Despite understanding the permanent inability to seek out genetic information and genetic relatives, donor-conceived people admit to pursuing genetic resemblance among strangers in a futile attempt to build their identity narrative (Marquardt, Glenn & Clark, 2010; Narelle, 2005). In a comparison between donor-conceived people, adoptees and naturally-conceived people, the majority of donor-conceived participants admitted to scanning the public, and wondering if similar looking people were relatives (Marquardt et al., 2010). This was significantly higher compared to adoptees and to naturally-conceived people who also shared the experience, despite assuming their parents were both genetically related. The inability for donor-conceived people to appropriately seek out their donor, and genetic relatives, irreversibly compromises identity development, and ultimately health (Hewitt, 2002).

However, much of the research surrounding motivation to seek contact with donors, or find out more information about donors, has again largely focused on parental reports. For instance, it has also been found that parents significantly underestimated their child's desire to obtain further information, as well as to have a relationship with their donor (Scheib, Riordan & Rubin, 2003). Of the donor-conceived children who desired having a relationship with their donor during adulthood (82%), less than half their parents were privy (Scheib, et al., 2003).

Lack of Medical Information. Not having information pertaining to the heritage of one, or both parents, also means not having a complete medical history, and may pose as another motivation to seek information about, or even contact with, a

donor (Allan, 2016a). This means that people with anonymous donors have no way of knowing their, or their children's, susceptibility to medical conditions such as cancer, heart disease, or diabetes; or to mental health conditions. Lacking such information puts donor-conceived people, and their children, at risk, which increases in significance as they age (Allan, 2011). Secrecy and anonymity also mean that health conditions that present in a donor later in life cannot be communicated to donor-conceived people, nor are diseases that present in donor-conceived people communicated to the donor or half-siblings. Similarly it also means that for donor-conceived people who are not aware, they, and associated health professionals, are likely to be unwittingly relying on an inaccurate medical history (Marquardt, Glenn & Clark, 2010).

How the absence of a complete and accurate medical history affects donor conceived people is not well understood. To an extent, the implications have been explored by Baron and Pannor (2008), however only within recipient parents. Only recipients who have suffered a hereditary illness themselves appeared to acknowledge the phenomenon, although only that they were relieved their child could not inherit a condition from them.

While recipients are generally not concerned, donor-conceived people are. Marquardt, Glenn and Clark (2010) found a large group of donor-conceived people feared the implications of not having a complete and accurate medical history. Concern for their children was also expressed. This concern reportedly presented during adolescence, and appeared to motivate donor-conceived people to identify and contact their donors. When such attempts were futile, negative effects precipitated (Marquardt, Glenn & Clark, 2010; Narelle, 2005; Pascoe, 2016). As effects are based on a limited number of questions and anecdotal reports, generalisation is difficult,

however the importance of medical history and the need to further investigate the implications of its absence for donor-conceived people is highlighted.

Risk and/or Fear of Consanguineous Relationships. There is a risk of donor-conceived people unwittingly forming a romantic relationship with an unknown sibling or donor (Pi, 2009) – particularly when donations were often made by, and distributed to, local residents (Dingle, 2015; Pascoe, 2016). This may pose as further motivation to seek information about, or even contact with, a donor. Attraction towards a genetic relation is referred to as Genetic Sexual Attraction and has become well known among adoption research (Greenberg, 1993). While the actual risk is difficult to determine as the number of donor-conceived people is undetermined (Allan, in press), the reality is, that if more than one family has received a donation from the same donor, forming a consanguineous relationship is possible. This risk is amplified among donor-conceived people who do not have information about their donor or siblings (Pi, 2015), or who are unaware that they are genetically related to persons outside of the family and are unable, or unlikely, to take precautions. Preliminary investigation reveals that donor-conceived people are significantly more aware of the risk of consanguineous relationships compared to adoptees and naturally conceived individuals (Marquardt, Glenn & Clark, 2010). However whether this affects intimate relationships is unknown as the matter has only been investigated as a single Likert scale question, and is yet to be discussed in detail within the literature.

Donor-Conceived Adolescents and Adults

There appear to be only a few formal investigations into donor conception that involve participants beyond pre-pubescence (Mahlstedt, LaBounty & Kennedy, 2010; Turner & Coyle, 2000). Within these several methodological limitations present. For instance, results based on older participants appear to be confounded by a range of

extraneous variables. These include: gender (Scheib et al., 2005; Vanfraussen, Ponjaert-Kristofferson & Brewaeys, 2001), current age and age of disclosure (Hertz, Nelson & Kramer, 2013; Turner & Coyle, 2000; Rumball & Adair, 1999; Scheib, Riordan & Rubin, 2005), family structure (Scheib et al., 2005), and circumstances of disclosure (Turner & Coyle, 2000). As research has only just begun, and these variables have only recently been identified, they are yet to be systematically analysed. Their contribution and interaction with other variables must be fully investigated to better understand the experiences of donor-conceived adults.

Recent attempts have been made to access this population, however due to the secrecy that shrouds donor conception, they have been difficult to identify. As a result, current research has sought participants by repeatedly and exclusively appealing to an American Internet support group (e.g., Jadv, Freeman, Kramer & Golombok, 2009; Mahlstedt, LaBounty & Kennedy, 2010; Sawyer, Blyth, Kramer & Frith, 2013; Turner & Coyle, 2000). It appears that as a result a small consistent group of participants have presented themselves in each investigation – again creating a methodological limitation. This diminishes external validity and inflates the data so it appears more substantial than it is. Furthermore, members of support network likely over represent those who experience identity issues and be biased towards the views of the organiser (Shanahan, 2011). In addition communication between network members is high, which would cultivate particular attitudes and emotional responses. This method of recruitment also means non-group members who share different experiences and attitudes are not represented in the investigations. Additionally, small samples are response biased, whereby donor-conceived people with the strongest views, in line with the researcher's, present first (Bruton, 2008).

Learning from Adoption and Other Substitute Families

An alternative approach to learning about donor conception and its effects, including the effects of accompanying secrecy and anonymity, has been through generalising research conducted on persons raised in substitute families. This includes stepfamilies, foster families, residential care, but most notably, adopted families (Triseliotis, 1983). Adoption and donor conception are similar as both systems have operated “in an atmosphere of stigma, shame and secrecy” (p. 289; Guichon, 2012). Although lagging behind, donor-conceived people now echo the same need for access to information, particularly medical history (Allan, 2016a), and similarly report experiencing genealogical bewilderment and identity issues (Biggs, 2011). Both adoptees and donor-conceived people also experience the same legal age-discrimination whereby access to information is limited by the legislation relevant to persons born, or conceived, within a particular time period. Both advocate for legislation that promotes equality and prioritises the child.

Despite the similarities there are distinct differences that some use to disrepute generalising data (Klock, 1997; Shenfield, 1994; Shenfield & Steele, 1997; Turner & Coyle, 2000; Walker & Broderick, 1999). The system of adoption is an institution that prioritises the needs of an existing child who requires a home and a family (Chisholm, 2012; Rose, 2012). In comparison, donor conception operates as a market, prioritising the recipients who, as a family with a home, pre-exist the child (Marquardt, Glenn & Clark, 2010). The families are also thought to be different due to lower divorce rates amongst adoptive recipients compared to donor conception recipients who, unlike adoptive families, have not engaged in a screening process (Marquardt et al., 2010).

The two cohorts are also reported to differ based on perceived ‘want’, with adoptees discerning abandonment by their biological parents (Shenfield, 1994; Shenfield & Steele, 1997; Rowland, 1985) and donor-conceived people appearing

very much wanted by their parents. However, as many donor-conceive people also report feeling abandoned by their donors (biological parent; Biggs, 2011; Infertility Treatment Authority, 2006; Tangled Webs UK, n.d.; as cited in Rose, 2009; Turner & Coyle, 2000), it appears the difference from adoption is rather the stage in which abandonment is perceived to have occurred; i.e., pre-conception versus post-conception. Thus it appears more appropriate to describe the difference as ‘unintentional’, rather than ‘unwanted’, and ‘intentional’, rather than ‘wanted’, for adoption and donor conception respectively. Despite these differences, in the absence of more appropriate sources of information, parallels have allowed a deeper understanding of issues such as genealogical bewilderment, feelings of loss of identity, and the effects of absence of medical and genetic information (Allan, 2012; Chisholm, 2012).

Changes in information accessibility for adoptees have proven informative. Previously adoptees were denied information relating to, and preceding, their adoption (Turner & Coyle, 2000). However, the importance of knowing about their adoption early, having the ability to seek contact with genetic relatives, and having information about their origins are each recognised as important in order for adoptees to develop their identity (Triseliotis, 1993). Having information has been found most critical from 11 years of age (Hoopes, 1990). Arguments presented for change in information access for adoptees mirror those currently used when discussing donor-conceived peoples’ ability to access information (Benward, 2012).

At present all Australian adoptees have access to previously unavailable personal information (Thomson Reuters, 2015). Only this year has similar recognition been given to donor-conceived people in the state of Victoria (Australia), which will move to retrospectively allow donor-conceived people to access the equivalent

information should their records exist (*Assisted Reproductive Treatment Amendment Act 2015* [Vic]). However, this progression is not national, as similar state government discussions have seemingly dismissed the need for information access by failing to amend legislation in favour of donor-conceived people (Needham, 2016). Another two are in the process of reviewing their legislation but are yet to act (Government of South Australia, 2016; Parliament of Tasmania, 2016).

QoL Among Donor-Conceived People

QoL among donor-conceived people has not been directly tested. This is likely due to previous lack of access to older donor-conceived populations, as abovementioned understanding QoL among donor-conceived people has been reliant upon parent reports and analogies drawn with adoption research findings.

Previous assumptions of lower QoL among adoptees due to the disadvantage of unknown or uncertain genetic origins have been unfounded (Cederblad, Höök, Irhammar & Mercke, 1999). Through more rigorous testing, adoptee's QoL has been found equivalent to the general population, irrespective of previous life events (Cederblad et al., 1999).

Formal investigation of QoL for donor-conceived people may reflect results found among adoptees, or may support theories that they have elevated QoL (as cited in McWhinnie, 2001), or may confirm Brewae's (1996) concerns and show that donor-conceived adults in fact have lower QoL. To fully understand QoL among donor-conceived people, there is a need for future research to directly assess the donor-conceived population using a consistent and reliable measure. This need has also been recognised by Marquardt, Glenn and Clark (2010).

Measuring QoL among an Australian donor-conceived population. The importance of QoL and its use in scientific research is increasing; so too its use in

identifying and allocating resources in today's extensive and expensive health care system (Asadi-Lari, Tamburini & Gray, 2004). However, there is no consensus on how QoL should be defined, or measured (Pennacchini, Bertolaso, Elvira & De Marinis, 2011). Consequently a number of QoL measures exist varying in reliability and information gathered (Richardson, Khan, Iezzi & Maxwell, 2012).

Each measure presents benefits and shortfalls, which are heavily dictated by characteristics within the population of interest, such as; age, culture, and presence of medical illness or disease (Richardson, Khan, Iezzi & Maxwell, 2012). Appropriately measuring QoL of donor-conceived people is therefore particularly difficult as donor-conceived people vary widely in age, socioeconomic status, and cultural affiliation (Braverman, Boxer, Corson, Coutifaris & Hendrix, 1998; Marquardt, Glenn & Clark, 2010; Nachtigall, Tschann, Quiroga, Pitcher & Becker, 1997). Furthermore as Australia has long been an ethnically diverse population (Hamilton, 2014) QoL measures implemented within the population need to have been widely tested and standardised appropriately.

One such QoL measure is the 15 dimensional (15D; Sintonen & Pekurinen, 1993), which has been translated and tested in a number of languages (Dahlberg, Alaranta & Sintonen, 2005; Okamoto, Hisashige, Tanaka & Kurumatani, 2013). Unlike other QoL measures (e.g., Hunt, McKenna, McEwan, Williams & Papp, 1981) the 15D can reliably discriminate between physically healthy, and unhealthy participants, without type II errors (Sintonen, 2001). This is an important consideration when engaging donor-conceived people as medical conditions are anticipated (Dingle, 2012; Grech, 2011). A recent review also found it to be a superior measure within the Australian population (Richardson, Khan, Iezzi & Maxwell, 2012).

The Current Study

By largely focusing on parent reports, younger children, repeatedly appealing to an online support group and relying on adoptee research, current literature has been unable to reliably evaluate the implications of donor conception, secrecy and anonymity on donor-conceived people. The relationship between donor-conceived adults and their parent/s, particularly following becoming aware of their donor conception, has not been given appropriate attention. What little attention has been given has focused on the relationship between child and non-biological parent. Furthermore, while adoption research indicates that growing up without a genetic parent, and being unable to access information effects identity and causes genealogical bewilderment (Sants, 1964), whether it is true among donor-conceived people is speculative. Anecdotal evidence reveals it is present for some donor-conceived people, however whether this can be generalised beyond such individuals is unclear.

This research first aimed to better understand the characteristics of the Australian donor-conceived population, including when and how they found out they were donor conceived, their family characteristics, and their circumstances surrounding disclosure. Circumstances surrounding disclosure include whether the persons was told, and if so by whom, as well as the presence of accompanying events. This is described below, accompanied by tables and figures.

The second aim of this research was to investigate the motivations for donor-conceived people to seek information and/or contact with their donor. It was hypothesised that motivations would vary by psychosocial factors explored within the first research aim. For instance, that people who had known about being donor conceived longer would more likely report being motivated by seeking accurate

medical history compared to those who had known for less time, who were hypothesised to report being motivated by curiosity. This was due to donor-conceived people recently using the need for an accurate medical history as the primary argument for changes in legislation that would identify their donor (Parliament of Victoria, Legislative Assembly, February 23, 2016).

To better understand how the psychosocial characteristics such as disclosure, and family dynamics relate to emotional wellbeing and coping amongst donor-conceived adults, aims 3-5 of the research sought to investigate the psychosocial factors predicting:

- 3a) Identity
- 3b) Genealogical bewilderment
- 4a) Feelings towards information and disclosure
- 4b) Feelings towards donor conception status
- 5a) QoL

It was hypothesised that factors such as; gender, circumstances surrounding disclosure (age told, years known, whether they were told by a parent, any associated events), as well as family dynamics (family type [co-parent present/co-parent not present], relationship with biological parent, relationship with non-biological parent) would predict identity, genealogical bewilderment, feelings towards donor conception, information and disclosure, as well as QoL.

More specifically, inline with previous research (Casey, Jadva, Blake & Golombok, 2013), it was hypothesised that donor-conceived people who report a positive relationship with their non-biological parent would report strong identity, and more positive feelings towards donor conception compared to donor-conceived people who do not report a positive relationship with their non-biological parent.

Consistent with previous theories (Baran & Pannor, 2008; Narelle, 2005; Pascoe, 2016) it was also hypothesised that donor-conceived people who found out about their conception from an earlier age, and who have known longer would more likely report strong identity compared to donor-conceived people who found out later in life, and who have known for a shorter amount of time.

Recognising the concerns raised by Brewaeys (1996) after a detailed review of donor-conception literature, it was also hypothesised that QoL, based on the 15D algorithm (Koskinen, Lundqvist, Ristiluoma, 2012), would be lower among donor-conceived people compared to members of the general population.

