SUPPLEMENTARY MATERIAL

The differences between embryo and gamete donation

Embryo donation is markedly different from both sperm and oocyte donation in a number of key respects. From a donor's perspective, donation of sperm or oocytes is a pre-meditated choice. Donation of embryos for family-building, however, typically arises when the donors have undergone fertility treatment themselves and have unused cryopreserved embryos at the completion of their own treatment. These embryos may be perceived as their own potential children and, where their treatment has been successful, as potential siblings of their own children (de Lacey, 2005, 2007b; Nachtigall et al., 2005; Provoost et al., 2009, 2011; Goedeke & Payne, 2009; Paul et al., 2010; Stiel et al., 2010; Blyth et al., 2011; Kato & Sleeboom-Faulkner, 2011; Goedeke et al., 2015). Consequently, fertility patients with unused embryos may be unwilling to contemplate donating their potential genetic children and their children's potential siblings to be raised in other people's families (de Lacey, 2005, 2007a, b Nachtigall et al., 2005; Provoost et al., 2009, 2011; Goedke & Payne, 2009; Paul et al., 2010; Stiel et al., 2010; Blyth et al., 2011; Kato & Sleeboom-Faulkner, 2011; Goedeke et al., 2015). However, for some, it is precisely the conceptualisation of their unused frozen embryos as the potential siblings of their children that motivates them to donate their embryos to others so that they may be afforded the opportunity of life (Elford et al., 2004; Paul et al., 2010). Where donation for family-building is contemplated or undertaken, donors may experience a continuing sense of duty towards the welfare of any resultant children (Frith et al, 2011; Goedeke et al., 2015,). This is shown in some potential donors' support for selection criteria for recipients including age, criminal history, educational level, financial status, sexual orientation, alcohol, tobacco and drug usage (Wånggren et al., 2013). While embryo donation may be "technically straight-forward" (Janssens, 2009), "very successful" and "cost

effective" (Hill & Freeman, 2011), it may be less attractive than other family-building options for prospective recipient couples because neither of them would have a genetic relationship with any resultant child(ren) and there may be concerns about the implications of the child/ren having genetic parents and siblings living in other families (Nordqvist & Smart, 2014; Goedeke, et al., 2015).

Thematic analysis of the data

This paper reports data from both phases of the study. Phase I data are mainly used to present quantitative findings illustrating frequency and type of contact, using descriptive statistics and Phase II data to draw out themes and reflections on the contact and building a relationship between provider and recipient families. Free text responses from Phase I were also analysed thematically. To analyse the qualitative data, from both Phases, we entered the transcripts of the interviews into NVivo 10 qualitative software and SL went through the data to develop the initial coding strategy. The coding strategy was based on a topic guide that covered: the history of the contact (how it started, who initiated it, why, and what reasons was contact sought); their experiences of the contact; how they saw and conceptualised these new relationships; issues both positive and negative with the contact; views on the future; and any service provision or policy lessons that had or advice for others. Once the initial coding was developed LF and EB also coded the data, and developed more codes and sub-sets of codes to fully cover all the data. Once the data had been coded by each member of team, we discussed our codes and our interpretations of the data and grouped our codes into the key themes presented in this paper.

We used Silverman's strategy of 'comprehensive data treatment' to aid the validity of the analysis. 'All parts of your data must, at some point, be inspected and analysed.' (Silverman,

2006:298). The analysis uses two main ways to 'show the data' (Seale, 1996). First, each point of data interpretation is illustrated with a number of quotes to provide the reader with a feel for the data and adequate evidence for the interpretation. Second, 'simple counting' mechanisms are employed to provide the reader with a sense of how many informants took a certain view. In this way we aim to reflect the diversity of our data that included both quantitative and qualitative responses. This analysis strategy was based on previous work conducted by LF (Frith et al, 2011).

Note on gender of the participants - previous researchers investigating fertility issues have experienced difficulty in engaging men; this project was no exception and the majority of participants are women. However, so as to maximise participant recruitment and to avoid the loss of potentially valuable data, while we indicated our preference for participation of both members of provider and recipient couples, no one wishing to participate was excluded because her/his partner/spouse did not.

Additional material on the results

Type and frequency of contact

Some families had received or provided embryos to more than one family, so for those in contact with more than one recipient or provider family, a combination of contact arrangements is reported (so in Tables 1 – 6, there are columns for each different family with whom they were in contact).

