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Donor information considered important to donors, recipients and offspring: an Australian perspective


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Abstract Donor conception research supports open-identity donor programmes and disclosure to donor-conceived offspring. This study examines Australian donors', recipients' and donor-conceived offspring's views on the importance of different types of biographical information about the donor. Participants (125 recipients, 39 donors (known, identity-release and anonymous), 23 donor-conceived offspring) completed an online or paper self-administered anonymous questionnaire. Individuals rated the importance of 15 types of biographical information and subsequently chose the three they deemed most important. All groups included donor's health history and name as key variables to be available to donor-conceived offspring. Recipients viewed the donor's decision to donate as important, donors thought their feelings about being contacted were important and donor-conceived offspring expressed an interest in the donor's own family. Sperm donors were less inclined to view the provision of information as important compared with offspring. For recipients, the importance of information became apparent once they had disclosed to their children. This is the first study to gauge Australian stakeholders' attitudes to release of information in the donor conception process. The findings support the move to open-identity donation systems and emphasize the importance of considering the varying perspectives of all stakeholders by policy developers. 

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KEYWORDS: donors, donor-conceived offspring, gamete and embryo donation, recipients, release of information

Introduction

Donor conceptions form a major component of assisted conception births around the world. In Australian and New Zealand fertility centres, approximately 10% of all treatment cycles involve the use of donated gametes or embryos

(Wang et al., 2009) and this figure does not include sperm donation carried out in hospitals or private clinics. Figures for the UK are similar with 10% of all babies born after IVF or donor insemination treatments being the result of donated spermatozoa, oocytes or embryos (HFEA, 2009). In the USA, donated oocytes or embryos are used in ~12%

of treatment cycles (Centers for Disease Control and Prevention, 2008), but there are no official records for sperm donation. Unofficial estimates suggest that between 30,000 and 60,000 children are born of sperm donation in the USA each year (Evan B Donaldson Adoption Institute, 2009).

In the past, the processes surrounding donor conception were secretive and few donor-conceived children were told of the manner of their conception. The donor was anonymous and only limited, non-identifying information (e.g. hair and eye colour, education and interests) was made available to recipients. More recently, however, social attitudes to donor conception have changed with a move from non-disclosure and secrecy towards openness. This is reflected in changing clinic and legislative practices of donor conception around the world. Legislation for open-identity donor systems allowing children born of gamete or embryo donation access to select identifying information about their donor on reaching maturity have been introduced in Sweden, The Netherlands, UK, New Zealand and the Australian states of Victoria and Western Australia (Daniels et al., 2005; Godman et al., 2006; Gong et al., 2009; Gottlieb et al., 2000; Janssens et al., 2006).

While a policy of open-identity donation may foster an environment in which more parents feel able to tell their children about the nature of their conception (Godman et al., 2006; Lalos et al., 2007), it does not provide a guarantee that parents will actually do so (Daniels et al., 2009; Gottlieb et al., 2000; Lalos et al. 2007; MacCallum and Golombok, 2007). Parental intention to disclose is influenced by many factors including parental views on the child's moral right to know about donor conception (Frith, 2001), parental relationship status (e.g. single, lesbian, heterosexual) (Godman et al., 2006; Scheib et al., 2003; Wendland et al., 1996), cultural and religious issues towards infertility (Gong et al., 2009), the extent of agreement between mothers and fathers or biological mothers and social mothers towards disclosure (Brewaeyts et al., 1997; Daniels et al., 1995; Shehab et al., 2008) and the attitudes and guidance of advising healthcare professionals (Skoog Svanberg et al., 2008). Scheib et al. (2003) contend that the ability to access substantial biographical information about the donor facilitates parental disclosure because parents feel better equipped to answer questions about the donor should they arise. A number of recent studies support this view with higher levels of accessible donor information being associated with higher rates of disclosure (Klock and Greenfeld, 2004; MacCallum, 2009).