Method

Background

While conducting a literature review on the topic of donor conception, the current study was developed in consultation with members of the Australian donor-conceived population. This was done by attending conferences and meetings (e.g., RUDC, 2015b), monitoring online forums and social media (e.g., Australian Donor Conceived People Network, n.d.), and following the most recent proceedings of political discussions and debates (e.g., Government South Australia, 2016; Parliament of Tasmania, 2016; Parliament of Victoria, Legislative Assembly, February 23, 2016). The need for research in the field was identified, so too the willingness of donor-conceived people to participate in research.

Questionnaire Formation

The questionnaire was a mix of existing, standardised scales used within previous research, and questions specifically devised for the purposes of this research.

A total of 195 questions were initially drafted. These were redrafted 10 times. Discussions between researchers which identified questions not related to one of the

seven key areas under investigation, which are discussed below, or which were found to be unclear, leading, convoluted, compounding, researcher biased, response biased, or unreliable, were removed or redrafted. Questions that required secondary information, such as asking about the feelings or attitudes of parents, were regarded beyond the aims of the study and removed. The same procedure was adopted when devising response options for the multiple-choice questions. After the questions and answers were selected the language, format, order, grouping of responses, and time commitment required by participants were assessed.

There were several considerations to improving the internal reliability and validity of the research. Multiple questions were devised to test the same construct for internal reliability. For example, questions relating to participant feelings were assessed through two items; once termed positively (e.g., “I like being donor conceived”) and once termed negatively (e.g., “I dislike being donor conceived”). Keeping an equal number of positive to negatively termed statements avoided response bias. All statements were randomly listed using an online randomiser (<https://www.random.org/lists/>). This order remained consistent for all participants in order to further protect validity. Likert scales were used in order to reliably make comparisons between participant subgroups, and to enable comparisons with future research. Multiple-choice questions also included an *other* option when appropriate to minimise both structural bias and narrow responding. In addition, for several constructs, response information was collected from both qualitative and quantitative measures to protect internal validity; particularly test sensitivity and specificity (Creswell, 2014).

Validity testing. An expert in the field and a donor-conceived adult initially reflected on the questionnaire. Incorporating an individual with no prior knowledge of

donor conception or the study extended validity testing further. This individual was instructed to access the questionnaire using an emailed web link, and to flag any questions that they believed to be unclear, leading, convoluted, compounding, researcher biased, response biased, or unreliable. They were also instructed to comment on language, format, order, spacing, font, grouping of responses, and time taken to complete the questionnaire.

All feedback was addressed until the test respondent had no further feedback. The survey was then tested on a range of devices, including computers, smart phones and tablets with a variety of browsers. Any error that was identified, all of which related to formatting, was addressed before the questionnaire was opened to participants.

Recruitment

This investigation aimed to recruit 60 Australian adult participants, making it the largest investigation of its kind. Of those who were exposed to the study information, and were eligible, a response rate between 40 to 50% was predicted (Fluid Surveys, 2014; Fryrear, 2015). After consent a 20% drop out was anticipated (Fluid Surveys, 2014). Based on these estimates between 150 and 187 potential participants need be exposed to the study information.

The lead researcher and principal supervisor discussed appropriate organisations, groups and individuals to target. As donor-conceived people are not easily identifiable from the general population, organisations, groups and individuals were identified that donor-conceived people might be associated. This included Universities, support groups and online groups (including social media based groups) that donor-conceived people have been known to seek assistance from, such as *Australian Donor Conceived People Network*, *Victorian Assisted Reproductive*

Treatment Authority (VARTA), *Victorian Adoption Network for Information and Self Help (VANISH)*, *Relationships Australia*, as well as wellbeing and health centres.

Individuals that were identified included publically recognised donor-conceived people, donors, recipients, professionals who work with donor-conceived people and their families, personal contacts of the researchers, as well as academics.

Universities were identified using www.australianuniversities.com.au. When a university was established in multiple locations, contact information was sought for each campus. Relevant academics were also identified by searching university website's 'find an expert' fields, using the key terms: "donor", "assisted reproduct*", "ART", "IVF", "conception", "reproduct*", and "infertility".

Through fertility clinics, parenting groups, and support groups (e.g., *Melbourne Anonymous Donors (MADmen)*, *Egg Donor Angels*), recipients and donors were also targeted, particularly recipients whose children were over 18 years, and donors who have had contact with at least one of their offspring. In order to generate a representative sample parenting groups, fertility groups and health centres that cater to members of LGBTI community and to single-mother recipients were also identified, so too professional networks whose members have contact with donor-conceived people, such as; *The Australian Medical Association*, *The Australian and New Zealand Infertility Counsellors Association*, *The Royal Australian College of General Practitioners*, and *Australian Psychological Society*, among others.

As per Figure 2 "other" organisations, groups and individuals were also contacted. This category included seminar organisers and a politician previously involved in events relating to donor conception. In addition, radio stations that featured segments on donor conception during the time of information distribution (e.g., *SeaFM* and *JoyFM*), newspapers that had previously published related

information, and documentary makers that had recently promoted donor conception (e.g., Horler & Paplinska, 2015; McLellan & Newell, 2015) were approached.

An email address was sought for each organisation, group and individual. In instances where only a phone number was available, a call was made requesting an email address. If no email address was available after a telephone conversation then the information was posted to the recipient (n=1).

Information was then distributed to each identified organisation, group and individual. This included a standardised letter (see appendix A), with an advertisement that stated the eligibility and time requirements, as well as a web link and quick response code (QR; see appendix B) that could be used to access further information (see appendix C) and the plain language statement (see appendix D). Information was distributed midweek, and in the morning. This was to increase response rate as information received on a Monday, Friday, or any day after 3pm is less likely to be acknowledged (People Plus, 2016).

Figure 2 illustrates the pattern of known information distribution. A total of 454 organisations, groups and individuals were informed of the research, 396 of which received an advertisement and plain language statement directly from the lead researcher. The distribution was nationwide (see figure 3).

Persons contacted were invited to further distribute the information to other individuals, groups or organisations and to display study information on their website, social media site, in newsletters, on notice boards, or in offices and waiting rooms. The final level of snowballing that occurred remains unknown. However, some recipients of the information voluntarily notified the researcher of further distribution, demonstrating that snowballing did occur.

Informed consent was obtained electronically from all participants prior to them completing the questionnaire. Initial contact indicated that the questionnaire would close midnight 31st August 2016, and a reminder email was sent 2 weeks before this date.

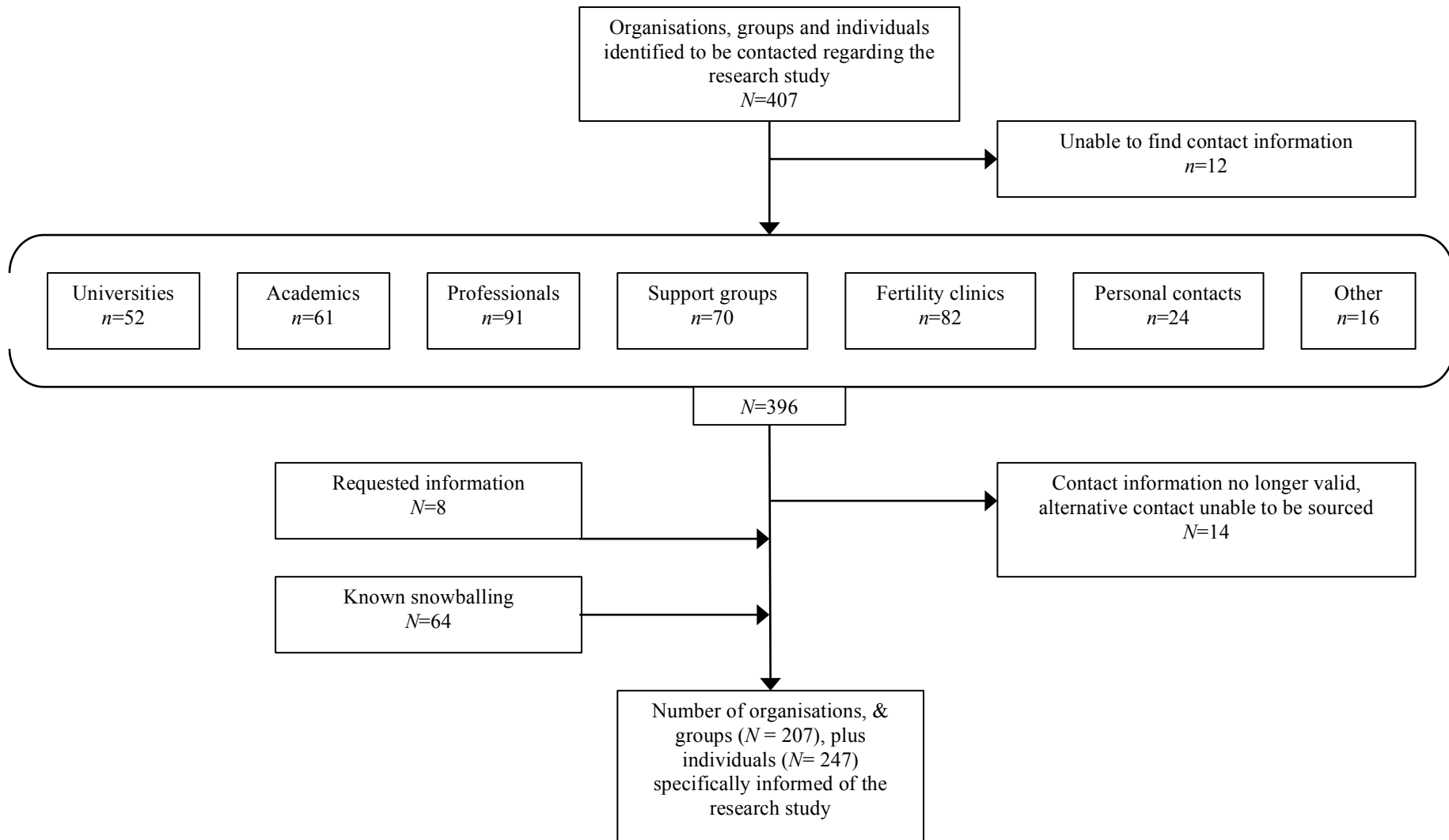


Figure 2. Flow chart demonstrating distribution of study information

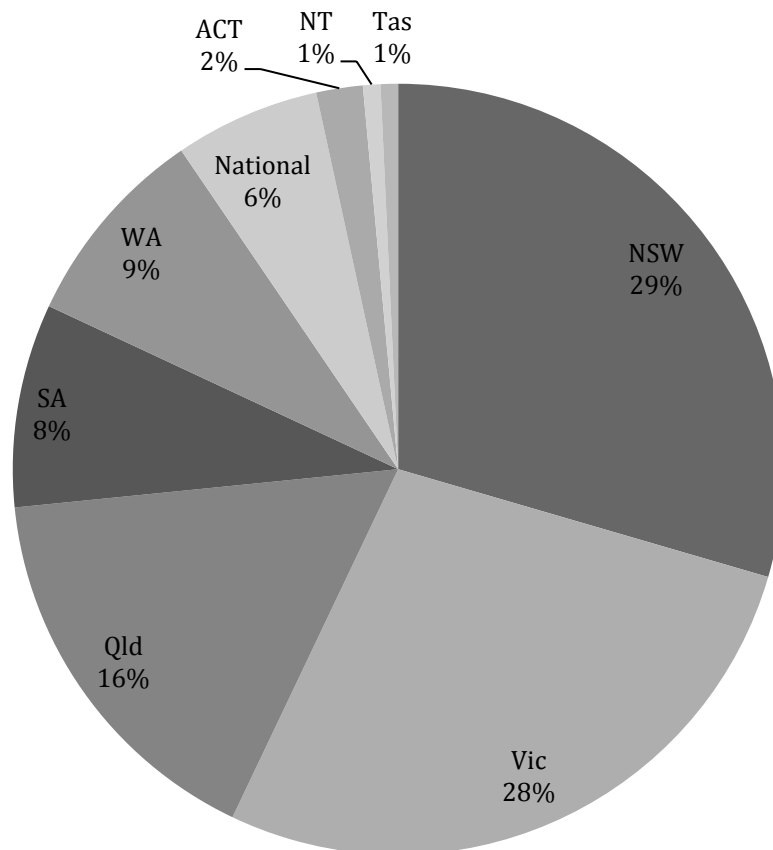


Figure 3. State distribution of organisations, groups and individuals identified as recipients of information. NSW, New South Wales; Vic, Victoria; Qld, Queensland; SA, South Australia; WA, Western Australia; National refers to organisations and groups that did not cater to a specific state; ACT, Australian Capital Territory; NT, Northern Territory; Tas, Tasmania.

Materials

A single online questionnaire was distributed as a web link and QR code. This could be completed anonymously by participants at a location of their convenience. To complete the questionnaire participants were required to have access to a device with Internet access. Paper versions were also available; no participant opted to complete it via paper copy.

Participants had the option of completing the questionnaire in one, or multiple sittings. Due to the anonymous nature of the questionnaire progress was monitored using cookies, therefore participants could only complete the questionnaire in multiple online sittings if the same device was used. After completing, subsequent attempts to access the questionnaire were denied. If participants thought this was incorrect researcher contact details were displayed, and the participant was invited to email for assistance (see appendix E). Incomplete questionnaires remained open until 31st August.

Questionnaire. The questionnaire (see appendix F) was comprised of both qualitative and quantitative questions relating to seven key areas; demographics of the participants, when and how participants learned of their conception, level of openness and avoidance towards their donor conception, procedures involved in seeking further information, motivations underlying seeking further information, how they feel (about; interchanges with fertility clinics and registries, information obtained, donor conception and disclosure, relationships and, themselves) and overall QoL. Together these key areas were used to evaluate the implications of donor conception, secrecy, and anonymity.

Demographics. Demographic information was collected using both qualitative and quantitative (multiple choice) questions. Participants were asked their age, place of birth, and the nature and quality of their relationship with their parent/s. In order to build rapport with participants, demographic information was presented first followed by qualitative response questions that invited participants to tell the researchers about themselves, and their families.

When and how participants learned of their donor conception. Participants were asked, “At what age (in years) did you learn you were donor conceived? Please

estimate if you are not sure”. Participants were provided with open-ended space to answer.

With a *yes/no/I don't remember* response, participants were also asked if they were explicitly informed of their conception and, if so, by whom. Response options included: *biological parent, non-biological parent, stepparent, sibling, aunty, uncle, other family member, medical professional, friend, my donor, Births Death and Marriages*. An *other* option was also included with space to type an alternative response. If they were not informed, participants were asked how they found out, and provided with a space for a free-text response.

All participants were asked whether they suspected donor conception, or sensed something was different about their family before donor conception was confirmed. Response options included *yes, no-but I suspected something was different about my family, no-not at all, I was too young*.

Secondly, events associated with disclosure were also investigated. Participants were asked “were there any particular circumstances under which you discovered that you were donor conceived?”. Response option included; *yes, no, can't remember*. When participants indicated that there were events accompanying disclosure, they were asked “under what circumstances did you discover that you were donor conceived?”. Response options included *during parent divorce, after the death of a family member, after conceiving a child of my own, during an argument, after illness*. These multiple-choice options were the common circumstances within previous research (Turner & Coyle, 2000). An *other* option, with free-text space, was also made available.

Openness and avoidance. To assess participants' openness of their donor-conceived status, participants were asked with whom they had discussed their

conception, with the following responses provided in multiple-choice format:

biological parent, non biological parent, biological grandmother, biological grandfather, non biological grandmother, non biological grandmother, my donor, brother, sister, donor sibling, other family member, partner, close friend, other friend, work colleague, another donor-conceived person, no one or other (with free-text space provided). How comfortable participants felt discussing the topic was further explored with the question “do you avoid talking about being donor conceived?”. *Yes/no/sometimes yes, sometimes no*, responses were available.