Table 1: Providers' contact with recipients (Phase I)

Nature of contact with recipient	Recipient 1	Recipient 2	Recipient 3
Direct	**9**	**1**	**0**
Via Snowflakes	**6**	**0**	**1**
Both direct and via Snowflakes	**2**	**1**	**0**

Table 2: Recipients' contact with providers (Phase I)

Nature of contact with provider	Provider 1	Provider 2	Provider 3
Direct	**17**	**3**	**0**
Via Snowflakes	**7**	**2**	**0**
Both direct and via Snowflakes	**3**[1]	**0**	**1**

Table 3: Who initiated contact? – Providers with recipients (Phase I)

	Recipient family 1	Recipient family 2	Recipient family 3
Me	**5**	**0**	**0**
My partner	**0**	**0**	**0**
Me and my partner together	**4**	**0**	**0**
Recipient family	**8**	**2**	**1**
Other	**0**	**0**	**0**

[1] One recipient was not in touch with their first provider

Table 4: Who initiated contact? – Recipients with providers (Phase I)

	Provider family 1	**Provider family 2**	**Provider family 3**
Me	**9**	**1**	**0**
My partner	**0**	**0**	**0**
Me and my partner together	**10**	**4**	**1**
Provider family	**7**	**0**	**0**
Other	**1**	**0**	**0**

It is of note here that slightly more recipients initiated contact than providers, although the small numbers do not merit any firm conclusions to be drawn from this. Given this very marginal difference it can be concluded that there is not significant difference between groups in this regard.

Table 5: Type and frequency of contact Providers (Phase I)[2]

Type and frequency of contact	Weekly	Monthly	2-6 x pa	1x pa
Exchange of cards (e.g. birthday, religious festival)	0	1	7	4
Exchange of letters	0	0	8	4
Telephone	1	4	2	0
Email	5	1	4	3
SMS	2	0	0	0
Skype	0	1	2	0

[2] For tables 5 and 6 figures above are greater than the total number of provider participants because some were in contact with more than one recipient family

Table 6: Type and frequency of contact Recipients (Phase I)

Type and frequency of contact	**Weekly**	**Monthly**	**2-6 x pa**	**1x pa**
Exchange of cards (e.g. birthday, religious festival)	0	0	11	6
Exchange of letters	0	0	5	5
Telephone	0	2	2	4
Email	2	5	16	2
SMS	0	1	1	0
Skype	0	0	1	0

In addition, PH1-RF2 mentioned that her provider had suggested *Facebook* contact but: 'we have declined so far because it feels strange because we don't know them.' However, they 'hope to talk with them and meet with them in the near future.'

Desire for contact and open 'adoption'

With a single exception – an American family currently residing outside the US – all study participants lived in the US, and one recipient family was in contact with providers who lived in Europe.

Reasons for open adoption:

> *To be able to have an open adoption so our children could know each other and we could watch our biological children grow up that option was priceless for us.* (PH2-PF1)

Recipients thought that on-going contact provided an important source of up-to-date information about their provider:

> *We have a resource to go to when our children, or when we, have questions. There's a direct connection. We firmly believe that the more information there is – the less questioning and insecurity our children have…. if, there is a medical issue, we can be made aware of it.* (PH2-RF4)

> *Then in June they flew down to [state in which we live] for our twins' birthday party and so they could be surprised with meeting their baby sister and for family pictures. Then when they heard of my son's accident they packed up and caught the first flight to [state in which we live] to be with us.* (PH2-PF1)

> *We went for lunch at their house and met the genetic families, as well as a genetic grandparent.* (PH2-RF4)

Positive aspects of contact

Both providers and recipients agreed that contact had to be mutually agreed, with recipients taking the lead in determining how this should develop so as to promote the children's best interests. As one recipient said:

> *As parents (both genetic and adoptive) we are the adults and should be mature enough to put our children's needs and desire above our own.* PH2-RF4

One positive aspect of contact mentioned by both providers and recipients was that it enabled providers to resolve any feelings of wanting the baby back or recipients' fears that their providers might want the baby returned:

Although, there were twinges of those feelings initially, it was exceptionally brief and having the direct contact gave us more comfort about our decision than we would have had otherwise. (PH2-PF3)

Negative aspects of contact

The down side of open adoption, is the placing family may make different parenting decisions than the adopting family and vice versa...so the question is what do you do at that point? What do you do if you see the placing family making parenting decisions that you don't like or vice versa? (PH2-RF1)

This recipient when reflecting on negative aspects of contact, considered what might happen if providers and recipients disagreed over the parenting of the child. In this respect there is nothing providers could do if they were unhappy with the care of the child – they have no legal responsibilities or rights over the child. It is also worth mentioning that in our data none of the providers expressed this (that they thought their 'child' was not being cared for appropriately) – so currently, at least, this is a concern that has not been realised.