It is evident from the literature that the extent of biographical information available to recipients and donor-conceived offspring varies within and between countries and is determined by the regulatory frameworks governing assisted reproduction treatment in that country (Gong et al., 2009; Schneller, 2005), which has potential to influence outcomes on disclosure. In Australia, there has been no research which critically evaluates, nor any national guidelines which stipulate the information that should be stored, updated and released. Registries that exist are based on assumptions rather than empirical evidence as to what information would be in the child's best interest. In Western Australia, information stored in clinic records includes the donor's physical characteristics (hair and eye colour, complexion, build, height), marital status, occupa-

tion, religion, family background, education, limited information on their interests and personality and a summarized health history. Since December 2004, state legislation has required the storage of donor's name, date of birth and postcode of residence and this information can be accessed by offspring upon reaching the age of 16 years. Donor information is recorded at the time of donation and is not routinely updated. Whether recipients perceive such information to be adequate for their or their offspring's needs has not been explored in an Australian context. Neither has the importance of the extent and availability of biographical information in the decision to disclose.

Donors may also have a perspective on what information they feel a donor-conceived offspring should have access to. While this issue has been assessed indirectly in studies of donor views on conditions of donations (Cook and Golombok 1995; Daniels et al., 1997, 2005), these studies were primarily conducted at a time when anonymity of donation was standard practice and contact by offspring was highly unlikely. The subsequent changing philosophy of donor conception from anonymous to open-identity systems now makes it imperative for the opinions of donors to be gauged and for donors to consider the possible short-term and long-term social and health implications of their donation through the lens of the donor-conceived offspring.

Few studies have examined the offspring's views, mainly because until recently most donor-conceived individuals have not known of their donor conception status. Therefore the type and extent of biographical information about the donor that the offspring would want remains largely unknown, although a number of studies have found that offspring exhibit curiosity about information on their donors as it has relevance for their view of self (Hewitt, 2002; McWhinnie, 2006; Scheib et al., 2005; Turner and Coyle, 2000).

This study aimed to gauge the views of Australian donors, recipients and donor-conceived offspring as to the importance of different types of information available for release and to compare opinions between donor parties. The study included individuals from known, identity-release and anonymous donor programmes reflecting the variation in donor programmes across Australian states. The study has direct relevance to Australian policy and to other countries around the world that embrace an open-identity donor conception system.

Materials and methods

Participants

Approval for this study was granted by King Edward Memorial Hospital Institutional Ethics Committee.

The study sought participation from gamete and embryo donors, gamete and embryo recipients and donor-conceived individuals by advertising nationwide on various Australian donor conception support website forums, emails to members of the Australian and New Zealand Infertility Counsellors' Association, the Reproductive Technology Council of Western Australia and Infertility Treatment Authority websites and to existing clinic patients of Concept Fertility Centre. Participation of donor-conceived offspring was restricted to individuals aged 12 years or older.

Table 1 Participants' demographic and treatment characteristics.

| Characteristic | Donors | | | Recipients | | | Donor-conceived offspring (n = 23) |
|-------------------------------|-----------------|----------------------|----------------|----------------------|-----------------------|----------------------|------------------------------------|
| | Oocyte (n = 24) | Spermatozoa (n = 15) | Total (n = 39) | Oocyte (n = 18) | Spermatozoa (n = 107) | Total (n = 125) | |
| Current age range | 24–39 | 25–62 | 24–62 | 28–57 | 18–62 | 18–62 | 15–34 |
| Current age categories | | | | | | | |
| <18 | NA | NA | NA | NA | NA | NA | 2 (9) |
| 18–27 | 2 (8) | 2 (13) | 4 (10) | 0 | 6 (6) | 6 (5) | 15 (65) |
| 28–37 | 20 (83) | 2 (13) | 22 (56) | 6 (33) | 42 (39) | 48 (38) | 6 (26) |
| 38–47 | 2 (8) | 6 (40) | 8 (20) | 8 (44) | 49 (46) | 57 (46) | 0 |
| 48+ | 0 | 5 (33) | 5 (13) | 4 (22) | 10 (9) | 14 (11) | 0 |
| Current relationship status | | | | | | | |
| Partnered | 18 (75) | 9 (60) | 27 (69) | | | | |
| Heterosexual | NA | NA | NA | 13 (72) | 26 (24) | 39 (31) | |
| Same-sex | NA | NA | NA | 3 (17) | 21 (20) | 24 (19) | |
| Single | 6 (25) | 6 (40) | 12 (31) | 2 (11) | 60 (56) | 62 (50) | |
| Donor programme | | | | | | | |
| Clinic recruited ^a | 2 (8) | 14 (93) | 16 (41) | 4 (22) ^b | 95 (89) ^b | 99 (79) ^b | 22 (96) |
| Known donor | 22 (92) | 1 (7) | 23 (59) | 13 (72) ^b | 10 (9) ^b | 23 (18) ^b | 1 (4) |

Values are *n* (%) unless otherwise stated.

