

Feedback form

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If this feedback is on behalf of an organisation, please name the organisation:	Please note i am happy for my feedback to appear on the acart website but i want my name withheld – i am not sure how to indicate this on the form
Please provide a brief description of the organisation if applicable:	
Address/email:	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of the public):	user

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☒ I **do not** give permission for my name to be released to persons under the Official Information Act 1982.

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We will acknowledge all feedback.

Questions about the issues discussed in the paper

Question 1: Altruistic donation v. commercial supply

Should it be possible to use commercially sourced gametes and embryos from other countries in New Zealand?

- | | | |
|--------------------------|---|-----------------------------|
| • In all circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • In no circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • In some circumstances? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |

If so, what circumstances might be acceptable, and what circumstances would not be acceptable?

Where the embryos/gametes are created via an "open donation" – both donor and recipient parties have had counselling to this effect in the manner that takes place with NZ donations, preferably both parties have met or at very least "skyped" as part of this counselling to ensure openness, where the offspring/donor have contact details of each other and are obliged to keep these up to date so that there is provision for them to be in contact with each other should this be desired in future - in the same manner as is indicated in the Hart Act. Where both donor and recipient parties agree to register their details on the Donor Sibling Registry so that other potential genetic siblings created via the donor can also be in touch with each other should this be desired. Where embryos/gametes are created via donor programmes that ensure adequate counselling for donors so they are fully informed of risks and are not coerced in any way to participate. Where the clinic overseeing the donor cycle is "reputable" – adheres to local certification etc such as those that are in "partnership" arrangements with NZ clinics at present (San Diego Fertility Centre, Pacific Fertility Centre)

Would a higher level of donor expenses increase the supply of locally sourced gametes?

Yes ☒ No ☐

Please give reasons for your views.

There is absolutely no question that the ideal situation is for NZ fertility patients to be able to use local donors – it does not involve overseas travel for the recipient couple, it allows easier contact between donor and offspring in future should this be desired, it saves a lot on expenses for the recipient couple and in a purely business sense (lets face it, Fertility IS a business!) it keeps money spent on fertility treatment in NZ rather than being paid overseas. Speaking from personal experience – having had 2 local egg donors and one local embryo donor and subsequently an overseas (US) egg donor – my preference would have been to have been successful with a local NZ donor – we would have avoided travelling overseas for treatment, we would have had a donor living in NZ which would have made future contact between our child and the donor easier and of course it would have been a lot cheaper – even if we had paid donor expenses in NZ. We were extremely lucky to find 2 local egg donors – i know many people less fortunate than us in this respect as they are so rare. The first was a friend of a friend of a friend – sourced by a email which we sent to all our contacts far and wide and asked them to “spread the word”. The second was the result of me walking around the streets of our local neighbourhoods and doing a “poster campaign” for want of a better term! I stuck up many many MANY posters in shop windows over the course of about a month. Both these techniques we chose because we wanted to “think outside the square” because we knew so many people advertised in magazines such as “Little Treasures” and we thought if we do that, we will simply be another person in the “queue” and unlikely to be successful. Sending out emails and sticking up posters were not things I would want to chose if there was an easier way – it meant losing all our privacy – people in shops would ask me all about egg donation and quite frankly I wished I didn’t have to be so public about it and have to rake up the difficult emotional journey of our IVF time every time i went into a shop. There is no question a local egg donor is very hard to find. I truly believe that if donors were more appropriately recompensed for the enormous undertaking they do we may well have more local donors to choose from – and people like me wouldn’t have to either lose all privacy/spend inordinate amounts of time/effort and heartbreak searching for donors. We would have very very happily paid donor expenses – it only seems fair. An egg donor goes through so much physically to do a donor cycle – the hormone ups and downs, the injections, the invasive procedures, anaesthetics etc etc NO WONDER donors are in short supply! As for any issues about “commercialising” donation – as long as good counselling is in place whereby donors are fully informed of risks and also fully informed about the importance of open donation/allowing potential for future contact with offspring – in other words going into the donation full informed and aware of risks and future “obligations” in terms of contact – then i think any risks of the donor being “exploited” are mitigated. I also think NZ should introduce a minimum age for such donors – definitely over 20 years perhaps slightly older? – as I think teenagers are too young to be undergoing these kind of arrangements except under special circumstances (e.g. for a family member).

Question 2: Right of access to identifying information about donors v. no right of access to identifying information about donors

Should it be possible to use gametes and embryos in New Zealand where donor offspring do not have access as of right to identifying information about donors?

- | | | | | |
|--------------------------|-----|-------------------------------------|----|--------------------------|
| • In all circumstances? | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| • In no circumstances? | Yes | <input checked="" type="checkbox"/> | No | <input type="checkbox"/> |
| • In some circumstances? | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
- If so, what circumstances might be acceptable, and what circumstances would not be acceptable?

