

## **ACART Consultation on Informed Consent. Submission by Maui Hudson**

Kia ora korua,

Here are my thoughts on the informed consent consultation document and its proposed advice.

### Initial consent process

a) Is more information req - I think you need to strike a balance between amount of information, range of potential situations, and what people can sensibly consent to in advance. Most situations don't come into focus until they are right in front of you. Consent is more dynamic agreement than a contract and should be flexible by nature. I'm not convinced that more information at the point of consent makes the process of ARP's easier. I'm not clear on the issue being addressed, philosophically informed consent should be informed and more information should relate to being better informed but practically this may not always be true.

b) consent to all assisted reproductive processes, where consent is required, must be in writing. I would change this to should be in writing. While getting written consent in advance is preferable I don't think it is sensible to make it an absolute esp as it removes the possibility for whanau consent to processes when the person themselves is unable to consent (ie has passed away). The times when written consent is not in place is around unexpected situations. From a Maori point of view, when that occurs others take responsibility for decisions that need to be made.

Question 3 - If consent for training is req then it will appear as part of a catch all generic statement or be used specifically in relation to disposal options.

### d) Gametes donors can place conditions

I agree with this. 83. An altruistic spirit is present in the Maori community but it is not always unconditional. Takoha has emerged as a key concept in our project around Maori views on biobanking especially as the use genetic material is closely connected to whakapapa. Takoha can be thought of as a gift with responsibility or

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even as the gifting of the responsibility itself. Donors should be able to place conditions on the use of the gametes.

Ongoing involvement of gamete donor

Question 5 – yes

f) this is pointing towards a change in thinking around the point of no return, a shift from implantation to fertilisation. My issue with this is that the gamete donor is still going to be listed as the 'genetic parent' on the genetic register. The existing situation of allowing the removal of consent seems like a more appropriate approach. An exception could be made if the embryo/s in dispute already has an existing sibling, on that basis that the new genetic whanau is already established so the affect of the birth on the donor is less significant (than for a new one).

### **3. Partner, family and whanau rights and interests**

g) I don't agree with the wording of this statement. I'm not sure how the issue has been identified and whether it relates to an actual situation. My understanding of the current situation is that the donor might be encouraged to discuss with whanau and get their support (rather than consent), this should continue. The current Fertility Standard practice seems appropriate to address a kawa emerging from our biobanking project 'Kia Tau te Wairua o te Tangata' which is about the level of comfort that people and their whanau have in a procedure.

It seems the argument about partners having undue influence has directed the thinking however if the family members aren't happy with the decision it doesn't make the situation better by not including them.

The main issue I have with the statement is that (as it stands) it sets a precedent that undermines whanau rights and interests to be involved in decisions relating to children that they (in the Maori sense) will be responsible for because of the shared whakapapa. I don't believe the statement is required.

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### Question 7

a) No

b) No

i) Regulations for informed consent

I don't think that regulations are required for informed consent. The argument seems to be things are going alright in the clinics but other jurisdictions have more guidance so we should too.

I think we need to be careful about using informed consent as the only way to protect the interests of people, their whanau, and the clinicians. Informed consent has a number of limitations partly because a number of the consent decisions are distant from the point of application. They work well for immediate clinical decisions, and may prompt consideration of possible events in the future but should also be subject to change. Disputes and uncertainty arise around unplanned or unexpected situations often related to changes in relationships. Why should a consent given at a time when people were happy together apply to a situation when they no longer are in the same space?

Consent is a direction not an agreement/contract.

na Maui