NA = not applicable.

^aClinic recruited donors are anonymous to the recipient at the time of donation. In some states of Australia, offspring have the ability to attain identifying information about the donor upon reaching maturity.

^bPercentages do not equal 100% as missing responses from three individuals.

Included participants were 125 recipients (107 spermatozoa, 18 oocyte), 39 donors (15 spermatozoa, 24 oocyte) and 23 donor-conceived offspring. Six embryo recipients and four embryo donors were excluded from the analysis due to small sample size. Twenty-two of the offspring were conceived from anonymous sperm donation; one offspring was conceived via known oocyte donation. Respondents were from all Australian states and mainland territories; however, the majority resided in the states of Western Australia (44.1%), Victoria (23.1%), Queensland (12.9%) and New South Wales (11.3%). Demographic and treatment related data for each group are presented in **Table 1**.

For oocyte donors, 21 out of 24 (87.5%) had donated within the last 2 years and the remaining three had donated within the last 3–5 years. Of the 15 sperm donors, 10 (66.7%) had donated within the last 2 years, two (13.3%) had donated 4–8 years ago and three (20.0%) had donated more than 20 years ago. Age (mean ± SD) of oocyte donors at the time of last donation was 31.4 ± 3.66 years and for sperm donors it was 37.9 ± 7.95 years.

Of oocyte recipients, five (27.8%) were waiting for treatment, three (16.7%) were actively undergoing treatment and 10 (55.6%) had completed treatment. For recipients of donor spermatozoa, the number of individuals at each treatment stage was 12 (11.2%), 41 (38.3%) and 54 (50.5%) for waiting, undergoing and completed treatment, respectively. Sixty-two (57.9%) recipients of donor spermatozoa and seven (38.9%) oocyte recipients had at least one donor-conceived child.

Of the donor-conceived offspring, six (26.1%) were male and 17 (73.9%) were female. Eight (34.8%) of the donor-

conceived offspring were told or learned of their donor conception as adults (>18 years of age), whereas five offspring (21.7%) learned of their origin before the age of 5 years. The remainder (43.5%) learned of their donor conception between the ages of 11 and 18. Fourteen donor-conceived offspring (60.9%) had siblings who were also born through the use of a donor. Five donor-conceived offspring (21.7%), including the individual conceived via known oocyte donation, had met their donor; the remainder did not have any identifying information about their donor.

Questionnaire

Participants completed either a self-administered online anonymous questionnaire or a paper version. The questionnaire contained demographic and treatment related questions, opinion statements relating to the release of identifying information, contact and disclosure issues and questions on the importance of 15 different types of biographical information about the donor that are available for release. The 15 items were donor's name, date of birth, photograph at the time of donation, the donor's age at donation, physical characteristics, health, information about his/her family, the number of donations made, feelings regarding contact, cultural background, religion, motivations for donation, occupation, education and hobbies/interests. Participants ranked the importance of each item on a 5-point Likert scale ranging from not important at all (1) to very important (5). Participants were also asked to choose three items from the list of biographical

information that they thought were the most important types of information that a donor-conceived offspring should know about their donor. The aim of the forced choice question was to encourage participants to give deeper consideration to the information presented and to avoid the potential to give socially desirable responses and non-differentiation which can occur with questionnaire methodology (Smyth et al., 2006). The questionnaire took approximately 15 min to complete and respondents were also given the opportunity to provide comments at the end of each block of questions.

Statistical analysis

Data were tabulated and descriptive statistics calculated for each stakeholder group. Analyses combined data from known and anonymous donation processes as the number of known donations was too small for meaningful separate analysis. The study did not separate recipient data on the basis of relationship status (single, same-sex, heterosexual couples) as there were no differences in mean scores for these participant groups. Mean scores on the information rating scales were compared between stakeholder groups and between disclosing and non-disclosing recipients using profile analysis. Profile analysis is an application of multivariate analysis of variance (ANOVA) suitable for comparison between groups on multiple dependent variables which are scored on a similar scale (i.e. types of information scored on a Likert scale) (Tabachnick and Fidell, 2001 p. 391). As the interaction term between type of information and stakeholder group was significant, the ratings between stakeholder groups were examined separately for each biographical item

using one-way ANOVA. Where significant between-group effects were observed, Bonferroni post-hoc tests were used to identify the source of the variation. Additionally, for each type of biographical information, the study calculated the percentage of respondents within each donor and recipient group who ranked the item as one of their top three choices. Spearman rank correlation coefficients were used to compare rankings within and between different stakeholder groups.