To assess participants’ views on others’ avoidance of the issue, participants were asked whether anyone, and if so whom, they felt avoided discussions relating to donor conception, with the same response options at the openness question above. Participants’ openness to discuss personal information more generally was also assessed with the question: “Do you avoid talking about other information about yourself?” with response options *yes/no/sometimes yes, sometimes no*. Thus, participants’ level of comfort discussing donor conception specifically could be assessed, after controlling for comfort discussing personal information more generally.

Accessing information. Questions were asked to assess how and where people attempt to access information about their donor conception. Three questions asked participants whether they had sought information through: registries within their state of conception if available (*yes/no/unsure*), fertility clinics (*yes/no/unsure*), or DNA testing (*yes/no*).

If participants had a known registry in their state or territory, they were asked: whether their information was on it and if this was voluntary or automatic (or unknown); whether they would volunteer their information if possible; whether they

had attempted to access information using the registry; and, if applicable, what information was provided. To ascertain information obtained using registries participants were asked “What information was provided...?”, with response options: *no information, donor code, physical characteristics, ethnicity, occupation, social information, familial medical history, number of offspring, non-identifying half-sibling information, information that records relating to my conception were missing or destroyed, or other* (with free-text space provided). These same responses were available to participants who had attempted to obtain information through a fertility clinic (*yes/no/somewhat*).

When participants indicated they had participated in commercial DNA testing they were asked to indicate which of the most popular tests they had participated in (*23 and Me, Ancestry DNA, Family Tree DNA, Home DNA Direct*). *I don’t remember* and *other* (with free-text space provided) options were also made available.

Participants were also asked using free-text to “estimate in dollars how much money [they had] spent seeking information” in order to understand if there had been financial implications.

What motivates participants to seek further information or contact. To assess participants’ motivations for seeking information participants were first asked whether they had attempted to obtain information about their donor (either successfully or unsuccessfully). *Another member of my family has attempted to/I have never sought information/I have always had information* responses were also available. The same responses were also made available in relation to asking about seeking contact with their donor.

Motivations for seeking information, as well as possible contact with one’s donor, was asked using two questions. Questions were only displayed when a

participant had indicated they had attempted to seeking information and/or contact – “what is your main reason for seeking information about your donor?”, and “what is your main reason for seeking contact with your donor?”. Participants were given the opportunity to give up to 5 answers using free-text by typing one motivation into each box; which were ranked in numerical order. The highest box represented the main motivation.

Participant’s feelings.

Feelings towards information seeking. Participants who had sought information from a fertility clinic or a registry were asked how they felt about the process, with response options: *very happy/happy/neutral/unhappy/very unhappy/other* (with free-text space provided). In addition, participants were asked to reflect on their interchange with a list of positively and negatively worded statements: e.g., *a good experience* was matched with *a bad experience* on the list, and participants were asked to select all that applied. Other options available were; *easy, difficult, stressful, enjoyable, upsetting, liberating, distressing* and *other* (with free-text space provided).

Feelings about donor conception and disclosure. Seventeen questions assessed participants’ feelings about donor conception. Participants indicated their level of agreement on a five-point Likert scale (1 = *strongly disagree*, 5 = *strongly agree*), to an equal balance of positively and negatively framed items, e.g., “I am happy about being donor conceived” and “I am sad about being donor conceived”. Negative items were reversed scored, before participants obtained a total score, with higher scores indicating more positive feelings about donor conception.

An additional rank-order question asked participants to answer “...whose welfare do you think was prioritised?”. Participants then dragged each of the five options (*myself, my parents, my donor, medical professionals, wider community*) into

an order so that the first option indicated the highest, and the last indicating lowest, priority allocated. The options were presented in random order as to not influence answering.

An additional 15 items assessed participant's feelings towards disclosure. On a 5-point likert scale (1 = *strongly disagree*, 5 = *strongly agree*), participants indicated their agreement with an equal number of positive and negatively worded items, e.g., "I am glad I know the truth about my conception" and "I wish I never learned I was donor conceived". After reverse-scoring negatively worded items, a total score was calculated with higher scores indicating more positive feelings towards disclosure.

Feelings towards relationships. Seventeen questions measured relationships, and how they are affected by donor conception, secrecy, and anonymity. The majority focussed on relationships with parents – six specific to non-biological parent and five specific to biological parent. Two questions were about romantic partners. Remaining questions were about the family as a unit. As not all relationships would be relevant to every participant (e.g., partners, and a person born to a single recipient parent may or may not have a non-biological parent or biological parent), questions about relationships also included a *not applicable* option. For each participant an average score of feelings towards relationships was calculated, with items with a non-applicable response excluded from participants' calculation. Higher scores indicated more positive feelings towards relationships.

Feelings towards self: Identity and genealogical bewilderment. Identity was assessed using eight items based on four key principles; self-efficacy, distinctiveness, self-esteem, and continuity (Belsky, 2010; Vignoles, Chryssochoou, Breakwell, 2002). For instance, items such as, "I have a strong sense of self-worth" from 1 = *strongly disagree* to 5 = *strongly agree* assessed self-esteem. Again, each positively

framed question was matched with a negatively framed question. For example “I feel worthless”.

Genealogical bewilderment was assessed through ten items. Again, participants were instructed to indicate their level of agreement to the same 5-point Likert scale to positively and negative framed matched statements, for example; “I feel insecure about who I am” and “I feel insecure about who I am”.

QoL. QoL was assessed using the 15D; a standardised measure (Sintonen & Pekurinen, 1993). QoL was established using 15 items across 15 dimensions, with one relating to each dimension assessed (mobility, vision, hearing, breathing, sleeping, eating, speech [communication], excretion, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity). The 15D is appropriate for persons aged 16 years and older (Sintonen, 2001). Participants were required to indicate on a 5-point ordinal scale of severity which statement most accurately described their level of functioning at the present time. For example in order to evaluate distress participants were required to indicate which of the proceeding statements was presently most true to them; *I do not feel at all anxious, stressed or nervous/I feel slightly anxious, stressed or nervous/I feel moderately anxious, stressed or nervous/I feel very anxious, stressed or nervous/I feel extremely anxious, stressed or nervous*.

Each dimension score was then collated to generate an overall score for QoL, with a score of zero indicating absence of life, and one; indicating no current impairments, and optimal QoL.

The 15D addresses various aspects of health, including physical, psychological and social health, as defined by the World Health Organization (WHO; WHO, 2003), and has found to be broader than other measures (Linde, Sørensen,

Østergaard, Hørslev-Petersen, Hetland, 2008). The 15D is a highly reliable measure of QoL for both groups and individuals with an intra correlation coefficient (ICC) of 0.93 (Linde et al., 2008). ICC above 0.7 indicates a test is suitable for group comparisons, while ICC above 0.9 indicates the test is also suitable for individual comparisons (Nunnally & Bernstein, 1994). It has demonstrated good reliability ($\alpha=0.88$) among a large Australian population (Richardson, Khan, Iezzi & Maxwell, 2012). In addition it possesses high construct validity, is sensitive to change, and it is highly generalisable without being laborious for participants; taking 5 to 10 minutes to complete (Sintonen, 2001).

Past research shows participants often fail to complete the question relating to sexual health, more than would be expected by chance (Sintonen & Richardson, 1994). In order to avoid missing data QoL questions were forced choice, meaning that in order to complete the questionnaire a participant had to answer to each statement. If a statement was skipped the participant was prompted to select a response before continuing.

Questionnaire Conclusion. A final question was presented that invited participants to volunteer feedback, or to elaborate or clarify any of their previous answers. This meant that should a question, or fixed response, not have been appropriate, then further information could be used to check construct validity within the data. Feedback can be used to revise and improve future use of the questionnaire.

Ethics

Ethics approval from Macquarie University Human Research Ethics Committee was obtained for this study (Reference No: 5201600165; see appendix F).

Participants

As depicted in figure 4, of the 110 people who accessed the questionnaire information using the web link or QR code (appendix C), 97 provided consent, and 74 proceeded to the questionnaire. Two participants did not meet age requirements and were thus ineligible, and excluded from analyses. Of the 72 eligible questionnaires, 69 were completed in full.

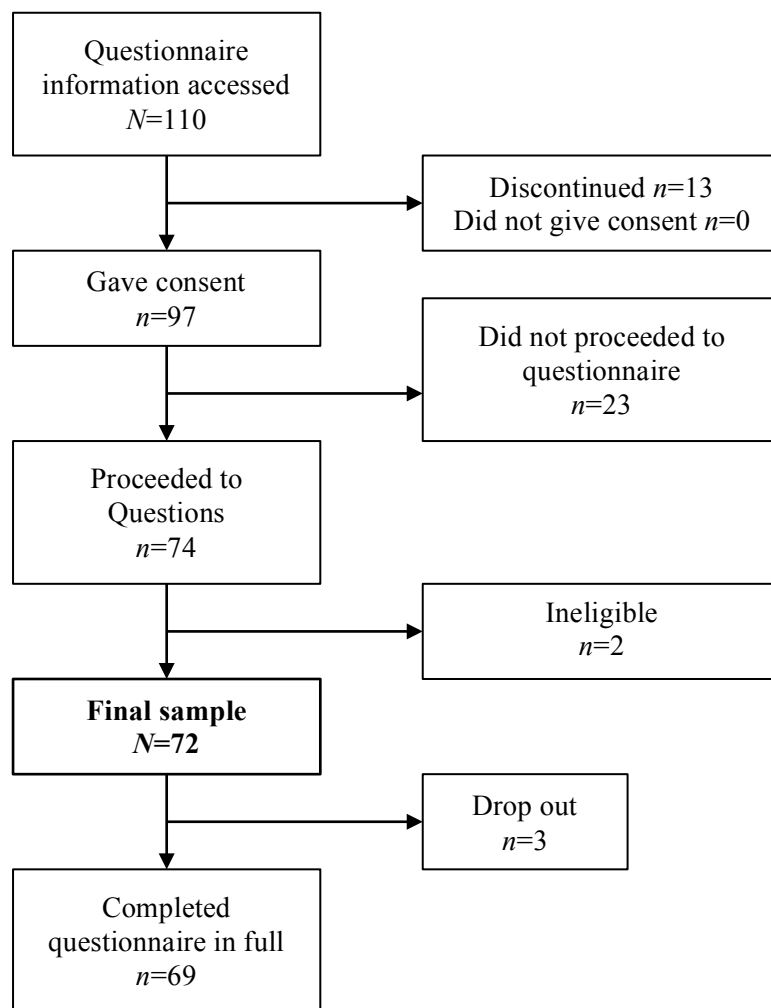


Figure 4. Distribution of questionnaire access, consent, and completion

Of the 63 participants to volunteer their gender, a disproportionate number were female (54 female, 9 male). Participants varied widely in age, from 20 to 53 years, with a mean age of 31 years ($SD=7.21$). All participants were conceived using donated sperm, as opposed to being born from egg and embryo donations. The

majority of participants were residing within Australia (94.4%; $n=68$), most commonly in Victoria or New South Wales (NSW). Geographical distribution of residence can be seen in further detail in figure 5.

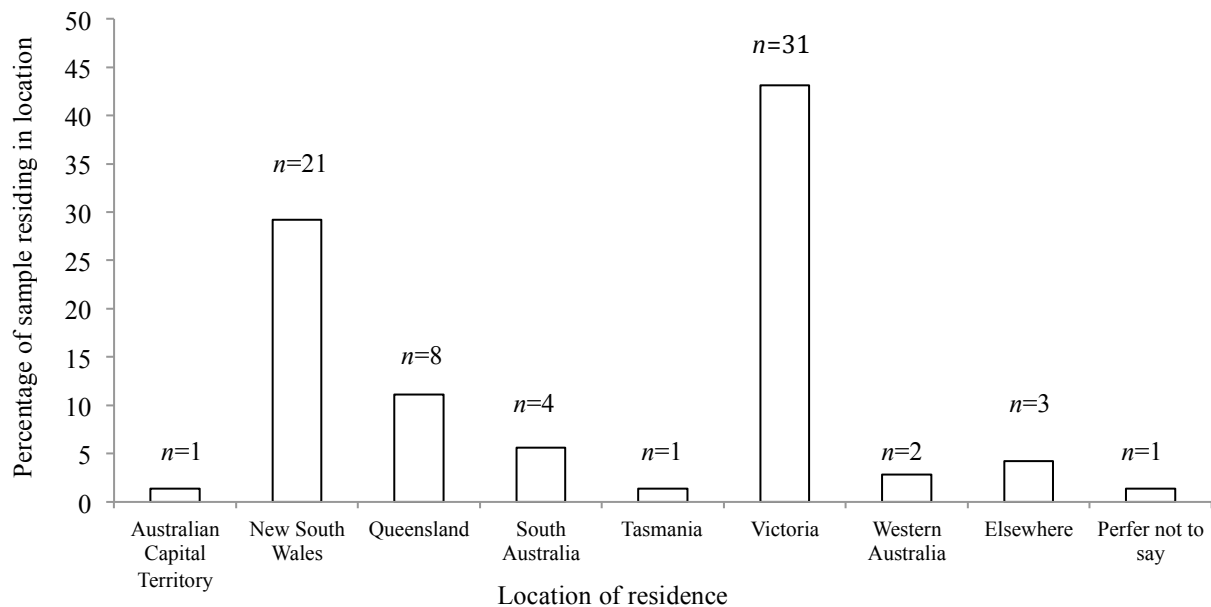


Figure 5. Geographical distribution of participants according to current residence

Results

Analytic Plan

This research first aimed to better understand the characteristics of the Australian donor-conceived population which is described below, accompanied by tables and figures. The second aim of this research was to investigate the motivations for donor-conceived people to seek information and/or contact with their donor. Aims 3-5 of the research sought to investigate the psychosocial factors predicting:

- 3a) Identity
- 3b) Genealogical bewilderment
- 4a) Feelings towards donor conception
- 4b) Feelings towards information and disclosure

5a) QoL

It was hypothesised that motivations would vary by psychosocial factors explored within the first research aim, which would also predict identity, genealogical bewilderment, feelings towards donor conception, feelings towards information and disclosure, as well as QoL. Specifically it was hypothesised that donor-conceived people who report a positive relationship with their non-biological parent would report strong identity, and more positive feelings towards donor conception compared to donor-conceived people who do not report a positive relationship with their non-biological parent. It was also hypothesised that donor-conceived people who found out about their conception from an earlier age, and who have known longer would report strong identity compared to donor-conceived people who found out later in life, and who have known for a shorter amount of time. Furthermore, it was hypothesised that QoL among donor-conceived people would be lower compared to the general population based on the algorithm by Koskinen, Lundqvist and Ristiluoma (2012).

SPSS Version 23.0 was used for all data analysis. Prior to analysis, data was checked for accuracy of entry, missing values were assessed and the assumptions of multiple regression, logistical regression and Mann-Whitney *U* test were checked, where applicable.

The results of the logistic regression analyses are based upon the inclusion of gender with three categories: male, female and unknown, as the unknown category represented more than 5% of participants. The analyses were also run with two categories of gender (male/female), using only 63 participants. As the results did not significantly change, three categories of gender are presented for all analyses.