I do wish we lived closer so we could visit in person more. I honestly don't know that there are any negatives other than the distance which I already mentioned. (PH2-PF4)

Since daughter has been born it has been very very difficult to keep up. She is a busy child and as the kids have gotten older our time to update is almost nonexistent. But I try to stay committed. I don't often hear a response from them anymore. They are probably just as busy. The negative on our end is that it just takes a lot of time and

when family/life is so involved with kids there is little time to communicate with them. (PH2-RF7)

Future contact and relationships

We have such an easy, open communication with the genetic parents that we feel it is a strong foundation that we are building, so that when/if the day comes that our daughter wants to have contact herself, we can easily make that happen. (PH2-RF9)

Discussion

Reflections on the studies conducted in New Zealand. "The adoption metaphor was useful in that for many donors and recipients it provided a familiar model for family-building that they could relate to." (Goedeke et al. 2015 p. 2344) However, these studies did not examine contact arrangements between recipients and providers in the medium term, noting that such investigation should provide a focus for future research.

A further element regarding contact between families highlighted in our study occurred when more than two families were connected following embryo adoption. This occurs when a provider provides embryos to more than one recipient family and when a recipient family receives embryos from more than one provider family. Study participants in this situation – albeit few in number – often recounted asymmetrical contact arrangements between the different families, thus making an inherently multifaceted arrangement even more complex. The potential implications of such variations may be profound for all family members and could provide a focus of future research.

Overview on literature on embryo donation and openness/telling children how they were conceived

Snowflakes® encourages participants in embryo adoption to be open with any child/ren who are born and to keep open lines of communication for future contact. This framework of 'openness' and the associated implications of this mean that this programme operates in a different way compared to the anonymous clinic-based donation programmes used in other settings. When comparing our data from this study to other studies on embryo donation, this different context must be borne in mind. To date, most probably reflecting the relatively low uptake of embryo donation, very little empirical research has investigated the psycho-social aspects of embryo donation for either provider or recipient families.

In our study, all participants had chosen to be open with their children, and this was an on-going process - telling the child and then paving the way for future contact. Clearly, our participants were highly likely to be in favour of openness, and our study sheds light on the reasons for this approach and why participants thought openness was the preferred option. Söderström-Anttila and colleagues (2001) investigated the attitudes of 46 donor couples and 27 recipient couples in Finland towards disclosure of embryo donation to their respective children and disclosure of the identity of the donor to the donor offspring. They found that most donors who thought donor children should be told about the nature of their conception also thought that they should also be able to learn their donors' identity. Comparatively fewer recipients thought that donor children should be able to learn the identify of their donor, and around half of those with children born as a result of embryo donation either had or intended to tell their children.

In the UK, a longitudinal study of an initial pool of 21 families including children conceived following embryo adoption and aged up to nine years has investigated child development, family functioning and parental attitudes towards disclosure (MacCallum & Golombok, 2007; MacCallum, 2009; MacCallum & Keeley, 2008, 2012). Summary results from these studies regarding parents' views on disclosure of donation are provided in Table 12

Table 7: Attitudes of British donor embryo recipient couples towards disclosure

	Respondents	Children's age	Told (%)	Plan to tell (%)	Undecided (%)	Not tell (%)
MacCallum & Golombok (2007)	21 mothers	2-5	9	24	24	43
MacCallum (2009)	21 mothers	2-5	9	24	24	43
MacCallum (2009)	16 fathers	2-5	6	19	19	56
MacCallum & Keeley (2012)	17 mothers	5-9	18	24	12	47

References

de Lacey, S. (2007a) Decisions for the fate of frozen embryos: fresh insights into patients' thinking and their rationales for donating or discarding embryos. *Human Reproduction* 22(6): 1751–1758.

de Lacey, S. (2007b) Patients' attitudes to their embryos and their destiny: social conditioning? *Best Practice & Research Clinical Obstetrics & Gynaecology* 21(1):101–112.

Elford, K., Lawrence, C., and Leader, A. (2004) Research implications of embryo cryopreservation choices made by patients undergoing in vitro fertilization. *Fertility and Sterility* 81(4): 1154–1155.

Frith, L., Jacoby, A., Gabbay, M. (2011) Ethical Boundary Work in the Infertility Clinic, *Sociology, Health and Illness* 33 (4): 570-585.