Results

Importance of types of information about the donor

Mean scores on the rating scales for different types of biographical information are shown in **Table 2**. Results of the profile analysis revealed a significant interaction between stakeholder groups and ratings of types of biographical information ($F_{(56, 688)} = 2.39$, $P < 0.001$) indicating that stakeholder groups vary in their perception of what information is important for release to donor-conceived offspring. Therefore, ratings between stakeholder groups were examined separately for each biographical item.

Donor-conceived offspring generally regarded all the types of information as important or very important as indicated by the high mean scores (**Table 2**). Sperm donors had the lowest mean scores on all 15 items. Post-hoc tests revealed that offspring had significantly higher mean scores than sperm donors on name ($P < 0.05$), date of birth ($P < 0.01$), provision of a photograph ($P < 0.001$), age at donation ($P < 0.001$), health ($P < 0.001$), number of donations ($P < 0.001$), feelings about contact ($P < 0.01$),

Table 2 Rating scores for different types of donor biographical information according to stakeholder group.

| Donor information | Donors | | Recipients | | Offspring (n = 23) | P-value |
|--------------------------------------|--------------------------|--------------------------------|--------------------------|----------------------------|------------------------------|---------|
| | Oocyte (n = 24) | Spermatozoa (n = 15) | Oocyte (n = 18) | Spermatozoa (n = 107) | | |
| Name | 4.04 ± 1.16 | 3.07 ± 1.34 ^a | 4.06 ± 1.16 | 3.28 ± 1.41 ^b | 4.39 ± 1.16 ^{a,b} | <0.001 |
| Date of birth | 3.58 ± 1.38 | 2.25 ± 1.36 ^a | 3.06 ± 1.26 | 3.32 ± 1.32 | 4.04 ± 1.19 ^a | 0.009 |
| Photo at time of donation | 3.83 ± 1.09 | 2.73 ± 1.22 ^a | 3.78 ± 1.11 | 3.64 ± 1.28 ^b | 4.43 ± 0.84 ^{a,b} | 0.001 |
| Age at donation | 3.46 ± 1.38 | 2.53 ± 1.12 ^a | 3.00 ± 1.24 ^b | 3.25 ± 1.31 ^c | 4.26 ± 0.86 ^{a,b,c} | 0.001 |
| Health at donation | 4.71 ± 0.75 ^a | 3.93 ± 0.88 ^{a,b,c,d} | 4.61 ± 0.50 ^c | 4.73 ± 0.61 ^b | 4.87 ± 0.46 ^d | <0.001 |
| Physical characteristics at donation | 4.42 ± 0.83 | 4.27 ± 0.80 | 4.22 ± 0.88 | 4.31 ± 1.01 | 4.70 ± 0.64 | NS |
| Family | 4.21 ± 1.14 | 3.33 ± 1.11 | 4.11 ± 0.83 | 3.90 ± 1.19 | 4.26 ± 1.25 | NS |
| How many times donated | 4.04 ± 1.16 ^a | 2.67 ± 1.29 ^{a,b,c} | 4.50 ± 0.79 ^b | 3.63 ± 1.34 ^{b,c} | 4.87 ± 0.45 ^c | <0.001 |
| Feeling re contact with offspring | 4.38 ± 0.88 | 3.73 ± 0.96 ^a | 4.44 ± 0.62 | 4.40 ± 0.97 | 4.74 ± 0.54 ^a | 0.021 |
| Job at donation | 2.75 ± 1.26 ^a | 2.47 ± 1.19 ^b | 2.78 ± 1.35 ^c | 3.22 ± 1.18 | 3.96 ± 1.11 ^{a,b,c} | 0.001 |
| Level of education at donation | 3.04 ± 1.12 ^a | 3.07 ± 1.22 ^b | 2.89 ± 1.32 ^c | 3.56 ± 1.13 | 4.22 ± 1.08 ^{a,b,c} | 0.001 |
| Hobbies and interests | 3.25 ± 1.11 ^a | 3.00 ± 1.20 ^b | 3.39 ± 1.24 | 3.76 ± 1.16 | 4.22 ± 0.90 ^{a,b} | 0.005 |
| Reasons for donation | 4.29 ± 1.12 | 3.27 ± 0.70 | 4.22 ± 1.06 | 3.92 ± 1.22 | 4.26 ± 1.05 | 0.041 |
| Cultural background | 4.04 ± 0.96 | 3.27 ± 1.03 ^{a,b} | 4.11 ± 0.90 | 4.15 ± 1.03 ^a | 4.74 ± 0.69 ^b | <0.001 |
| Religion | 2.42 ± 1.41 | 1.87 ± 1.19 ^a | 2.83 ± 1.15 | 2.80 ± 1.34 | 3.43 ± 1.41 ^a | 0.007 |