Missing Data

Inspection of the data revealed less than 5% missing data on any variable, and

indicated data was missing at random. One participant partially completed demographic information. Two participants did not complete questions relating to motivations, identity, genealogical bewilderment, family relationships, or QoL. In order to retain as much information as possible missing data was addressed pairwise. Only when missing data related to the research question was the case excluded. This meant that the initial aim was addressed using a sample of 72, while the later aims were addressed using a sample of 69.

Inter-Rater Reliability

Before analyses were conducted the motivations, which participants entered as free-text, were categorised into themes in order to aid in analysis and to increase statistical power (Field, 2013). For example responses such as; *for medical information, to get an accurate medical history, to find out if there are genetic conditions I should be aware of* were collated into the category *to obtain medical history*. Two researchers completed categorisation and the level agreement was established by dividing the level of agreement between researchers. This was then multiplied by 100 and displayed as percentage reliability. Inter-rater reliability was 96.26%. Disagreements were discussed until reliability was 100%.

Aim 1: Characteristics of Donor-Conceived People

Age at disclosure and years known. Age at which participants found out they were donor conceived varied widely; from always knowing (0 years old) to finding out at 36 years of age ($M=15$, $SD=9.67$). Participants indicated that they had known for less than a year to 49 years ($M=15$, $SD=10.57$). Only one participant indicated that they had always known about their donor conception, however a small group (10%; $n=7$) did indicate that, while they have not always known, they knew before they were 4 years old.

Location of conception. Donor-conceived people appear to be conceived Australia wide (see figure 6), in a number of settings. As per figure 7, donor-conceived people were not necessarily conceived in a registered fertility clinic, some were conceived in private doctor's rooms (e.g., rooms of a General Practitioner), or at home. Some participants were unsure what clinic their parent/s sought treatment, or if a clinic was used at all; of those all bar 1 had known for less than 12 months.

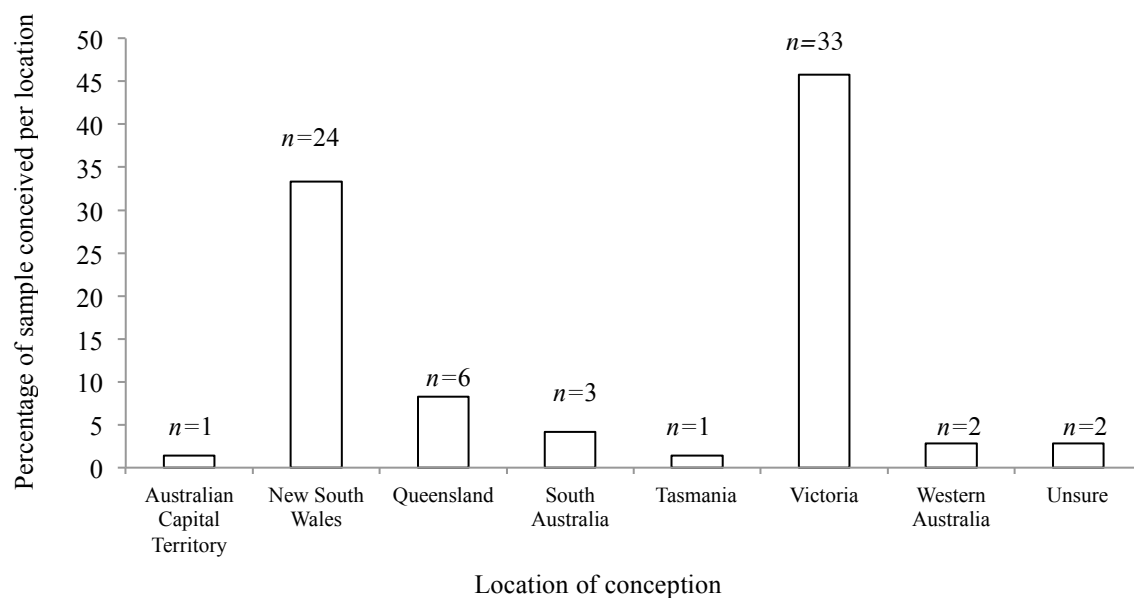


Figure 6. Geographical distribution of participants according to state of conception.

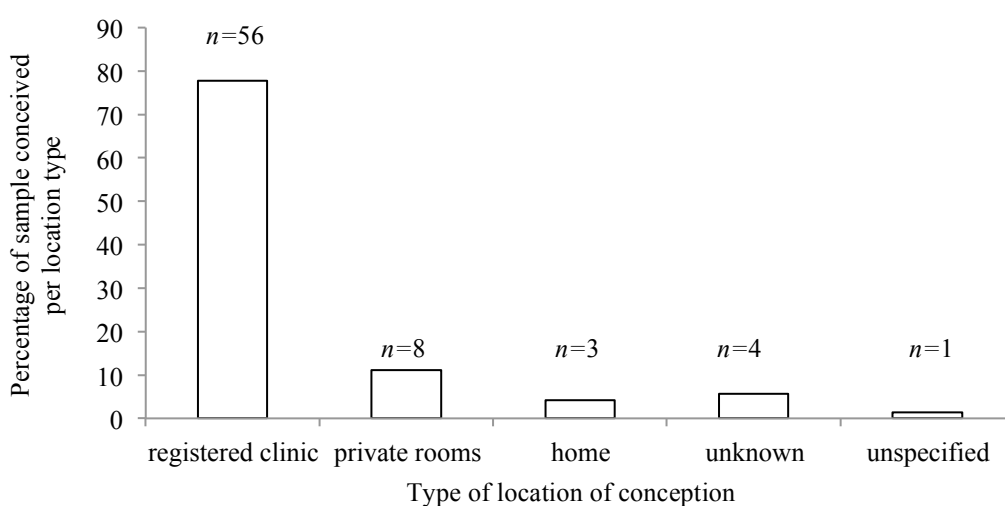


Figure 7. Distribution of participants according to type of location where conception was performed

Family structure. As per previous research (Sawyer, Blyth, Kramer & Frith, 2013; Scheib, Riordan & Rubin, 2005), family type was dichotomised based on the presence or absence of a co-parent. For instance, *co-parent present* included intact recipient couples, while *co-parent not present* included single-recipient families and separated recipient couples, see table 1. In instances where one or more parents were deceased (15.3%; $n=11$), family type was displayed as family type before death.

Table 1

Distribution of recipient type and current family structure

		Family structure					
		Co parent present		Co parent not present		Total	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Recipient type	Heterosexual couple	33	45.8	35	48.6	68	94.4
	Same-sex couple	0	0.0	1	1.4	1	1.4
	Single	-	-	3	4.2	3	4.2
	Total	33	45.8	39	54.2	72	100

Circumstances surrounding disclosure.

Disclosure. The majority of participants were told of their conception (93.1%; $n=67$). Of those who were told, it was most likely by a parent (92.5%; $n=64$). The remaining either did not remember (2.8%; $n=2$), or found out after reading materials relating to their conception (4.2%; $n=3$), e.g., parent diary. In some instances, parents told participants after they came across information implicating donor conception, such as receiving inconsistent DNA or medical test results, or after asking questions about genetics.

While the majority of those who were told they were donor conceived

indicated that they previously assumed that both their parents were biologically related to them (40.3%; $n=27$), a large proportion indicated that while they did not suspect donor conception, they did *suspect something was different about [their] family* (32.8%; $n=22$). Three per cent ($n=2$) suspected donor conception specifically. A large number of participants felt that at the time of disclosure they were told too young to have thought about their conception (22.4%; $n=15$). One did not answer the question. Of those who discovered they were donor conceived independently (4.2%; $n=3$), all indicated that they assumed their non-biological parent was in fact biological.

Events accompanying disclosure. All but one participant answered questions about the events associated with disclosure, or discovery, of donor conception. Almost half of participants (45.8%; $n=33$) indicated there were associated events; these can be seen in more detail in figure 8. One participant could not remember.

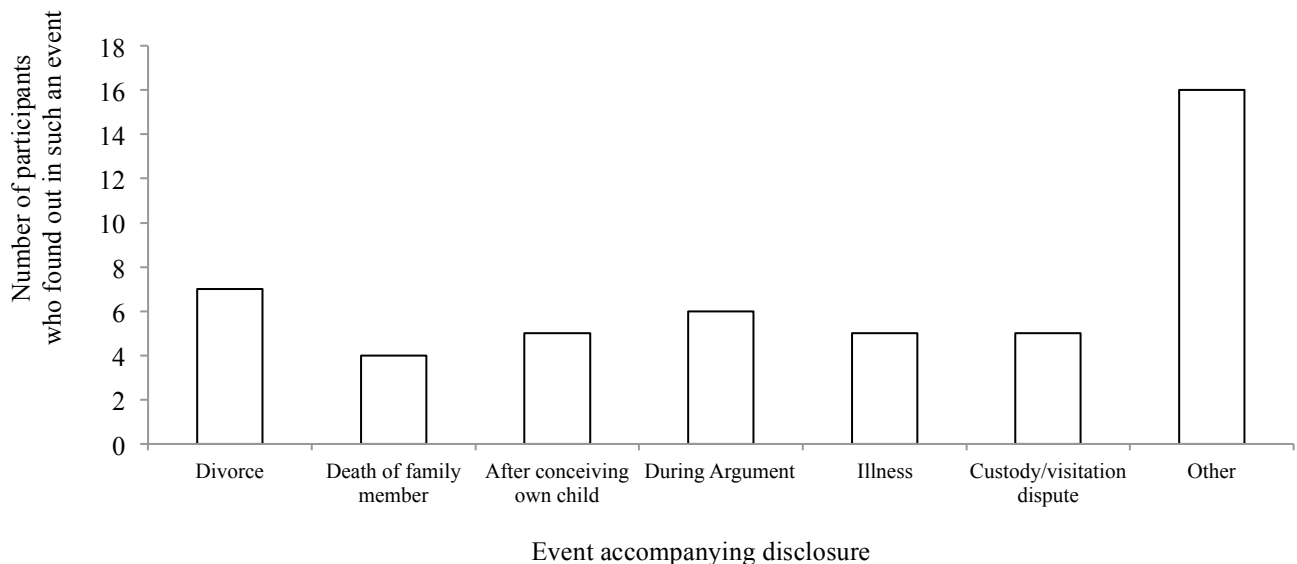


Figure 8. Frequency of events coinciding with disclosure, participants could list multiple events.

Other events accompanying associated with disclosure included: while on holiday, on birthday, after legislative changes, and while the participant, or a friend, was receiving fertility treatment.

Aim 2: Motivation to seek Information and Contact with Donor

Motivations for seeking information about donors. Ninety per cent of participants ($n=65$) indicated that they had sought information about their donor, of those the majority reported the attempt was successful (58.5%; $n=38$). A small number indicated another family member had sought information about their donor (8.7%; $n=6$). Only two participants explicitly indicated that they had not been motivated to seek information about their donor. No participant had always had information. All donor information was made available to a small number of participants without then having actively seeking it out (2.9%; $n=2$); e.g., finding their donor through DNA testing, without prior knowledge of being donor conceived.

A logistic regression analysis was planned to assess whether gender; age the participant found out, and the number of years they have now known, about their conception; family structure, whether a parent told them and if there were accompanying events could predict the likelihood of a participant seeking information about their donor. However, with such an uneven sample the results could lead to unreliable conclusions, and thus analysis was not attempted.

The process of seeking information had cost individuals between AU\$0 and AU\$5,000 ($Mdn=350.00$). Many of those who had spent less indicated that they had only just started seeking information, while higher numbers reflected multiple unsuccessful attempts to obtain information.

Of the 65 participants motivated to seek information about their donor, the most commonly reported primary motivations (first listed) were curiosity and seeking

medical history. Each was equally ranked as a primary motivation (30.4%; $n=17$), these were followed by reasons relating to genealogical bewilderment (28.6%; $n=16$), it being a right (8.9%; $n=5$), or other; *to thank him* (1.8%; $n=1$). Remaining participants did not list motivating factors. No participant listed finding out about half-siblings as their primary motivation.

Participants could list up to five motivations. Among the 65 participants to list at least one motivation the five most common were: curiosity, to obtain medical history, to relieve symptoms of genealogical bewilderment, to find half-siblings, or because they believed it their right (see figure 9). Genealogical bewilderment included motivations such as *where do I come from?*, *looking for the other half of me*, *to better understand myself* and *to gain a sense of who I am* among similar others. ‘Other’ included less common motivations (e.g., *to learn reasons for donation*, or to avoid the participant’s children forming consanguineous relationships).

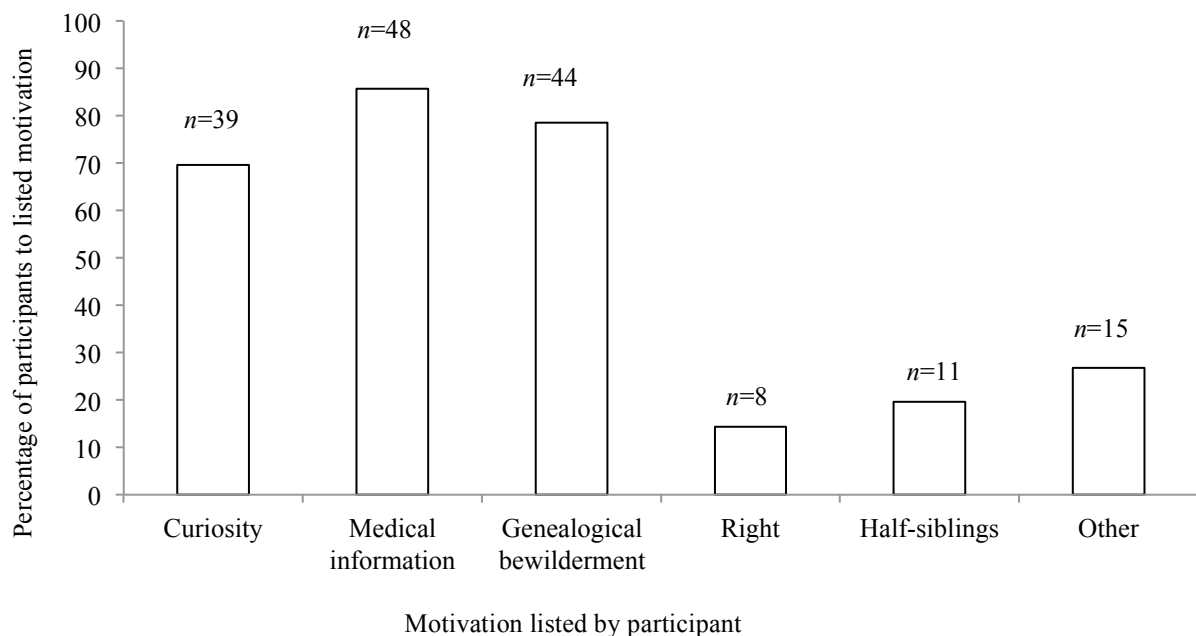


Figure 9. Distribution of motivations indicated by participants who had, or

planned to, seek information about their donor. As participants could list up to five, each participant may have contributed to percentages of more than one motivation.

To assess the psychosocial factors predicting motivations for finding out more information, five binary logistic regressions were performed; one for each motivation; curiosity (*yes/no*), to obtain medical history (*yes/no*), and to relieve symptoms of genealogical bewilderment (*yes/no*), to perform a human right (*yes/no*), and to find out about half siblings (*yes/no*).

