

# **ACART Consultation on Informed Consent. Submission by the Bioethics Centre, Otago University.**

## **Informed Consent and Assisted Reproductive Technology**

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At Page X the discussion document says

### **“Regulations**

(A) Requirements for informed consent should be set out in regulations, where appropriate”

The Report goes on to say that this recommendation is not made because of any perceived operational problems, but because of transparency and minimizing the risk of any misunderstanding. We wonder whether this is a sufficiently strong reason for introducing new regulation. Consent is just as important, possibly even more so, in other areas of health care yet we do not require the same level of regulation there. Does this recommendation run the risk of ‘ART exceptionalism’? (The idea that there is something different in kind about ARTs that requires a special or exceptional level of regulation.)

At Page 10 the Report discusses the need for better access to information and 43 suggests that the Fertility Services Standard is not freely available and says, ‘This creates an obstacle for donors, patients and anyone with an interest in the information who may wish to access it.’ This claim is qualified by the phrase ‘who may wish to access it’ and while it is certainly *possible* that one of these groups might wish to access it, is there reason to think that any of them in fact do? Moreover, given that fertility service providers in New Zealand tend to be very good at providing information (and ACART has noted there are no operational problems) is there any reason to suppose that in the event someone wanted to see the Standard they couldn’t? It’s not obvious to us what the argument for regulation is, and we wonder whether it’s an instance of ART exceptionalism.

Alternately providing a copy of the Fertility Services Standard on the ACART website may be sufficient to address this concern about access to information.

At Page 11, para 49 it says ‘The principle of transparency would appear to demand that anyone should be able to readily access, or receive on request, the information set out in the standard.’ We note that the preceding paragraph says existing arrangements for providing information are working well, so para 48 and 49 appear to contradict each other. We’re not sure what is meant by the ‘principle of transparency’: it appears to mean something like ‘all relevant information should be available in a standardised and written way’, but’s it’s not clear why that is a duty, nor whether it is consistent with informational requirements for other areas of medicine.

At Page 12, para 57 it says ‘Clinic practice is to obtain consent in writing. This is a good practice standard.’ The report claims that this is a requirement that should be included in regulation. We’re not sure what the argument for regulation is if in fact clinics are following

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best practice. Later it does note that in Canada written consent is a requirement in their regulation, and consistency with other jurisdictions is an argument, albeit not an especially strong one.

At page 15 the report discusses the conditions that donors might place on the use of their gametes. At para 78 it considers whether someone might limit use to married couples, single women, and same sex couples. Would saying you did not want your gametes to be used by same sex couples be acceptable? When would conditions become unacceptable? Presumably skin colour, ethnicity and religion would not be permitted, but why?

Page 15, para 83 last sentence should be checked for sense, that wasn't clear to us.

We agree with ACART's proposed advice at page 25 in regard to disputes about embryos: i.e. when one party withdraws consent.

We would also support this being made an explicit part of the informed consent discussion when couples first attend the IVF clinic and any regulations that are promulgated.

The following article provides an interesting analysis of the ethics and relevant case law in this area.

Zoe Lawton, "Non-consensual Artificial Paternity" (2013) 7 New Zealand Family Law Journal 248.