Values are mean ± SD. Higher scores represent increased importance; highest possible score = 5.

P-values are from one-way ANOVA. Groups sharing superscript letters differ significantly from one another (Bonferroni statistic).

NS = not significant.

occupation ($P < 0.01$), education ($P < 0.05$), hobbies and interests ($P < 0.05$), culture ($P < 0.001$) and religion ($P < 0.01$). In addition, offspring significantly differed from sperm recipients on the variables of name ($P < 0.01$), photograph ($P < 0.05$), age at donation ($P < 0.01$) and the number of donations ($P < 0.001$); from oocyte donors on the variables of occupation ($P < 0.01$), hobbies ($P < 0.05$) and education ($P < 0.01$); and from oocyte recipients on age ($P < 0.05$), occupation ($P < 0.05$) and education ($P < 0.01$).

When asked to re-evaluate and rank the three most important types of information to be made available, there was general agreement between donor sperm and oocyte groups ($\rho = 0.869$, $P < 0.001$). Of sperm donors, 80% felt that their feelings regarding contact was the most important information to be made available to offspring, followed by information on their health (53%) and their name (47%). No sperm donors ranked information about their job, hobbies, religion, age at donation or number of times they donated in the top three most important features. Features ranked most important by oocyte donors were their health status (88%), name (62%) and feelings regarding contact with offspring (33%).

The types of information ranked highest amongst oocyte recipients were name (78%) reason for donation (56%), health (39%) and family (39%). Donor's hobbies, religion, education and age at donation were not ranked in the top three most important by any oocyte recipient. For recipients of donor spermatozoa, the most highly ranked feature was donor's health (72%), followed by donor's name (40%) and a photograph of the donor (32%). Less than 5% of sperm recipients ranked donor's education, job, religion, age at

time of donation and number of times the donor donated in the top three most important. There was strong correlation between sperm and oocyte recipients in the order of ranking of information ($\rho = 0.846$, $P < 0.001$).

In response to the forced choice question, donor-conceived offspring ranked name (61%), health (48%) and information about the donor's family (39%) as the three most important pieces of biographical information that should be available to them. As shown in Figure 1, this was highly correlated with rankings from both recipients ($\rho = 0.827$; $P < 0.001$) and donors ($\rho = 0.864$; $P < 0.001$).

When given the opportunity to respond in the open-ended comments, recipients and offspring provided insight into other salient factors that should be considered for release. Recipients noted personality characteristics and personal values of the donor ($n = 2$), the number and location of potential donor siblings ($n = 9$) and information about whether the donor is still alive ($n = 2$). Offspring ($n = 2$) also raised the importance of personalised information such as a letter from their donor rather than formulaic options on a questionnaire. Despite being given the opportunity to comment, donors did not provide any alternative perspective to the importance of information beyond reiterating the relevance of storing health and family structure details (e.g. number of offspring) ($n = 4$).