No – this is not acceptable

Please give reasons for your views.

As mentioned above, our preference was to find a local donor – however after unsuccessfully going through 2 different egg donors and then an embryo donor cycle, we decided to look overseas. Initially we had ruled out going overseas because we thought any donor cycles there had to be anonymous. However we found out that if a donor agrees to an open donation this is possible. We chose a donor and then via the USA clinic we made contact with her and asked if she would agree to an open donation. WE had received some photos of her and a profile providing various details (as is standard with US egg donations, even closed ones), and we thought it only fair to provide our donor with a photo and info on us – which we did. We received an email from the clinic advising us that our donor had agreed to an open donation. We had our donor legal agreement amended from the clinic's standard "anonymous" one, to an agreement which outlined the parameters of the open donation (e.g. future contact opportunities, that donor and us would register our details on the Donor Sibling Registry etc). This was not an easy task trying to put in words in a legal agreement the parameters of an open donation but was vitally important to us. You see we simply would not have gone ahead with the donor cycle without knowing we had done all we could to ensure the ability of our future child to be fully informed about their genetic donor – and also safeguard as much as possible, the potential for our child to make contact with their donor in future should they wish. We also felt ethically and morally it was vitally important for us to allow the donor the potential to make contact in future and also keep her informed about any offspring – this is a huge emotional undertaking for all concerned including the donor – it did not sit "right" with us to allow us to take her eggs and then never allow her to know any more about what happened! (As an aside – we also did not feel right about using a donor which had not yet had her own children – so we only considered a donor who had had a least one of her own children – we felt it was ethically wrong to use a donor who had not experienced motherhood and would then hopefully have a fuller appreciation of what she was doing and the emotions around donating her eggs. It also sat better with us knowing that – although the risks were small – something could happen as a result of the donor cycle which could affect her fertility – we didn't want our donor not to have had children herself just in case anything happened as a result of our cycle.)

Coming back to the right to identifying information – I have been to adoption seminars here in NZ and read many books on the issues around egg donation/offspring. All of the research I have read and my own experiences have pointed to the importance of open donation. I truly believe that just as some years ago we had the issue of closed adoptions coming to the fore and many children wanting to "trace" their birth mother, so too could we have many many children feeling like they have a "gap" in their knowledge and wishing they had more information and the ability to make contact with their genetic donor.

I think openness "normalises" the experience. It doesn't create "skeletons in the closet" which can be revealed later down the track resulting in emotional harm. I think openness protects both the offspring and donor – empowering both of them in the sense they have access to key information about their own selves and important actions they have taken in their life. Depriving either party of this is not human, not ethical and I think in a few years time, just as we view closed adoptions, we will look back in regret that so many closed donations were allowed. I think its important to acknowledge that people change over time – donors grow older and may start wondering about their donations, children of donor cycles grow into adults and start wondering. It is hard to predict how people will feel and its important to safeguard the OPPORTUNITY for contact and information – even if it is not wanted right now. There are other reasons too of course – accessing important health information for genetic diseases, stopping unwitting intermarriage between donor offspring - these are important reasons also for ensuring open donations. But above all, I think it is a child's right to know where they have come from – both in terms of birth parents and genetic donors.

I think if NZ could ensure any overseas clinics they have a relationship with set up appropriate open donation programmes, then I don't have any issue with allowing embryos to be imported. I think a positive side to all of this could be that if NZ does allow import of embryos created in the US via open donation, it will be an incentive for NZ couples to chose open donation – thereby minimising anonymous donations and allowing future ivf donor offspring more safe guarding when it comes to information about their donor and making contact with their donor in future.

Question 3: Family size limitations

Should it be possible to use donated gametes or embryos in import/export where the use may exceed New Zealand limits on the number of families assisted?

- | | | | | |
|--------------------------|-----|--|----|--------------------------|
| • In all circumstances? | Yes | <input checked="checked" type="checkbox"/> | No | <input type="checkbox"/> |
| • In no circumstances? | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| • In some circumstances? | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |

If so, what circumstances might be acceptable, and what circumstances would not be acceptable?

Please give reasons for your views.

I am not as 100% clear on my views about this as some of the other issues. I think limits are needed but these could perhaps be more than one other family. It would be a real shame if limits were put in place which meant that there was a donor shortage (ie it comes down to the supply of donors overseas – and I am not sure what that is at present,) I think it also could have cost implications which could be passed onto the recipient couple (again im not sure, but imagine if a donor is able to provide 5 separate donations to different recipient couples then her fee is likely to be a lot less than if that donor can only donate to one couple) Whilst in an ideal world you would minimise the number of families assisted with the same donor, practical issues of supply and cost need to also be taken into consideration too. I think on balance my preference would be to allow multiple families to be assisted by the same donor so long as anonymity is not preserved – ie you have open donations and people are registered on the donor sibling registry, then you can minimise risk of incest and also ensure that full genetic siblings are able to make contact. And with a limit (e.g. 5?) you are ensuring the numbers of offspring are contained.