For each logistic regression the predictor variables assessed against the outcome variables were; gender; age the participant found out, and the number of years they have now known, about their conception; family structure; circumstances under which they discovered they were donor conceived, including whether a parent told them, and if there were any particular events accompanying disclosure.

Hosmer-Lemeshow goodness-of-fit test and Nagelkerke's R^2 were used to assess how well the model fitted the data, by providing a gauge of the level of significance of each model. Nagelkerke's R^2 was used over other pseudo R^2 values due to its ability to reach a perfect score (Field, 2013).

Multicollinearity. To check that predictor variables were not linearly related a correlation matrix was analysed using Kendall's tau (τ); see table 2. τ was used as it was considered a more robust statistic considering the sample size, and the tied ranks present within the data (Field, 2013). Values above 0.80 indicated multicollinearity. Multicollinearity was not found. As correlation matrices can miss subtle forms of multicollinearity (Field, 2013), variance inflation factor (VIF) was also calculated. VIF confirmed the findings of the correlation matrix, i.e., no multicollinearity present.

Table 2

Correlation matrix of predictor variables

Predictor	[1]	[2]	[3]	[4]	[5]	[6]
[1]	1.00					
[2]	0.33**	1.00				
[3]	0.09	-0.04	1.00			
[4]	-0.05	0.11	-0.57**	1.00		
[5]	-0.21	-0.09	-0.07	0.03	1.00	
[6]	0.02	-0.01	-0.25*	0.32**	-0.16	1.00

Note. Variables entered: [1] gender, [2] family type (co-parent/nil co-parent present), [3] years known about donor conception, [4] age person found out about being donor conceived, [5] told by parent (*yes/no*), [6] events accompanying disclosure; * $p < .05$; ** $p < .001$.

Analyses. The logistic regression model was statistically significant for the motivation; to obtain medical history, $\chi^2(7) = 14.35, p = .045$. The model explained 40.7% (Nagelkerke R^2) of the variance of being motivated by wanting to obtain medical history and correctly classified 89.1% of cases. Specifically, as the number of years one knew about their conception increased so too did their likelihood of being motivated by wanting to obtain accurate medical history. The remaining models were not statistically significant: curiosity, $\chi^2(7) = 9.42, p = .224$; to relieve symptoms of genealogical bewilderment, $\chi^2(7) = 9.09, p = .246$; to find half siblings, $\chi^2(7) = 4.72, p = .694$; or because they believed it their right, $\chi^2(7) = 13.61, p = .059$. Refer to table 3 for more information.

Table 3

Motivations for information about donors, by individual psychosocial factors

Predictors	Curiosity		Medical history		Genealogical bewilderment		Right		Find siblings	
	e ^B (CI 95%)	p	e ^B (CI 95%)	p	e ^B (CI 95%)	p	e ^B (CI 95%)	p	e ^B (CI 95%)	p
Constant	212.47	.066	70 327.61	.069	1.01	.998	0.21	.688	3.87	.653
Gender										
Unknown		.497		.999		.606		.351		.983
Male	0.90 (0.10-8.23)	.924	1.00 (0.08-13.38)	.999	0.29 (0.02-4.40)	.373	0.09 (0.00-2.34)	.148	1.00 (0.81-12.26)	.998
Female	0.26 (0.02-3.84)	.330	2.87 (0.00-)	.999	0.23 (0.01-4.80)	.341	0.36 (0.01-17.10)	.606	1.22 (0.07-22.96)	.894
Years known	0.91 (0.83-1.00)	.061	0.77 (0.61-0.97)	.026	0.88 (0.78-1.01)	.056	1.16 (0.97-1.28)	.114	0.94 (0.83-1.05)	.269
Age at disclosure	0.91 (0.81-1.03)	.137	0.81 (0.65-1.02)	.076	0.89 (0.77-1.02)	.119	1.08 (0.90-1.30)	.421	0.94 (0.82-1.08)	.382
Family type ^a	0.43 (0.09-2.07)	.292	1.78 (0.25-12.74)	.565	0.85 (0.16-4.44)	.849	6.59 (0.27-158.43)	.245	0.56 (0.11-2.88)	.489
Told by parent ^b	0.31 (0.02-3.99)	.365	0.11 (0.00-14.82)	.380	0.00 (0.00-)	.999	0.10 (0.01-1.82)	.121	1.10 (0.10-12.64)	.938
Surrounding event ^c	1.95 (0.47-8.05)	.354	1,17 (0.15-9.00)	.880	0.64 (0.14-2.98)	.571	0.10 (0.01-1.59)	.103	0.27 (0.04-1.64)	.155

Note. ^ascored as *co-parent present/co-parent not present*; ^bscored as *yes/no*; ^cscored as *yes/no*

Motivations for Seeking Contact with Donors

Seventy-one per cent of participants indicated that they had attempted to contact their donor ($n=49$). The remaining indicated that they 1) had never sought contact (21.7%; $n=15$), 2) another member of their family had attempted contact (5.8%; $n=4$), or 3) they had always had contact with their donor (1.4%; $n=1$).

Of primary motivations, seeking an accurate medical history and to relieve symptoms of genealogical bewilderment were equally listed as the primary motivation (30.6%; $n=15$), followed by curiosity (20.4%; $n=10$), to form a relationship (4.1%; $n=2$), and to find half siblings (2%; $n=1$). The remaining (12.2%; $n=6$) listed an alternative (other) motivation as their primary motivation.

A binary logistic regressions was performed to assess whether gender; age the participant found out, and the number of years they have now known, about their conception; family structure, whether a parent told them and if there were accompanying events could predict the likelihood of a participant seeking contact with the donor. The outcome variable (attempting contact; *yes/no*) included those who had attempted contact and those who had not. For this analysis those who had always had contact with their donor, or whose siblings had attempted contact, were excluded. The model was not significant $\chi^2(7) = 4.84, p = .679$.

Of participants motivated to seek contact with their donor, they could list up to 5 motivations. The most commonly listed motivations were: curiosity, to obtain medical history, to relieve symptoms of genealogical bewilderment, to form a relationship or to find half-siblings, see figure 10. 'Other' included less common motivations (e.g., *to thank him, I want them to know I exist, and I want a true birth cert[ificate]*). Unlike motivations for seeking information, believing it was a 'right' was listed less often (6.1%) and therefore classified as 'other'.

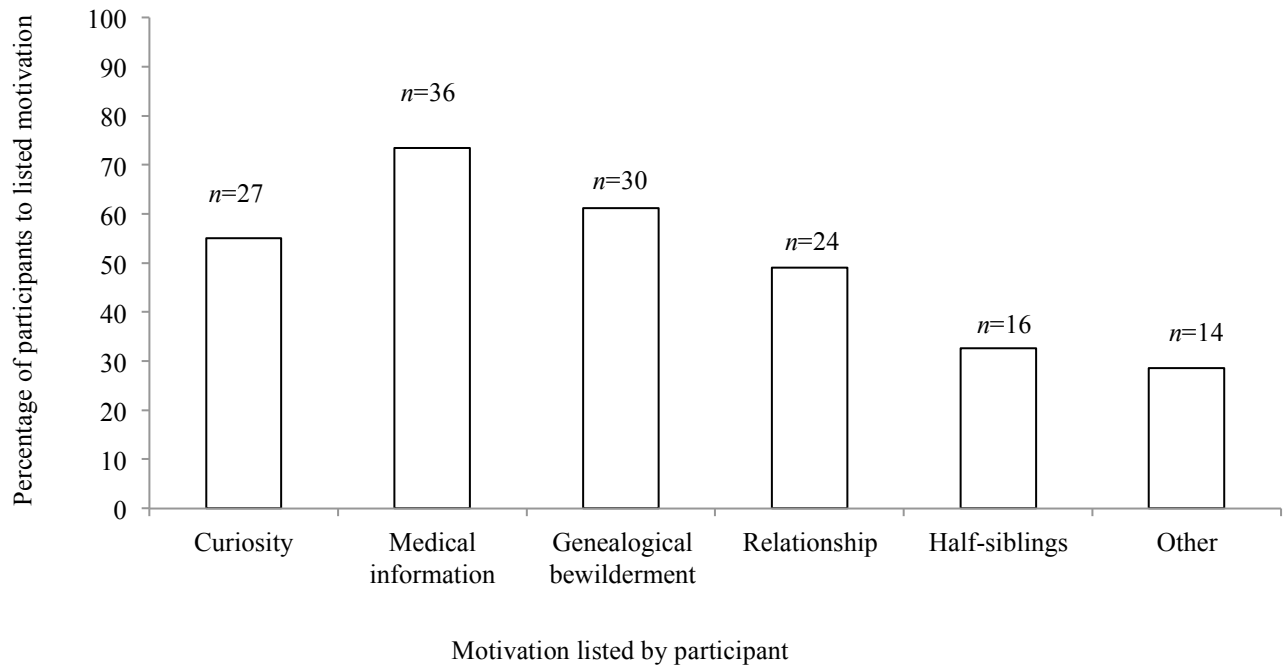


Figure 10. Distribution of motivations indicated by participants who had attempted contact with their donor. As participants could list up to five, each participant may have contributed to percentages of more than one motivation.

To assess the association between psychosocial characteristics of donor-conceived people and their motivations for seeking contact with their donor, five binary logistic regressions were performed; one for each motivation; curiosity (*yes/no*), to obtain accurate medical history (*yes/no*), to relieve symptoms of genealogical bewilderment (*yes/no*), to form a relationship (*yes/no*), and to find out about half siblings (*yes/no*).

For each logistic regression the predictor variables assessed against the outcome variables were; gender; age the participant found out, and the number of

years they have now known, about their conception; family structure, whether a parent told them and if there were accompanying events.

The logistic regression model was not significant for: curiosity; $\chi^2(7) = 13.18$, $p = .068$, to obtain medical history; $\chi^2(7) = 3.22$, $p = .864$, to relieve symptoms of genealogical bewilderment $\chi^2(7) = 5.83$, $p = .559$, wanting a relationship $\chi^2(7) = 10.05$, $p = .118$, nor for finding half siblings, $\chi^2(7) = 7.00$, $p = .429$. For more information see table 4.

The following page contained errors, which have been corrected in a forthcoming article in Fertility and Sterility. Full citation to be advised.

Aims 3- 5: Identity, genealogical bewilderment, feelings towards donor conception status and disclosure, and QoL. A series of logistic regressions were considered the most appropriate, and statistically robust analysis based on the data (Field, 2013; Ingram, Gleser & Derman, 1994). To perform a binary logistic regression, outcome variables were dichotomised according to median score (those who scored below the sample median, and those who score at, or above, the median). The median was chosen, as opposed to the mean, as neither skew nor outliers influence it. This allowed for two equal groups. See table 5 for more information. Remaining assumptions of logistic regression were recognised and met by the data. Sixty-nine participants were included in each analysis as they successfully completed all questions relating to the dependent variables.

The logistic regression analyses were conducted to predict:

- a) The strength of identity
- b) Genealogical bewilderment
- c) Feelings towards donor conception
- d) Feelings towards information and disclosure, and
- e) QoL

Predictor variables included: gender; age the participant found out, and the number of years they have now known, about their conception; family structure; circumstances under which they discovered they were donor conceived, including whether a parent told them, and if there were any particular events accompanying disclosure; as well as relationship with biological parent; and relationship with non-biological parent.

Table 5

Descriptive characteristics for outcome variables assessed using binary logistic regression, and predictor variables not described elsewhere

	<i>M</i>	<i>SD</i>	<i>Mdn</i>	Minimum	Maximum
Identity	27.25	4.24	28	17	34
Genealogical bewilderment	28.58	8.87	30	11	45
Feelings towards donor conception	45.42	13.23	46	19	69
Feelings towards information and disclosure	57.12	7.62	59	27	65
Sample QoL	0.8916	0.0846	0.8952	0.6859	1.00
Standardised sample QoL	0.9409	0.0081	0.9349	0.9300	0.9680
Relationship with biological parent	3.85	1.15	4.20	1	5
Relationship with non-bio parent	3.30	1.12	3.17	1	5

Identity. A test of the full model against a constant only model was not statistically significant, indicating that the predictors as a set could not reliably distinguish donor-conceived people with high identity scores, compared to those with low identity scores, $\chi^2(9)=10.85, p=.286$. For more information refer to table 6.

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and were therefore excluded from analysis. QoL in donor-conceived people ($Mdn=0.8952$) was significantly lower compared to QoL within the general population ($Mdn=0.9349$) at the time of assessment, $U=4.34$, $p=.004$.

Discussion

The present study aimed to better understand the Australian donor-conceived population, including how and when they found out about their donor conception. Furthermore, it aimed to understand the motivations of members to seek information and/or contact with their donor, and to understand how the psychosocial characteristics of family dynamics and circumstances around disclosure relate to identity, genealogical bewilderment, feelings towards donor conception, feelings towards information and disclosure, as well as QoL.

It was hypothesised that gender, circumstances surrounding disclosure (including age told, years known, whether they were told by a parent, any associated events), as well as family type (co-parent present/co-parent not present), would predict one's likelihood of seeking information and/or contact, as well as the likelihood that they would report each motivation (curiosity, to obtain medical history, for information about half-siblings, to relieve systems of genealogical bewilderment, believing it is a right, or to form a relationship). For instance, it was hypothesised that people who had known about being donor conceived longer would more likely report being motivated by wanting an accurate medical history compared to those who had known for less time, who were hypothesised to report being motivated by curiosity.

As part of the final three research aims, it was hypothesised that the same predictors as those relating to aim two, with the addition of relationship with biological and non-biological parents, would predict donor-conceived peoples'

identity, genealogical bewilderment, feelings towards donor conception, information and disclosure, as well as QoL. For instance it was hypothesised that donor-conceived people who report a positive relationship with their non-biological parent would report strong identity, and have a more positive attitude towards donor conception compared to donor-conceived people who do not report a positive relationship with their non-biological parent. Consistent with previous theories (Baran & Pannor, 2008; Narelle, 2005; Pascoe, 2016) it was also hypothesised that donor-conceived people who found out about their conception from an earlier age, and who have known longer will report stronger identity compared to donor-conceived people who found out later in life, and who have known for a shorter amount of time.

Characteristics of Donor-Conceived People

A diverse sample of donor-conceived people presented. The study incorporated males and females, who varied widely in age, were distributed across Australia, grew up on a range of family types, and presented various experiences. Contrary to research investigating the impacts of disclosure on younger donor-conceived people (Persaud, 2016), donor-conceived people in this study were more likely to have found out later in life. Consistent with previous literature (Kirkman, Rosenthal & Johnson, 2007), finding out from someone other than a parent was not uncommon, although finding out directly from a donor was. In some such cases it is possible for parents to be unaware their child knows the true history of their conception, and while this study aimed to represent this group, it appeared that majority of non-disclosing parents were made aware of the disclosure prior to participation.

Donor-conceived people were found to span large geographical area. However a disproportionate number of individuals conceived and living in Victoria and NSW

presented. This was not unexpected. Victoria is considered the least conservative Australian state, enforcing the most progressive donor-conception related legislation, (Allan, 2016a) followed by NSW (Sifris, 2014). Victoria was also one of the first jurisdictions in the world to legislate donor conception (Johnson, Bourne & Hammarberg, 2012) under the *Infertility (Medical Procedures) Act 1984* (Vic), and established Australia's largest provider (*Monash IVF*; Medew & Baker, 2013). Meanwhile socially infertile recipients were known to seek treatment in NSW as, unlike other states, it did not legally require recipients be medically infertile (Rickard, 2001). Victoria and NSW states are also the most populous in Australia (Australian Bureau of Statistics; ABS, 2016). By this token, it may be that these states do in fact have the most donor-conceived people, or the most donor-conceived people aware of their conception.