Offspring were given an opportunity to comment on their reasons for choosing the items they did and 15 wrote comments. Emerging themes pertained to the importance of family ties ($n = 5$), a sense of incomplete self-identity ($n = 3$), the importance of genetic connectedness ($n = 3$) and a need to satisfy curiosity and a sense of uncertainty/fear

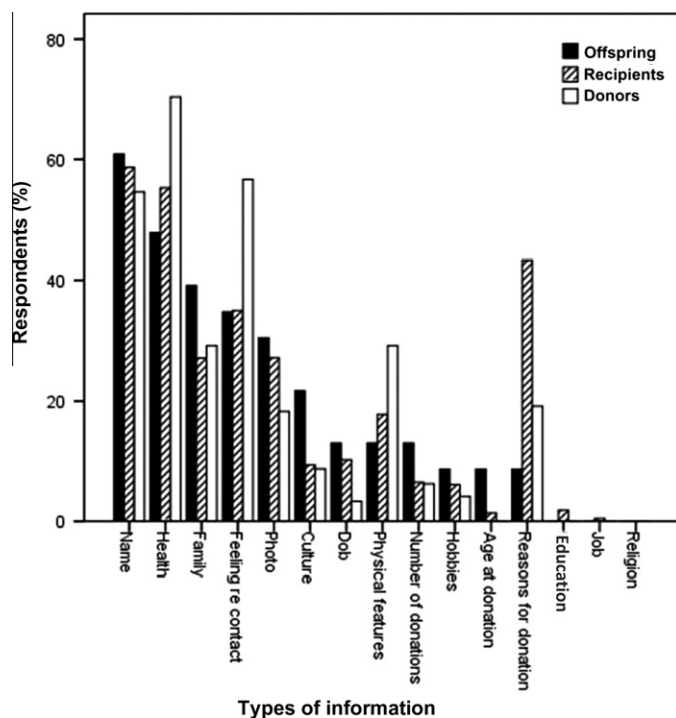


Figure 1 The percentage of respondents in each stakeholder group who ranked each type of biographical information in the top three most important. Responses are ordered according to frequency of responses by donor-conceived offspring. Values for donors are the average of sperm and oocyte donors; values for recipients represent the average of sperm and oocyte recipients.

of serendipitous encounters with donor-conceived siblings ($n = 3$). Two donor-conceived offspring commented that the information was not only important for them, but that it was also important to enable their own offspring to become acquainted with their genetic lineage.

Recipients' intention to disclose and importance of information

Of all recipients, 96% agreed or strongly agreed with the opinion statement 'A child born from sperm, egg or embryo donation should be informed about the manner of their conception', 2.4% (3/125) were neutral and 1.6% (2/125) disagreed or strongly disagreed. When asked if the child had a 'right to receive identifying information about their donor(s) when they reach maturity', 93.6% were in favour, 3.2% (4/125) were neutral and 3.2% (4/125) disagreed.

Of the 69 recipients who had a donor-conceived child, 71% (44/62) of sperm recipients and all (7/7) oocyte recipients had already disclosed to their child. Of the 18 recipients who had not yet disclosed, 16 stated that they intended to tell, one was unsure and one was not intending to disclose.

When ratings of importance were compared between recipients who had children and had disclosed, recipients who had children but had not disclosed and recipients who did not yet have children, it was found that disclosing recipients rated information as more important on average than the other two groups ($F_{(2, 122)} = 9.25, P < 0.001$). Follow-up analyses of individual items indicated that recipients did not vary on ratings of importance of donor health, culture, religion and education (Table 3).

Discussion

This study examined the perspective of each of the Australian stakeholders involved in the donation process as to their opinions on what information is important for release to donor-conceived offspring. When participants were asked to choose the three most important types of biographical information there was a general consensus between participant groups. Information about health status was consistently ranked highly by all stakeholder groups, as was the donor's name thereby supporting the trend by many health professionals to recommend openness as the model of best practice. Despite general agreement between stakeholders in the types of information felt to be particularly important, this study also revealed variation in stakeholder perspectives. Notably, sperm donors tended to view release of information as less essential to donor-conceived offspring, amongst recipients there was a heightened awareness of the importance of information following disclosure and for donor-conceived offspring all information was viewed as vital.