Hammarberg, K. and Tinney, L. (2006) Deciding the fate of supernumerary frozen embryos: a survey of couples' decisions and the factors influencing their choice. *Fertility and Sterility* 86(1): 86–91.

Janssens, P. (2009) Colouring the different phases in gamete and embryo donation. *Human Reproduction* 24(3): 502–504.

Kato, M. and Sleeboom-Faulkner, M. (2011) Meanings of the embryo in japan: narratives of IVF experience and embryo ownership IVF experience and embryo ownership in Japan. *Sociology of Health and Illness* 33(3): 434–447.

MacCallum, F. (2009) Embryo donation parents' attitudes towards donors: comparison with adoption. *Human Reproduction* 24(3): 517–523.

MacCallum, F. and Golombok, S. (2007) Embryo donation families: mothers' decisions regarding disclosure of donor conception. *Human Reproduction* 22(11): 2888–2895.

MacCallum, F. and Keeley, S. (2008) Embryo donation families: a follow-up in middle childhood. *Journal of Family Psychology* 22(6):799–808.

MacCallum, F. and Keeley, S. (2012) Disclosure patterns of embryo donation mothers compared with adoption and IVF. *Reproductive Biomedicine Online* 24(7):745-748.

MacDougall, K., Becker, G., Scheib, J., and Nachtigall, R. (2007). Strategies for disclosure: How parents approach telling their children that they were conceived with donor gametes. *Fertility and Sterility* 87(3): 524–533.

Melamed, R., DeSousa Bonetti, T., Braga, D., Madaschi, C., Iaconelli, A., and Borges, E. (2009) Deciding the fate of supernumerary frozen embryos: parents' choices. *Human Fertility* 12(4):185–190.

Nachtigall, R., Becker, G., Friese, C., Butler, A., and MacDougall, K. (2005) Parents' conceptualization of their frozen embryos complicates the disposition decision. *Fertility and Sterility* 84(2): 431–434.

Nachtigall, R., MacDougall, K., Lee, M., Harrington, J., and Becker, G. (2010) What do patients want? expectations and perceptions of IVF clinic information and support regarding frozen embryo disposition. *Fertility and Sterility* 94(6): 2069–2072.

Newton, C., McDermid, A., Tekpetey, F., and Tummon, I. (2003) Embryo donation: attitudes toward donation procedures and factors predicting willingness to donate. *Human Reproduction* 18(4): 878–884.

Provoost, V., Pennings, G., De Sutter, P., Gerris, J., Van de Velde, A., and Dhont, M. (2011) To continue or discontinue storage of cryopreserved embryos? Patients' decisions in view of their child wish. *Human Reproduction* 26(4): 861–872.

Provoost, V., Pennings, G., DeSutter, P., Gerris, J., Van de Velde, A., DeLissnyder, E., Dhont, M. (2009) Infertility patients' beliefs about their embryos and their disposition preferences. *Human Reproduction* 24(4): 896–905.

Provoost, V., Pennings, G., De Sutter, P., Van de Velde, A,. and Dhont, M. (2012) Trends in embryo disposition decisions: patients' responses to a 15-year mailing program. *Human Reproduction* 27(2): 506–514.

Roberts, E. (2007) Extra embryos: the ethics of cryopreservation in Ecuador and elsewhere. *American Ethnologist* 34(1): 181–199.

Seale, C. (1999) *The Quality of Qualitative Research* SAGE, London.

Silverman, D. (2006) *Interpreting Qualitative Data: Methods for analysing talk, text, and interaction*, Third edn, SAGE, London.

Söderström–Anttila, V., Foudila, T., Ripatti, U-R., and Siegberg, R. (2001) Embryo donation: outcome and attitudes among embryo donors and recipients. *Human Reproduction* 16(6): 1120–1128.

Stiel, M., McMahon, C., Elwyn, G., and Boivin, J. (2010) Pre-birth characteristics and 5-year follow-up of women with cryopreserved embryos after successful in vitro fertilisation treatment. *Journal of Psychosomatic Obstetrics & Gynecology* 31(1):32–39.

Wånggren, K., Alden, J., Bergh, T., and Skoog Svanberg, A. (2013) Attitudes towards embryo donation among infertile couples with frozen embryos. *Human Reproduction* 28(9): 2432–2439.

Zweifel, J. E., Christianson, M., Jaeger, A. S., Olive, D. L., and Lindheim, S. R. (2007) Needs assessment for those donating to stem cell research. *Fertility and Sterility* 88(3): 560–564.