Question 4: Prohibitions on the use of sex selection

Should it be possible to use imported embryos subject to sex selection for reasons prohibited in New Zealand?

- | | | |
|--------------------------|---|-----------------------------|
| • In all circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • In no circumstances? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |
| • In some circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

If so, what circumstances might be acceptable, and what circumstances would not be acceptable?

Please give reasons for your views.

I dont believe parents have the right to determine the sex of their offspring. This is too much "playing with nature" for me. The focus of ART should be creating healthy children NOT picking the sex of a child.

Question 5: Scope of informed consent

Should explicit consent to export gametes and embryos to and from New Zealand:

- Be required in all circumstances? Yes ☐ No ☐
- Not be required? Yes ☐ No ☐
- Be required in some circumstances? Yes ☐ No ☐

What are those circumstances?

Please give reasons for your views.

I really dont know the answer here – but my gut feeling is that there surely is little difference between a donor donating an egg which becomes an embryo which is implanted in a US clinic, vs that same donor's embryo being imported into NZ to be implanted into the same recipient in a NZ clinic? Isnt the key issue that the donor has agreed to donate to a particular PERSON or COUPLE NOT where the transfer takes place?

Question 6: Use of gametes and embryos overseas in procedures or research prohibited or precluded in New Zealand

Should people be able to export gametes and embryos for uses prohibited or precluded in New Zealand?

- | | | |
|--------------------------|------------------------------|-----------------------------|
| • In all circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • In no circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • In some circumstances? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

If so, what circumstances might be acceptable, and what circumstances would not be acceptable?

Im sorry this issue is very complex and I dont have time at moment to give this consideration

Please give reasons for your views.

Question 7: Other areas where there may be a mismatch between New Zealand and overseas requirements

Are there other areas of potential mismatch that should be considered? Please describe.

Definitely donor counselling overseas needs to make donors aware of the benefits of open donation. Also records absolutely need to be safeguarded – like we have the Hart register in NZ – overseas clinics need to have something secure in place – perhaps this is the Donor Sibling Registry – but should be endorsed by government to ensure it remains in place.

Question 8: Ranking issues in importance

Please put in order the importance you give to each of the following issues in regard to import and export of gametes and embryos with 1 being the most important.

Altruistic donation

5

Right of donor offspring to access identifying information about donors

1

New Zealand requirements for family size limitations

3

Explicit informed consent to export to another country

4

New Zealand prohibitions on the use of sex selection [box]

2

Use of gametes and embryos overseas in procedures or research prohibited or precluded in New Zealand

6

Another issue or issues (please describe)

Question 9

Do you have any other comments or suggestions about the issues discussed in this background paper?

One more point about the "Justice and Equality" issue cited in 2.12 - I don't think this is a valid point because this situation is already occurring at present with local fertility treatment. I know a number of people who have had to stop fertility treatment not because they wanted to emotionally or the doctors told them to, but because they simply could not afford to continue. Not everyone can afford to "buy" fertility treatment locally! Unless you make local treatment much much more affordable (e.g. fully fund unlimited cycles) then I don't see how this is a valid reason for trying to discourage overseas treatment.

Also a final comment - I wrote half of this submission in an airport lounge waiting for a flight back to NZ after having a FET cycle at a US clinic, the remainder back in NZ jetlagged. My husband and I went to the US for treatment when our 3 donor cycles in NZ (and 5 cycles with my own eggs) failed - it was a "last resort". We were fortunate to get 8 blastocysts from the US cycle - we had 2 put back the first time resulting in our child. We then really got concerned about risk of twins and decided to do all future transfers with one embryo only. I went back to the US 2 months ago and had one embryo put back - negative, and am now in the 2 week wait having had another put back. Each of these trips is extremely costly, time consuming and exhausting. The temptation to put back more than one embryo grows each time we get a fail - we know medically speaking SET is best but with the embryos in the US it's hard not to be tempted. I truly believe if we were able to import our embryos the only effect would be that we would absolutely only do SET not multiple transfers in future - surely a good thing?! We are also fortunate to currently have enough money (just) to plan to return for 4 further transfers if required to use all the remaining embryos but this could change - it is such a shame that due to the inability to import these we may not be able to complete our family. I can't see anything but benefits to allowing this law change.

I am happy to be contacted for further information about our experience/situation if you would like this.