Compared with donor-conceived offspring, sperm donors consistently viewed the availability of biographical information as less important until asked to give further consideration through ranking. In contrast oocyte donors tended to rate the majority of items similarly to offspring. These findings are likely to reflect a combination of factors including a greater orientation bias of women to issues surrounding family formation, gender response style differences to questionnaires and the fact that the majority of oocyte donors in this study were recruited by the recipient with the potential for ongoing contact. Previous studies of

Table 3 Rating scores for different types of donor biographical information according to recipient disclosure status.

| Donor information | No children (n = 56) | Children | | P-value |
|-----------------------------------|--------------------------|--------------------------|----------------------------|---------|
| | | Not disclosed (n = 18) | Disclosed (n = 51) | |
| Name | 2.91 ± 1.38 ^a | 2.78 ± 1.22 ^b | 4.14 ± 1.15 ^{a,b} | <0.001 |
| Date of birth | 2.95 ± 1.27 ^a | 2.89 ± 1.37 ^b | 3.78 ± 1.17 ^{a,b} | 0.001 |
| Photo at time of donation | 3.32 ± 1.31 ^a | 3.39 ± 1.20 | 4.12 ± 1.07 ^a | 0.002 |
| Religion | 2.57 ± 1.28 | 2.94 ± 1.51 | 3.02 ± 1.26 | NS |
| Cultural background | 4.02 ± 1.12 | 3.89 ± 1.18 | 4.37 ± 0.75 | NS |
| Reasons for donation | 3.77 ± 1.29 | 3.67 ± 1.24 | 4.27 ± 1.02 | 0.048 |
| Physical characteristics | 4.05 ± 1.12 ^a | 4.17 ± 1.10 | 4.61 ± 0.69 ^a | 0.012 |
| Health at donation | 4.64 ± 0.72 | 4.67 ± 0.48 | 4.80 ± 0.45 | NS |
| Age at donation | 3.00 ± 1.30 | 2.89 ± 1.32 | 3.57 ± 1.37 | 0.038 |
| Level of education at donation | 3.20 ± 1.33 | 3.50 ± 0.92 | 3.75 ± 1.04 | NS |
| Job at donation | 2.84 ± 1.26 ^a | 3.17 ± 1.15 | 3.51 ± 1.10 ^a | 0.016 |
| Hobbies and interests | 3.39 ± 1.28 ^a | 3.56 ± 1.20 | 4.10 ± 0.94 ^a | 0.006 |
| Family | 3.59 ± 1.30 ^a | 3.83 ± 1.15 | 4.33 ± 0.79 ^a | 0.003 |
| How many times donor donated | 3.41 ± 1.45 ^a | 3.50 ± 1.25 | 4.22 ± 1.03 ^a | 0.004 |
| Feeling re contact with offspring | 4.11 ± 1.16 ^a | 4.44 ± 0.70 | 4.73 ± 0.53 ^a | 0.002 |

Values are mean ± SD. Higher scores represent increased importance; highest possible score = 5.

P-values are from one-way ANOVA. Groups sharing superscript letters differ significantly from one another (Bonferroni statistic).

NS = not significant.

attitudes to donor conception have found that females are more positive towards disclosure and the provision of identifying information compared with men (Skoog Svanberg et al., 2003, 2008). This highlights the importance of infertility counsellors engaging sperm donors into deeper discussion about the donation process during implications counselling such that the perspective of the donor-conceived offspring is considered paramount.

It is clear from these data and the responses to open-ended comments that donor-conceived offspring view all information as highly relevant and important to their view of self. Of note, when asked to rank the three most important features, in addition to health and name, family information was deemed to be most important, reflecting offspring's interests in their genealogical origins. When explored further in the open-ended comments, it was apparent that donor-conceived offspring's interest in the donor's family was in response to natural curiosity, the perception of a right to information about genetic heritage and the importance of this information for their personal identity. These findings support the benefits of having information about donor's family structure available on registries and are consistent with the findings of earlier research (Freeman et al., 2009; Hewitt, 2002; Jadva et al., 2010; McWhinnie, 2006; Turner and Coyle, 2000).

The current study noted reciprocal views on contact between the donor and offspring. Sperm donors felt that offspring should be aware of the donor's view on being contacted, a perspective that was shared by donor-conceived offspring. Views on contact were less important for oocyte donors, but this may be due to the fact that most oocyte donors in the present study were known to their recipients and may have already considered such issues during implication counselling. In Australia, existing mandatory registries do not have a protocol for stipulating stakeholder preference for contact. Views on contact are neither stated in registries nor have the capacity to be updated to reflect the possibility that stakeholder preferences may change over time. Crawshaw et al. (2007) found that a donor's view on donation and contact with any resulting offspring may vary according to life circumstances. Similarly in a survey of 32 semen donors, Daniels et al. (2005) found that 25% had reconsidered their previous decision and now wished to be more open, whereas 12% had decided on anonymity after being unsure initially. Disruption to donor's current family constellation was a major reason for reconsideration to anonymity.