Such a presentation confuted claims that studying donor conception is only possible among children of same-sex recipient couples (Vanfraussen, Ponjaert-Kristofferson & Brewaeys, 2001), and illustrated the diversity of experiences of donor-conceived people. This study was able to acquire a sample donor-conceived people from a variety of family types, notably from heterosexual recipient couples, and who were conceived when stigma was prominent and secrecy was encouraged (Allan, 2012). It was also able to do so without appealing exclusively to support networks, members of which may have been biased towards a particular mindset due to the communication that is expected between members.

Additionally, this is now the largest group of Australian donor-conceived people to participate in research. This has allowed for an understanding of the population in greater detail than previously available, and thus the extent to which previous research can be appropriately generalised.

Motivations of Donor-Conceived People to Seek Information and Make Contact with Donors

To the best knowledge of researchers, motivations for seeking information, and for contacting donors, has never been investigated. Thus, motivations were gathered using free-text whereby participants volunteered their answers qualitatively. A preliminary review of the data revealed strong themes. These were consistent with anecdotal accounts (Allan, 2016a), and as the same motivations consistently presented, it became apparent that donor-conceived people are similarly motivated.

The hypothesis that gender, circumstances surrounding disclosure (age told, years known, whether they were told by a parent, any associated events), as well as family type (co-parent present/co-parent not present) would affect one's likelihood of seeking information could not be analysed as the overwhelming majority of the sample had sought information. This suggests that to seek information about their donor is the norm. However, how such factors influenced one's likelihood of indicating particular motivation was mixed. The hypothesis that donor-conceived people who had known about their conception for a greater length of time would more likely indicate wanting to obtain medical history as a motivating factor was supported. However, the hypothesis that those who had known for a shorter amount of time would more likely indicate curiosity as a motivating factor was not supported. The same factors were also unable to predict whether one would be motivated by: relieving symptoms of genealogical bewilderment, to find half siblings, or believing it a right.

The findings of the supported hypothesis show that the longer an individual knew about their conception the more likely they were to be motivated by seeking an accurate medical history. This may indicate that the longer an individual is aware they

are donor-conceived the more aware that they are of the implications of missing such information. For example, they may have experienced more occasions of needing to recite their family's medical history. However, it may also be that for some people who are older, they have known about their conception longer, and thus are becoming more conscious of it as their health increases in priority. Albeit, the later conclusion assumes that older participants had known longer, and while this was apparent for a large proportion of the group, many older participants had known for a short amount of time, while many younger participants had known since infancy.

Interestingly, while curiosity was not the most commonly listed motivation for information, when listed it was likely to be the primary motivation (first listed). While donor-conceived people argued the importance of accurate medical history in previous legal discussions regarding transparency of information (Allan, 2016d; Parliament of Victoria, Legislative Assembly, February 23, 2016), curiosity was seldom mentioned. Public perception that donor-conceived people are just wanting access to their medical history may be influenced by it being the more socially acceptable excuse within the community. That is, on the occasion that an Australian donor-conceived person has reported being curious about their donor, it has been met with community backlash (e.g., 'It'sonlyme', 2015; 'Politically Incorrect', 2015; Rodrigues, 2015). This information further suggests that an online questionnaire, and de identifying data, produced a safe environment that fostered honesty.

No psychosocial factors could accurately predict one's likelihood of seeking contact with their donor. Among those who had sought contact, no psychosocial factor could accurately predict what motivated individuals. Thus it appears that what motivated a person to contact their donor was explained by factors outside of the model, or that motivations remained consistent among donor-conceived people

irrespective of such factors.

However, it was apparent that motivations to seek contact with a donor, mirrored motivations listed for seeking information. The exception being that donor-conceived people commonly believed seeking information was within their rights, which was seldom mentioned in relation to seeking contact. The second difference was that when attempting contact some donor-conceived people were motivated by the desire to form a relationship with their donor; this was not listed as a motivation when seeking information. The absence of believing it a right to contact the donor was unexpected as some donor-conceived people are now legally entitled to contact their donor (via fertility clinic of conception, or statutory authority; e.g., *Infertility [Medical Procedures] Act 1984* [Vic]).

Consistent with observations by Adams and Allan (2013) this study also found that there were financial repercussions for seeking information about one's donor conception, particularly among those who had been looking for information longer. It may be that those who have attempted to fulfill their motivation for seeking information have experienced more unsuccessfully attempts, disinclined to stop seeking information, and spending money, due to possible distress associated with genealogical bewilderment.

Donor-Conceived People's Identity, Severity of Genealogical Bewilderment, Feelings Toward Donor Conception and Information and Disclosure, and QoL

The hypothesis that gender, circumstances surrounding disclosure (age told, years known, whether they were told by a parent, any associated events), family type (co-parent present/co-parent not present), as well as the parent-child relationship would impact donor-conceived peoples' identity, so too their level of genealogical

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1999). In order to understand QoL among donor-conceived people, future research is required to evaluate QoL in more detail.

Clinical Implications

In order to access information, or contact their donor, donor-conceived people conceived in Western Australia or Victoria are subject to mandatory counselling before information is sought (Blyth & Frith, 2009; e.g., *Assisted Reproductive Treatment Act 2008* [Vic]). People born within other jurisdictions may also be required to attend similar counseling sessions as clinic policy. This was introduced to check that a person was “sufficiently mature to understand the consequences of seeking the information” (p.7 Blyth & Frith, 2009). However, in order to retain therapeutic value, clinicians need to understand the population and the difficulties donor-conceived people face. This study offers treating clinicians information about donor-conceived people in order to assist therapy in two prominent ways. Firstly, it has gone some way to help clinicians understand more about the donor-conceived population (their clients), which can further aide in rapport and in meeting their needs. For example, there does not appear to be a ‘typical’ presentation of a donor-conceived person - they vary widely in age and personal experiences, they may or may not have been told about their conception by their parents, or in a planned manner. This can also be used to aide in communication as donor-conceived people have reported communicating with professionals about donor conception, and trusting professionals, is particularly difficult (Turner & Coyle, 2000). Secondly, it can assist clinicians in prioritising time by understanding which areas are likely to require attention. One overarching area is QoL. Other areas are more likely to be client specific, for example, if a donor-conceived person presented from a separated family, and reported a negative relationship with their biological parent, the clinician can spend time

investigating the client's experiences of genealogical bewilderment and feelings towards donor conception which, according to our study, are more likely to be an issue for the patient.

Legislative implications

Many countries now recognise the effects of anonymity on donor-conceived people and permit only open-identity donors (Allan, 2016a; Blyth & Frith, 2009). However, this has previously only been prospective, so while many people are protected against any negative effects, the majority of current adults have been born to anonymous donors.

In Australia, legislation and recommendations relating to donor conception are state specific. This means that donor-conceived people within this study varied on the legislation by which they are bound, which was not necessarily their state of residence. Only in Victoria, is information to be made available retrospectively to all people conceived there (after March; *Assisted Reproductive Treatment Amendment Act 2015* [Vic]). This means that Victorian recipients who travelled interstate for donor-conception treatment, their child will be unable to obtain the same level of information as other Victorian's. The findings of this study support the call (Allan, 2016d) for equality, and for information to be made available to donor-conceived people Australia wide, irrespective of age.

Research will be required after the implementation of new legislation, particularly to understand the implications of unfulfilled motivations. For example many donor-conceived people will have the ability to obtain previously inaccessible information allowing them to fulfill their desire to obtain an accurate medical history, or information about half-siblings. However a number of factors are likely to present hindering a donor-conceived person's ability to achieve their goals. These include;

discovering records are missing, modified or destroyed (Dingle, 2014; Hewitt, 2002; Needham, 2016; New South Wales Government, 2015; Rowland, 1985), finding a donor has died, or that a donor has chosen to sign a contact veto (to be introduced in Victoria March 2017; *Assisted Reproductive Treatment Amendment Act 2015* [Vic]). The prevalence and implication of each are unknown, so too the extent to which they will affect the lives of donor-conceived people, including identity, genealogical bewilderment, feelings towards donor conception, feelings towards information and disclosure, and QoL.

Limitations and Future Directions

Although the present study adds to the growing understanding of donor conception, secrecy and anonymity, it has several limitations. Firstly, although now the largest known sample of Australian donor-conceived adults, despite aiming to holistically evaluate donor conception, the results can only be applied to people conceived using donated sperm. No person conceived using egg or embryo donation participated in this study. There was also difficulty in comparing donor-conceived people who were told about their conception, to those who discovered the truth independently. This study hoped to represent this previously under-represented group. While the existence of this group was confirmed, due to such low numbers their data was could not be analysed reliably.

The dynamics of the sample may have further restricted the generalisability of findings. Despite the practice being available Australia wide, not all states were represented in the sample. In order to substantiate whether results extend nationwide, it is recommended that this study be replicated with a more extensive sample to increase reliability. Recruiting participants over a longer timeframe may assist with this, and links with fertility clinics may offer an avenue for future research where

donor-recipient families could be followed longitudinally from the period of pre-conception. It is also apparent that generalisation, where possible, is restricted to donor-conceived people who are aware of their conception, which is believed to be a small proportion of all donor-conceived adults (Narelle, 2005; Turner & Coyle, 2000). However, due to the nature of donor conception, identifying and directly accessing this portion of the population is not currently possible.

Furthermore, of those who identified a gender, the majority were female (85.7%). While it is not known how many donor conceived-people there are, and this being the first Australian study investigating demographics in detail, it is unlikely that among the general population donor-conceived females outnumber donor-conceived males six to one. A similar trend has presented in the international literature (Jadva, Freeman, Kramer & Golombok, 2009), thus while it appears a difficult endeavor, future research needs to strive to be more inclusive of males. Recruitment strategies may be one method. As this study relied heavily on third party distribution and snowballing, if males are less inclined to communicate donor-conception, or their feelings in general (Parkins, 2012), they may not have been identifiable to persons who did receive the information.

Finally, it would be interesting to assess whether having a child of one's own changed one's motivation to seek information or contact with a donor, as well as feelings towards donor conception, and information and disclosure. Some participants volunteered information revealing that for them having children impacted their motivations for seeking information (e.g., "...for my children"). The same can be said for the death of a parent. A group of participants volunteered the information that at least one of their parents was deceased. However, there were no means included in which to measure this. Such an implication may have affected how participants

responded to questions or may have presented as a confounding variable. Future research could incorporate specific questions to control for such dynamics and establish the effects. It is also noteworthy that such information (relating to children and deceased parents) was often volunteered in early qualitative style questions (e.g., “...describe your family”), which demonstrated their importance within this study.

While this study was able to evaluate the current donor-conceived population, it is recognised that frequent research is needed in order to remain relevant. This population is continuing to develop and expand with an average of 4 new Australian donor-conceived people identifying themselves each month (2015-2016; Australian Donor Conceived People Network, n.d.)

This study also supports the concerns of donor-conceived people that previous research has overlooked the biological-parent-child relationship. Turner and Coyle (2000) noted that while investigating donor conception participant feedback highlighted the focus on non-biological parent relationships and questioned the studies validity. As such, relationships with biological and non-biological parents were treated equally within this investigation and, consistent with comments made by participants in Turner and Coyle’s study, was in fact an area of significance. Future research therefore should also acknowledge the impact of both relationships in donor-conception.

Concluding Remarks

First, this study was able to demonstrate that members of the donor-conceived population, particularly those born in an era of secrecy and anonymity, are accessible; including those whose parents were heterosexual recipients couples (*cf.* Vanfraussen, Ponjaert-Kristofferson & Brewaeys, 2001), and that a more representative sample can be generated than previously thought possible. The research extended the current

understanding and representation of donor-conceived adults, by undertaking a more thorough investigation about the effects of donor conception, secrecy, and anonymity. This has been accomplished among an adult donor-conceived population circumventing the need to rely on international data (where donor conception practices are different), parent reports and data from younger populations or support group members.

Second, the results of this study shed some light on who donor-conceived people are, and what kind of lives they have led. This research suggests that donor-conceived people are a heterogeneous population. They appear to live in a variety of family types, are diverse in age, have known about their donor-conceived status for varying degrees of time, and are finding out about their conception at various ages and under various circumstances. Previously due to their inaccessibility characteristics of this population have been greatly overlooked, or speculated at best. In research that has assessed donor conception such characteristics have recently been identified as confounding, for which this study has acknowledged and controlled for.

Third, it was the first study to investigate motivations of donor-conceived adults to seek information about, and contact with, their donors. Donor-conceived people appear to be similarly motivated. Although highlighted in anecdotal accounts (such as that presented at Government of South Australia, 2016; Parliament of Tasmania, 2016; Parliament of Victoria, Legislative Assembly, February 23, 2016), this research is able to confirm that having an accurate medical history is particularly important to donor-conceived people who have known about their conception for longer. It also showed that donor-conceived people are motivated to seek information in order to uphold their right, to reduce symptoms of genealogical bewilderment, to find half siblings, and to fulfil curiosity. Furthermore this research showed that

forming a relationship with their donor is also, to a lesser extent, important to donor-conceived people, and has motivated them to seek contact with their donor.

Lastly this study has helped to establish further understanding about identity, genealogical bewilderment, feelings towards donor conception, feelings towards information and disclosure and QoL among donor-conceived people. The range in scores showed that each effects donor-conceived people to different degrees and supports the notion that while genealogical bewilderment is relevant for many donor-conceived people it appears to be more of an issue for some than others (Allan, in press). The extent to which each is effected by various psychosocial factors, as well as parent-child relationships was also established; notably the significance of the relationship between biological-parent and adult-child.

This study fills a significant gap in the literature on donor-conceived people, and will benefit from further longitudinal research covering donor-conceived people over the course of their life span. Furthermore it informs the direction of future research by offering a more in-depth understanding of the diversity of this population. Due to the consistent developments relating to donor conception, progression in legislation, and the augmentation of donor-conceived people aware of their donor-conceived status, it is important to continue this research in order to best serve those who are most profoundly affected by donor conception, secrecy, and anonymity: the donor-conceived people.

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Appendix A

Letter Sent to Organisations with Information About Study Information



Project Title: A Study on the Effects of Donor Conception, Secrecy and Anonymity, based on Responses of Donor Conceived Adults

Principal Researcher(s): A/Prof Sonia Allan

Associate Researcher(s): Caitlin Macmillan

Project Number: 5201600165

To whom it may concern,

Ms Caitlin Macmillan, a post-graduate researcher at Macquarie University, is conducting an investigation into what, if any, effect donor conception has had on persons born from the practice. A/Prof Sonia Allan is supervising the project.

Persons *over 18 who are donor conceived, conceived in Australia*, are invited to take part in a 60-minute online survey. This survey is comprised of questions relating to their thoughts, attitudes, and experiences towards being donor conceived. A variety of question types are included. Questions include multiple choice, Likert scale response questions and qualitative questions. The weblink is as follows: https://mqedu.qualtrics.com/jfe4/form/SV_9ZyilK6XXttNTn

With this letter an advertisement and plain language statement has been included. Please forward on information to persons who may be interested and who meet the criteria, they are invited to forward the information on further.

Participation is voluntary. Information will remain confidential. Participants are not required to give their name. Information that may be identifiable, such as names, dates, or codes, will be de identified. This questionnaire will be available online until midnight 31st August 2016. Results of the project will be available January 2017.