With respect to offspring view on contact, while the current study did not specifically ask why offspring rated knowledge of the donor's views on contact as important, it can surmise from their comments that their intent was not to disrupt the donor's current family life but to gauge receptivity. This is consistent with the findings of Scheib et al. (2005), who reported that, while donor-conceived youths were curious about their donor, they did not want to intrude on the donor's life and would prefer contact be facilitated through the clinic or to have information about the donor's stated preference regarding contact.

Recipients in this study strongly favoured disclosure with 74% of participants with children having already disclosed and a further 23% stipulating their future intention to disclose. Previous research has suggested that parental

intention to disclose is influenced by the extent and availability of information about the donor (Klock and Greenfeld, 2004; MacCallum, 2009; Scheib et al., 2003). While the current study did not directly assess this, an interesting finding was that disclosure enhanced recipients' awareness of the importance of information for disclosure to their offspring. Recipients with children who had disclosed perceived identifying information as more important than recipients who had children but who had not disclosed and those who were yet to have children. It is speculated that disclosure stimulates curiosity and potentially opens a 'Pandora's box' of questions by offspring. This result has direct implications for clinical practice in that counsellors need to facilitate recipients' understanding that the information needs of donor-conceived offspring are not static and vary according to developmental and relationship milestones.

Recipients in this study regarded the donor's reasons for donation as an important piece of information to be recorded and made available for release to their offspring. Anecdotally in clinical practice, the question of donor motivation is frequently raised by recipients with an anticipation that it pertains to altruism, as payment for donation is an emotive issue. Thus, it is proposed that recipients regard this information as particularly important for their offspring's view of self and that a donor who has been altruistic enables the recipient to make the narrative of the birth story more sensitive to the perceived needs of their donor-conceived child.

In the pursuit of a healthy offspring, it is understandable why donor's health was rated highly by all stakeholder groups. Health information stored in donor registries across Australia reflects a health synopsis of the donor's life at the time of donation but, like information on contact, typically there is no legal obligation for the donor to provide, or the clinic to seek updated information, and this has significant policy implications for the regulators of assisted reproduction treatment. The importance of having the capacity to update registries to reflect the changing circumstances of stakeholders has been recently highlighted (Kramer, 2010). In the current study, stakeholders' comments reflected the need to give or receive up-to-date information. Indeed some donors reported experiencing difficulties when trying to provide new personal information.

There are some limitations to this research. Firstly, there is the potential for response bias with an internet-based sample where participants were primarily recruited through donor conception support networks. These groups may feel more strongly about the importance of different types of information than individuals who did not participate. The high proportion of recipients who had disclosed to their offspring may also represent a bias, but this also could be considered a strength as these individuals' responses are likely to be guided by their personal experience of information needs following disclosure. Moreover, the current findings on recipients are consistent with that of Scheib et al. (2000) who investigated importance of donor attributes amongst a representative sample of recipients at the Sperm Bank of California. Secondly, the majority of responding donor-conceived offspring were adults who had been conceived through anonymous sperm donation with limited actual information or potential to obtain information about their donor. Information needs may vary according to

developmental life stages and thus younger offspring may have different information requirements compared with adult donor-conceived offspring. However, the current findings in adult donor-conceived individuals are in broad accordance with Scheib et al. (2005) who gauged adolescents' views. Moreover, adult offspring who have not been privy to information about their donor may be best placed to guide policy makers as to the type of information that should be stored and made available because they have been most affected by the process. Finally, while this study has focused on the principal stakeholders, little is known about partner or extended family perspectives and future studies in this area would contribute valuable information to the expanding landscape of donor conception research.

In conclusion, the findings of this study have direct relevance to Australian policy and likely to be relevant to other countries involved in donor processes. In Australia, the Standing Committee of the Attorneys-General is considering how the different laws across Australia governing donor conception can be harmonized with the view to the development of one national donor registry (www.scag.gov.au/). It is paramount that the views of stakeholders involved in donor conception are integral to this process. This study provides a foundation for the development of best practice policy for consistent and stakeholder orientated guidelines and registries. It further highlights the importance of implications counselling in regards to offspring-centric considerations by both recipients and donors.

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