If you require any further information please contact Caitlin Macmillan at the following email: caitlin.macmillan@hdr.mq.edu.au

Kind regards

Caitlin Macmillan

Macquarie University: Department of Health Systems and Populations

L6 625 75 Talavera Rd

Macquarie University NSW 2109

Email: caitlin.macmillan@hdr.mq.edu.au

Appendix B

Study Advert



ARE YOU DONOR CONCEIVED?

OR DO YOU KNOW SOMEONE WHO IS?

CLICK OR SCAN:

https://mqedu.qualtrics.com/SE/?SID=SV_9ZyzilK6XXttNTn



18+

Donor conceived
adults



Online questionnaire
60 minutes



Australia
wide

Macquarie University HREC 5201600165

Faculty of Medicine and Health Sciences
Department of Health Systems and Populations

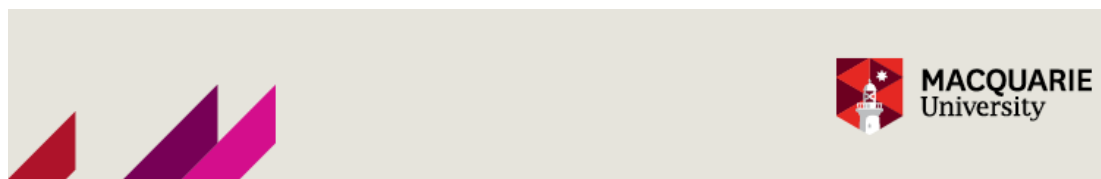


MACQUARIE
University
SYDNEY • AUSTRALIA

Appendix C

Further Information About Study

When the weblink or quick response code on advert about study is used, the following information is displayed, with a link to begin the questionnaire which first takes participants to the plain language statement (appendix D)



Introduction

ARE YOU AN AUSTRALIAN DONOR CONCEIVED ADULT?

Little is known about the thoughts and feelings of donor conceived people. If you are an Australian donor conceived adult you are invited to participate in a study into what, if any, effect donor conception has on adults (18+ years) born as a result.

What does participation involve?

Participation involves completing an online questionnaire. This will take around 60 minutes. Participation is voluntary.

This questionnaire can only be completed once. The questionnaire can be completed on a computer, tablet, or smartphone when internet is available.

This questionnaire can be done at a time of your choosing. Questionnaire closing date is 31th August 2016. Please choose a time when you will have 60 minutes when you are unlikely to be interrupted.

More information

**If you require more information please email Caitlin Macmillan:
caitlin.macmillan@hdr.mq.edu.au**

This study has been approved by: Macquarie University HREC 5201600165

Click the 'next' button (>>) to continue to questionnaire

Appendix D

Plain Language Statement and Consent Form

Participants are invited to download the plain language statement to keep.



CRICOS Provider 00002J

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

This statement is yours to keep.

Date: 1st April 2016

Project Title: A Study on the Effects of Donor Conception, Secrecy and Anonymity, Based on Responses of Donor Conceived Adults

Principal Researcher(s): A/Prof Sonia Allan

Associate Researcher(s): Caitlin Macmillan

Macquarie University HREC Approval number: 5201600165

Purpose and Background

While many people know what donor conception is, little is known about how it feels to be donor conceived, and even less is known about the effects of donor conception. For over a century people experiencing difficulties conceiving a child have been able to approach doctors or clinics whereby anonymous sperm could be used to assist in their wishes to have a baby. Doctors would then instruct them to tell no one, including the child, and to never think about the method of conception again. Over time, egg and embryo donation also became possible. As donor conception became more widespread, parents, donors, and donor conceived people have increasingly called for information and questions have grown about the impacts of secrecy and anonymity. This research plans to investigate what, if any, effect anonymous donor conception, or secrecy surrounding the practice, has had on persons born as a result.

Procedures

Participation involves completing a questionnaire online, estimated to take 60 minutes. This can be completed at a location of your choice on computer, tablet or smart phone where Internet access is available. A variety of questions are included. Some questions will have a range of answers presented whereby you may choose the most appropriate response, others will ask how much you agree or disagree with a statement from strongly disagree to strongly agree. There will also be some unstructured questions whereby you are invited to document your thoughts and feelings in response to various statements and scenarios. The online questionnaire will be available until 30th August 2016

All information you supply will be confidential; any identifying information that is presented (names, dates or codes etc.) will be de-identified. You are not required to document your name, instead you will be allocated a randomly generated number that is unique to you. You may use this code in the event that further access to the questionnaire is required, or regarding information obtained.

Possible Benefits

There are no direct benefits from your participation in this project.

However, some participants may;

- a) Feel that it is beneficial to be able to provide information about their experiences,

- b) Benefit from feeling that they are being listened to and heard
- c) Feel positive in knowing that they are providing information that may lead to changes to future policy and support services; that may encourage recipient parents to disclose; and/or that will help people understand the how donor conceived people feel.

Possible Risks

Due to the sensitive nature of the topic under investigation, there is a small risk that these questions will cause distress. At any time of distress you may exit the questionnaire. If you require support please contact your General Practitioner, or Lifeline (ph; 131114), which offers 24-hour crisis support. Alternatively you may contact local support services:

- Donor Conception Support group (dcs.org.au) email: dcsupport@hotmail.com
- Australian Donor Conception Network (australiandonorconceptionnetwork.org) email: donorconceptionnetwork@gmail.com
- Relationships Australia, South Australia; 1300 364 277
- Queensland Counsellor, Antonia Lockitch; 0418 668 448
- Victorian Assisted Reproductive Treatment Authority; (03) 8601 5250

Participation is voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. It is your decision whether to take part, or not to take part, or to take part and then withdraw

Data Storage

Storage of data will comply with University regulations and kept in secure electronic storage. Electronic information will be stored in password-protected files on a computer, which will only be accessible by the Principal and Associate researchers

Optional consent

We would like you to consider giving your permission for us to use information collected as a part of this research study, in other ethically approved research studies relating to donor conception. If you agree, the information will remain confidential with storage continuing to comply with University regulations. Please tick the appropriate box on the consent form.

Results of Project

Results will relate to the collated data, no individual results will be available. If you would like information about the results of the study you may email Caitlin.macmillan@hdr.mq.edu.au

Complaints

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Further information, queries, or any problems:

For further information concerning this research project you may contact the Associate Researcher: **Caitlin Macmillan**
Macquarie University: Department of Health Systems and Populations
Email: caitlin.macmillan@hdr.mq.edu.au

This statement is available for you to keep by downloading:

[Plain language statement and consent form](#)

Do you consent to participate in the research project: *A Study on the Effects of Donor Conception, Secrecy and Anonymity, Based on Responses of Donor Conceived Adults*

Yes

No

Optional consent: Do you consent to the use of information collected in this study, for other future ethically approved research investigating donor conception?

Yes

No

Appendix E

Message Displayed When Multiple Cookies Detected

It appears that you have already completed this survey.
If you believe this is incorrect please email caitlin.macmillan@hdr.mq.edu.au for assistance.

Appendix F

Questionnaire Including Quality of Life Scale (Sintonen & Pekurinen, 1993).

Thank you for taking the time to participate in the research project: *A Study on the Effects of Donor Conception, Secrecy and Anonymity, Based on Responses of Donor Conceived Adults*. The information that you provide is confidential. If at any time information you provide is identifying, or potentially identifying, this will be coded to protect confidentiality.

Please note that the topic considered may elicit emotional responses in some people. If at any time you experience distress, you may exit the questionnaire. If you require support please speak to your General Practitioner, or call Lifeline (131114) a 24-hour support call service. Alternatively you may contact any of the following services that caters to the needs of donor conceived adults, and their families:

Donor Conception Support group (dcsupport.org.au) email: dcsupport@hotmail.com

Australian Donor Conception Network (australiandonorconceptionnetwork.org) email:
donorconceptionnetwork@gmail.com

Relationships Australia, South Australia 1300 364 277

Queensland Counsellor: Antonia Lockitch 0418 668 448

Victorian Assisted Reproductive Treatment Authority; (03) 8601 5250

If you have any questions or concerns, please contact Caitlin Macmillan, email: caitlin.macmillan@hdr.mq.edu.au

To provide clarity about who is being referred to within certain questions, and what different terms mean, please read through the following definitions:

Biological Parent: mother or father on birth certificate who used their own sperm/eggs to conceive you. Also referred to as biological social parent

Non-biological parent(s): parents who raised you, such as those on your birth certificate, but who are not genetically related to you. Also referred to as non-biological social parent(s).

Social Parent(s): the person/people who live with you and have reared you as your parent(s) (this includes a biological parent and a non-biological parent whether of different or same sexes; or a sole parent)

Sibling: siblings who you grew up with, this may be genetic siblings, half-siblings, step siblings etc.

Donor-sibling: siblings who share the same donor but not the same parents

Gamete: sperm or egg

Donor: Provider of egg, sperm, or embryo in your conception, who is not considered your legal parent, is not on your birth-certificate, and did not raise you

Open Identity Donor: A donor who consents to the release of identifying information upon the offspring's request, or recipient parent's request on behalf of the offspring

Anonymous Donor: A donor who donates under the assumption of donor anonymity

Donor registry: a registry that stores information. The amount of information stored and level of accessibility to the information depends on state laws and year of conception. Some states may have more than one type of registry and some states do not have a registry.

In what year were you conceived?

In what year were you born?

At what clinic were you conceived?

Which state was this clinic located?

In what state or territory do you currently live?

Australian Capital Territory

New South Wales

Northern Territory

Queensland

South Australia

Tasmania

Victoria

Western Australia

Elsewhere:

Prefer not to say

Which donation was required for your conception?

Sperm

Egg

Embryo (or donated egg, and donated sperm)

Within in the space provided, please describe yourself:

Within the space provided **please describe your family situation** (e.g. raised by my social mother and father...; raised by same sex parents...; raised by single parent who has always been single; parents separated when I was young...; siblings...; step siblings...; etc)

Within the space provided **please describe your relationship with your biological parent** (e.g. father, mother). If this question is not applicable please write "N/A" and continue to next question (e.g., raised by non-biological parent/s)

Within the space provided **please describe your relationship with your non-biological parent** (e.g. social father, social mother). If this question is not applicable please write "N/A" and continue to next question (e.g., raised by single mother who has always been single and also a biological parent)

At what age did you find out that you were donor conceived? If unsure please indicate to the best of your knowledge

Did someone tell you that you were donor conceived?

Yes

No

I don't remember

You have indicated that you were originally told about your conception:

Who initially told you that you were donor conceived? Please select all that apply:

Biological parent

Non biological parent

Step parent

Sibling/s

Aunty

Uncle

Other family member

Medical professional (e.g. Doctor)

My donor

Friend

Births Deaths and Marriages

Other:

Did you already suspect that you were donor conceived?

Yes

No - but I suspected something was different about my family

No - not at all

I was too young

With whom have you discussed being donor conceived? Please tick all that apply:

Biological parent

Non biological parent

Biological grandmother

Biological grandfather

Non biological grandmother

Non biological grandfather

My Donor

Brother/s

Sister/s

Donor sibling/s

Other family member/s

Partner

Close friend/s

Other friend/s

Work colleague/s

Another donor conceived person

No one

Other:

You have indicated that you were not originally told about your conception

How did you learn that you were donor conceived?**Did you already suspect that you were donor conceived?**

Yes

No - but I suspected something was different about my family

No - not at all

I was too young

With whom have you discussed being donor conceived?

Biological parent

Non biological parent

Biological grandmother

Biological grandfather

Non biological grandmother

Non Biological grandfather

My donor

Brother/s

Sister/s

Donor sibling/s

Other family member/s

Partner

Close friend/s

Other friend/s

Work colleague/s

Another donor conceived person

No one

Other:

Discussions**Do you feel anyone of the following avoids discussing donor conception? Please select all that apply:**

Biological parent

Non biological parent

Biological Grandmother

Biological Grandfather

Non biological grandmother

Non biological grandfather

My donor

Brother/s

Sister/s

Donor sibling/s

Other family member/s

Partner

Close friend/s

Other friend/s

Work colleague/s

No one avoids discussing the topic

No one knows that I know about my conception

Other:

Do you avoid talking about you being donor conceived?

- Yes
- No
- Sometimes yes, Sometimes no

Do you avoid talking about other information about yourself?

- Yes
- No
- Sometimes yes, sometimes no

Circumstances

Were there any particular circumstances under which you discovered that you were donor conceived?

e.g. after the death of a relative; during an argument; after falling ill; etc.

- Yes
- No
- Can't remember

Under what circumstances did you discover that you were donor conceived?

During parent divorce	During an argument
After the death of a family member	After illness
After conceiving a child of my own	Other:

Your experiences

Using the scale provided, please indicate how strongly you agree, or disagree, with each statement. Please base your answers on your feelings at the present time.

Strongly Somewhat Neither agree Somewhat Strongly

	disagree	disagree	nor disagree	agree	agree
If you don't know where you came from, you can't know where you are going	☐	☐	☐	☐	☐
I feel grateful that a donor helped to conceive me	☐	☐	☐	☐	☐
My non biological parent's heritage is important to me	☐	☐	☐	☐	☐
I feel relieved that I am donor conceived	☐	☐	☐	☐	☐
I feel more wanted being donor conceived	☐	☐	☐	☐	☐
I am sad about being donor conceived	☐	☐	☐	☐	☐
I feel sure of who I am	☐	☐	☐	☐	☐
My genetic heritage is important to me	☐	☐	☐	☐	☐
A recipient, or recipient couple, should measure up to all standards required by a good adoption agency before becoming entrusted with a child	☐	☐	☐	☐	☐
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I feel abandoned by my donor being donor conceived	☐	☐	☐	☐	☐
I find being donor conceived embarrassing	☐	☐	☐	☐	☐
Being donor conceived is a burden	☐	☐	☐	☐	☐
I feel that seeking information about my donor is betraying my parent/s	☐	☐	☐	☐	☐
I wish I never learned I was donor conceived	☐	☐	☐	☐	☐
I feel a strong sense of identity	☐	☐	☐	☐	☐
I feel my parent/s made the right choices regarding my	☐	☐	☐	☐	☐

conception

I feel comfortable with who I am	☐	☐	☐	☐	☐
I resent being donor conceived	☐	☐	☐	☐	☐
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I feel insecure about who I am	☐	☐	☐	☐	☐
I am glad I know the truth about my conception	☐	☐	☐	☐	☐
I feel that my donor is under no obligation to reveal themselves	☐	☐	☐	☐	☐
I wish I never learned that I was donor conceived	☐	☐	☐	☐	☐
You are never too young to find out you are donor conceived	☐	☐	☐	☐	☐
I feel indifferent to being donor conceived	☐	☐	☐	☐	☐
I feel worthless	☐	☐	☐	☐	☐
I feel that my donor has an obligation to answer questions that I may have	☐	☐	☐	☐	☐
I don't feel like I am in control of my future	☐	☐	☐	☐	☐
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I am happy about being donor conceived	☐	☐	☐	☐	☐
I have feelings of doubt about myself	☐	☐	☐	☐	☐
I am disappointed I am donor conceived	☐	☐	☐	☐	☐
Finding out I was donor conceived caused me distress	☐	☐	☐	☐	☐
I feel alone in relation to being donor conceived	☐	☐	☐	☐	☐
I like being donor conceived	☐	☐	☐	☐	☐
I am angry about being	☐	☐	☐	☐	☐

I am angry about being donor conceived	☐	☐	☐	☐	☐
I feel that am a good person overall	☐	☐	☐	☐	☐
I feel confused about who I am because I am donor conceived	☐	☐	☐	☐	☐
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I support anonymous gamete donation	☐	☐	☐	☐	☐
Overall I feel like a failure	☐	☐	☐	☐	☐
I have feelings of loss of identity	☐	☐	☐	☐	☐
It was not in my best interests to know the history of my conception	☐	☐	☐	☐	☐
I have a strong sense of self worth	☐	☐	☐	☐	☐
I feel I was too young when I found out I was donor conceived	☐	☐	☐	☐	☐
I am astounded that I am donor conceived	☐	☐	☐	☐	☐
Parents should be able to choose between an anonymous or open identity donor	☐	☐	☐	☐	☐
I am always trying to improve myself	☐	☐	☐	☐	☐
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
My world was turned up-side-down when I found out that I was donor conceived	☐	☐	☐	☐	☐
All gamete donations should be open identity	☐	☐	☐	☐	☐
If parents want to keep their child's conception a secret that is their prerogative	☐	☐	☐	☐	☐
I would consider using an anonymous donor if it was required in order for me to have a child	☐	☐	☐	☐	☐

FOR THIS TO HAVE A SCALE

Using the scale provided, please indicate how strongly you agree, or disagree, with each statement. Please base your answers on your feelings at the present time.

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
I have a good relationship with my biological parent	☐	☐	☐	☐	☐	☐
I have a good relationship with my non biological parent	☐	☐	☐	☐	☐	☐
I feel lied to by my biological parent	☐	☐	☐	☐	☐	☐
I feel lied to by my non biological parent	☐	☐	☐	☐	☐	☐
I feel loved by my biological parent	☐	☐	☐	☐	☐	☐
I feel loved by my non biological parent	☐	☐	☐	☐	☐	☐
	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
Absence of a genetic link with my non biological parent/s has not impacted our relationship	☐	☐	☐	☐	☐	☐
My being donor conceived has been difficult for my partner	☐	☐	☐	☐	☐	☐
I feel equally loved by both my parents	☐	☐	☐	☐	☐	☐
I feel wanted by my biological parent	☐	☐	☐	☐	☐	☐
I feel wanted by my non biological parent	☐	☐	☐	☐	☐	☐
I feel seeking information about my donor would have a negative impact on my family	☐	☐	☐	☐	☐	☐
	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable

I feel contacting my donor would have a negative impact on my family	☐	☐	☐	☐	☐	☐
I fear forming a relationship with an unknown sibling or donor	☐	☐	☐	☐	☐	☐
Secrecy of donor conception had a damaging effect on my family relationships	☐	☐	☐	☐	☐	☐
I feel betrayed by my biological parent	☐	☐	☐	☐	☐	☐
I feel betrayed by my non biological parent	☐	☐	☐	☐	☐	☐

How do you refer to your donor?

If this has changed over time, how did you previously refer to your donor?

Which is the most applicable to you in relation to **seeking information about your donor?**

- I have unsuccessfully attempted to obtain information about my donor
- I have successfully obtained some information about my donor
- Another member of my family has attempted to, or has successfully obtained information about my donor (e.g. sibling, parent, etc.)
- I have never sought information about my donor
- I have always had information about my donor

You have indicated that you have had, or have attempted, to **seek information about your donor.**

What were the main reason/s for searching for information? (e.g. curiosity, medical history, etc.). If more than one motivation is applicable please list in order or priority, up to five:

Motivation 1:	
Motivation 2:	

Motivation 3:

Motivation 4:

Motivation 5:

What information do you have relating to your donor? Select all that apply:

Donor code

Donor name

Contact information

Non identifying information
received at the time of conception

Medical information

I have no information

Non identifying information
obtained after conception
(example; information requested
from Births Deaths Marriages,
clinic, etc)Answers to specific questions
(example; through
correspondence)

Other:

How does this make you feel?

Very Happy

Happy

Neutral

Unhappy

Very Unhappy

You have indicated that you have had, or have attempted, to make contact with your donor. What were the main reason/s for seeking contact with your donor? (e.g. curiosity, medical history, etc.). If more than one motivation is applicable please list in order or priority, up to five:

Motivation 1:

Motivation 2:

Motivation 3:

Motivation 4:

Motivation 5:

Which is the most applicable to you in relation to seeking contact with your donor?I have unsuccessfully attempted to make contact
with my donor

I have never sought contact with my donor

I have successfully made contact with my donor I have always had contact with my donor

Another member of my family has attempted to, or
has successfully made contact with my donor (e.g.
sibling, parent, etc.)

Have you, or were you, open about the search for your donor with your parent/s? Please explain

Do you think one day you might be interested in seeking contact with your donor?

Yes

No

Unsure

What would be your main reason/s for seeking contact with your donor? (e.g. curiosity, medical information, to develop a relationship, etc.). If more than one motivation is applicable please list in order or priority, up to five:

Motivation 1:

Motivation 2:

Motivation 3:

Motivation 4:

Motivation 5:

Regardless of level of information you have about your donor, would you have preferred having an open identity donor? (A donor who consents to the release of identifying information upon the offspring's, or recipient parent's request)

Yes

No

Unsure

Donor Registry

Does the state or territory of your conception have a "donor registry"?

Yes

No

Unsure

Is your information on the registry?

Yes, my information was automatically included in this registry

Yes, I have voluntarily included information in this registry

No

Unsure

If your state had a registry would you volunteer your information to be included in the registry?

Yes

No

Unsure

Seeking information

Have you tried to obtain information using a donor registry?

Yes

No

What was your experience like? Please select all that apply

Easy

Difficult

Stressful

Enjoyable

Upsetting

A good experience

A bad experience

Liberating

Distressing

Other:

What information was provided to you via the registry?

No information

Donor code

Physical characteristics

Ethnicity

Occupation

Other:

Social Information e.g. hobbies, interests

Familial medical history

Number of offspring

Non-identifying half-sibling information e.g. year of birth

Information that records relating to my conception were missing or destroyed

Have you tried to gain information relating to your conception from a fertility clinic?

Yes

No

What has your experience been with fertility clinics and obtaining information? Please select all that apply:

Easy

Difficult

Stressful

Enjoyable

Upsetting

A good experience

A bad experience

Liberating

Distressing

Other:

Did the clinic attempt to assist you?

Yes

No

Somewhat

What information did they provide? Please select all that apply:

No information

Donor code

Social information (e.g. hobbies, interests)

Familial medical history

Physical characteristics

Ethnicity

Occupation

Other:

Number of offspring

Non-identifying half-sibling information e.g. year of birth

information that records relating to my conception were missing or destroyed

DNA testing

Have you participated in commercial DNA testing? (Example; 23andMe, Family Tree DNA, Ancestry DNA, etc.)

Yes

No

Which one/s have you participated in? Please select all that apply:



Other:

I don't remember which one I used



What information have you received that relates, or might relate, to your donor or donor siblings?

Please estimate in dollars how much money have you spent seeking information? e.g. fees for registry, fees for mandatory counselling, advertising, DNA tests, interstate travel, legal fees etc.

\$

Notifications

Do you believe all donor conceived people should be notified of their conception?

Yes

No

Maybe

How should this notification occur?

Donor conception practices

When you were conceived whose welfare, do you think, was prioritised? Please rate from highest to lowest priority by dragging the statements into the order that reflects your thinking

Wider community

My donor

My parent/s

Myself

Medical professionals

Based on your experiences what age do you feel it was, or will be, most critical to have

identifying information (this includes identity, medical history, family history etc)

During childhood: ages 0 to 11 years

During adolescence: ages 12 to 18 years

During early adulthood: 19 to 29 years

During adulthood: 30 years and older

It is crucial at every age

It depends on factors unrelated to age

At no time is it critical to have access to such information

Other (e.g. at age 25; between 16-18 years; before age 5; etc.).

Health

Have you ever suffered a medical condition, disability, or illness that you believe you inherited from your donor?

Yes:

No

Unsure

Have you *ever suffered* from any of the following? If applicable you may select more than one option

Depression

Anxiety

Alcohol abuse or Alcohol dependence

Substance abuse or Substance dependence

Post natal Depression

Eating Disorder

Social Phobia (social anxiety)

Panic disorder

Agoraphobia

Separation Anxiety

I have suffered a different mental health condition:

I have never suffered a mental health condition

Quality of Life

Please read through all the alternative responses to each question before selecting the statement which best describes *your present health status*. Please continue through the

next 15 statements in this manner, give only **one** answer to each.

Mobility

I am able to walk normally (without difficulty) indoors, outdoors and on stairs

I am able to walk without difficulty indoors, but outdoors and/or on stairs I have slight difficulties

I am able to walk without help (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others

I am able to walk indoors only with help from others

I am completely bed ridden and unable to move about

Vision

I see normally, i.e. I can read newspapers and TV text without difficulty (with or without glasses).

I can read papers and/or TV text with slight difficulty (with or without glasses).

I can read papers and/or TV text with considerable difficulty (with or without glasses).

I cannot read papers or TV text either with glasses or without, but I can see enough to walk about without guidance.

I cannot see enough to walk about without a guide, i.e. I am almost or completely blind.

Hearing

I can hear normally, i.e. normal speech (with or without a hearing aid).

I hear normal speech with a little difficulty.

I hear normal speech with considerable difficulty; in conversation I need voices to be louder than normal.

I hear even loud voices poorly; I am almost deaf.

I am completely deaf.

Breathing

I am able to breathe normally, i.e. with no shortness of breath or other breathing difficulty.

I have shortness of breath during heavy work or sports, or when walking briskly on flat ground or slightly uphill.

I have shortness of breath when walking on flat ground at the same speed as others my age.

I get shortness of breath even after light activity, e.g. washing or dressing myself.

I have breathing difficulties almost all the time, even when resting.

Sleeping

next 15 statements in this manner, give only **one** answer to each.

Mobility

I am able to walk normally (without difficulty) indoors, outdoors and on stairs

I am able to sleep normally, i.e. I have no problems with sleeping.

I have slight problems with sleeping, e.g. difficulty in falling asleep, or sometimes waking at night.

I have moderate problems with sleeping, e.g. disturbed sleep, or feeling I have not slept enough.

I have great problems with sleeping, e.g. having to use sleeping pills often or routinely, or usually waking at night and/or too early in the morning.

I suffer severe sleeplessness, e.g. sleep is almost impossible even with full use of sleeping pills, or staying awake most of the night.

Eating

I am able to eat normally, i.e. with no help from others.

I am able to eat by myself with minor difficulty (e.g. slowly, clumsily, shakily, or with special appliances).

I need some help from another person with eating.

I am unable to eat by myself at all, so I must be fed by another person.

I am unable to eat at all, so I am fed either by tube or intravenously.

Speech

I am able to speak normally, i.e. clearly, audibly and fluently.

I have slight speech difficulties, e.g. occasional fumbling for words, mumbling, or changes of pitch.

I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering.

Most people have great difficulty understanding my speech.

I can only make myself understood by gestures.

Excretion

My bladder and bowel work normally and without problems.

I have slight problems with my bladder and/or bowel function, e.g. difficulties with urination, or loose or hard bowels.

I have marked problems with my bladder and/or bowel function, e.g. occasional 'accidents', or severe constipation or diarrhea.

I have serious problems with my bladder and/or bowel function, e.g. routine 'accidents', or need of catheterization or enemas.

I have no control over my bladder and/or bowel function.

Usual Activities

I am able to perform my usual activities (e.g. employment, studying, housework, free-time activities) without difficulty.

I am able to perform my usual activities slightly less effectively or with minor difficulty.

I am able to perform my usual activities much less effectively, with considerable difficulty, or not completely.

I can only manage a small proportion of my previously usual activities.

I am unable to manage any of my previously usual activities.

Mental function

I am able to think clearly and logically, and my memory functions well.

I have slight difficulties in thinking clearly and logically, or my memory sometimes fails me.

I have marked difficulties in thinking clearly and logically, or my memory is somewhat impaired.

I have great difficulties in thinking clearly and logically, or my memory is seriously impaired.

I am permanently confused and disoriented in place and time.

Discomfort and Symptoms

I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

I have mild physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

I have marked physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

I have severe physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

I have unbearable physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

Depression

I do not feel at all sad, melancholic or depressed.

I feel slightly sad, melancholic or depressed.

I feel moderately sad, melancholic or depressed.

I feel very sad, melancholic or depressed.

I feel extremely sad, melancholic or depressed.

Distress

I do not feel at all anxious, stressed or nervous.

I feel slightly anxious, stressed or nervous.

I feel moderately anxious, stressed or nervous.

I feel very anxious, stressed or nervous.

I feel extremely anxious, stressed or nervous.

Vitality

I feel healthy and energetic.

I feel slightly weary, tired or feeble.

I feel moderately weary, tired or feeble.

I feel very weary, tired or feeble, almost exhausted.

I feel extremely weary, tired or feeble, totally exhausted.

Sexual Activity

My state of health has no adverse effect on my sexual activity.

My state of health has a slight effect on my sexual activity.

My state of health has a considerable effect on my sexual activity.

My state of health makes sexual activity almost impossible.

My state of health makes sexual activity impossible.

Conclusion

If you wish to contribute further information please do so in the space provided:

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Thank you for contributing to the research project *A Study on the Effects of Donor Conception, Secrecy and Anonymity, Based on Responses of Donor Conceived Adults*. The information you have provided is confidential.

If you experienced any distress during the completion of this questionnaire, or if you experience any distress afterward, please seek support. Please contact your General Practitioner or call Lifeline (ph; 13 11 14); a 24-hour crisis support line. Alternatively you may contact local support services:

- Donor Conception Support group (dcsg.org.au) email: dcsupport@hotmail.com
- Australian Donor Conception Network
(australiandonorconceptionnetwork.org)
email: donorconceptionnetwork@gmail.com
- Relationships Australia, South Australia. Ph: 1300 364 277
- Queensland Counsellor: Antonia Lockitch 0418 668 448 If you require any further information, or have any other concerns, please you can contact the Associate Researcher (Macquarie University):
caitlin.macmillan@hdr.mq.edu.au Or Sonia Allan
sonia.allan@mq.edu.au Results of this investigation will be available upon request, please email caitlin.macmillan@hdr.mq.edu.au to request a copy of the results. Results will be available October 2016
- Victorian Assisted Reproductive Treatment Authority; (03) 8601 5250

Appendix F

Confirmation of ethics approval and subsequent modifications

Office of the Deputy Vice-Chancellor
(Research)

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ABN 90 952 801 237



21 April 2016

Dear A/Prof Allan

Reference No: 5201600165

Title: *A Study on the Effects of Anonymous Donor Conception Based on Responses of Donor Conceived Adults*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)).

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated May 2015) (the *National Statement*).

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely



Dr Karolyn White

Director, Research Ethics & Integrity,
Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

Details of this approval are as follows:

Approval Date: 14 April 2016

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form		Received 9/03/2016
Response addressing the issues raised by the HREC		Received 13/04/2016
Letter to Organisations	1	1/04/2016
Plain Language Participant Information Statement & Consent Form	1	1/04/2016
Text Advertisement with Link to Questionnaire	1	13/04/2016
Advertising Flyer	1	13/04/2016
Questionnaire	1	13/04/2016
Debrief	1	13/04/2016
Quality of Life measure (15-D)	1	13/04/2016
Permission to use Quality of Life measure (15-D)		
Text for online forums and Facebook	1	13/04/2016

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