

# New Technologies and Ethics: Researching the Personal

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In New Zealand, assisted reproductive technologies (ARTs) are both a relatively common medical technology, and a deeply personal topic. Those seeking to use them are often on a deeply personal journey, one that is lengthy and fraught with emotion and difficult choices. This creates an array of ethical issues when designing research into the impacts of ART use, ART regulation, and considering public engagement. One of the chief considerations for those conducting social research on ARTs is collecting and integrating these stories into the research in an ethical manner. A number of research steps, including locating participants, carrying out interviews and discussions in a sensitive manner, and using the information collected while respecting confidentiality all raise serious ethical questions. However difficult, no research would be complete without including a variety of the lived experiences – infertility, childlessness, those seeking ARTs, and those using (or have used) ARTs. Resolving some of these ethical issues is essential to creating spaces where productive and positive public engagement can occur.

My PhD is seeking to understand attitudes and values towards ARTs in New Zealand with the aim of designing deliberative policy-making processes that better serve both the complex nature of the technology, and the diverse community. Part of the research involved conducting interviews with a range of people involved in the ART and ART policy communities, as well as users and potential users. I then piloted a citizen jury, where a group of interested citizens learnt about ARTs, and deliberated some of the key policy issues. Both of these research methods raised ethical issues, and a number of research design choices were dictated by such concerns. In this paper I introduce ARTs and show how the personal nature of the research became quickly apparent to me. I discuss the key ethical principles of anonymity and empathy, before relating them to the issue of public engagement on the topic of ART.

## **Assisted Reproductive Technology**

Assisted reproductive technologies are a group of technologies that involve the manipulation of human reproductive tissues (such as eggs and sperm) outside the human body and in the presence of a medical doctor. The technology central to ART is in-vitro fertilisation (IVF), which was developed in the United Kingdom in the late 1970's. IVF consists of a doctor mixing sperm and egg in a dish and cultivating any resulting fertilised eggs into embryos. These embryos are then implanted into a uterus, where they may go on to become a successful pregnancy. Other ARTs are essentially

variations on IVF, and their use depends on the reason for ART use. One of the most important variations is the use of donated reproductive tissue in IVF. Sperm can be donated relatively easily, and can be inserted directly into the uterus, side-stepping the need for any IVF. Egg donation requires a drug regimen and minor surgical procedure, and must be used in conjunction with IVF. Additionally already fertilised eggs can be donated as embryos. Another variation is surrogate pregnancy, which involves the implantation of the embryo into a different uterus to that of the intended mother, with the woman who becomes pregnant known as the surrogate mother. Each of these techniques and technologies has a high failure rate, which a number of factors including skill of the doctor involved, age of the participants, and reason for needing treatment play a part.

Another important subset of ARTs is so-called repro-genetic technology, which seek to test or alter the genetic make-up of future offspring in specific ways. The main repro-genetic ART is pre-implantation genetic diagnosis (PGD). In PGD, several cells are removed from an embryo and tested for certain gene variations. The embryos are then selected for implantation based on whether certain gene types are present or absent. Currently this can be used to determine the sex of embryos and test whether an individual embryo is the carrier for a specific version of a gene. However genetic technologies are rapidly developing, and repro-genetic technologies are likely to be able to give much more complete information in the near future. They are also likely to become cheaper, faster, and more routine. ARTs are widely used in a number of countries around the world and are responsible for the birth of more than five million children (Bauquis, 2012).

ARTs raise a range of social, legal, economic, and ethical issues for society to deal with. Many types of knowledge are possibly relevant to understanding and dealing with these issues. For example, legal, social work, and psychological knowledge help to understand and ameliorate the potential ramifications of splitting social, legal, biological, and gestative (in the case of the mother) parentage across several people. Many economic and philosophical issues are raised by the potential for sale of reproductive tissue and surrogate service. Likewise, the high cost of ARTs without public subsidy raises issues around fairness and equality that are chiefly political, social, and economic in nature. The questions around the citizenship of offspring born using internationally donated reproductive tissue or surrogates, is both a technical legal question, and a social and political one. Cultural, ethical, and religious forms of knowledge can help address questions about the nature of life and the meaning of being human. These few examples demonstrate the potential breadth of knowledge that can be applied to ART use and policy, in addition to the basic medical and scientific knowledge required to create and implement ARTs.

Although ARTs have been relatively commonplace in New Zealand for more than 25 years, there is little public understanding about their use, or discussion about appropriate policy mechanisms. A small but significant body of New Zealand-specific literature around ART use and policy was created prior to the passing of the HART Act (Caldwell & Daniels, 1992; Coney & Else, 1999; Daniels, 2003; Daniels & Caldwell, 2002; De Luca, 2003; Henaghan, 1991; Parker, 2004). Combined with the small group of people involved and the technical nature of the subject matter, there is not much information available about ART policy, and even less analysis (see Park, McLauchlan, & Frengley, 2008 for one example). There are significant ethical issues associated with conducting research on ART use and policy, and these issues impact on public engagement with the issue.

### **Researching ARTs**

My research interviews (and subsequent citizen juries) presented me with a range of ethical issues to work through, but provided an essential perspective on the lived experience of ART policy. Likewise interviews provided experience with users, potential users, and those who would chose not to use. The experience was also a clear reminder to me that while my interest in the topic could be described as ‘academic’ or even abstract, for many people assisted reproduction is an on-going issue that dominates their lives, sometimes for years. These lessons were reinforced during both interviews, and in the later policy jury. In many ways, ARTs are not exceptional, as all social research must deal with ethical concerns. However the complex nature of ARTs– on one hand a fairly routine medical procedure and on the other a deeply personal journey – does pose certain specific challenges, some of which are difficult to overcome.

### **Anonymity and confidentiality**

The preservation of anonymity and confidentiality of research participants is paramount to good ethical conduct. Anonymity requires that the identity of the participants is kept secret, while confidentiality allows for the disclosure of routine or unimportant information (Wiles, 2013). The use of these practices is rooted in an understanding of informed consent, where the participants fully understand the purpose of the research and the intended use of information. Their participation may then be contingent on either anonymity or confidentiality, gained through the use of anonymised quotes or pseudonyms. However there are increasing moves to reduce or avoid anonymity in research, particularly when information is intended to be widely disseminated (Tilley & Woodthorpe, 2011). I believe that ARTs are an area where participants may speak more freely when there are guaranteed anonymity, and the research therefore benefits significantly.

The small ART community my research focuses on contains people who hold multiple roles and are easily identifiable, even without their names. Many felt they would be easily identified if they were widely quoted under a pseudonym, and wished to avoid this in order to give a more candid interview.

I felt it was crucial to obtaining the consent necessary for interviews to negotiate with each participant. I assumed anonymity and have avoided pseudonyms, instead opting to ascribe quotes to general roles, such as “ART provider” or “ACART/ECART member”. In the case of people with multiple roles (where the primary role was taken) this is less than ideal, and certainly some limits of the utility of the research results. However, given the controversial and personal nature of the topic, it is necessary to ensure the best and most ethically research.

### **Empathy, respect, and the researcher**

The expression of empathy and respect for research participants is essential, and is relevant in two ways. The role of the researcher with respect to the participants is often difficult, and the subject of much debate (Fontana & Frey, 2008). While some argue that researchers should be ‘unbiased’ or ‘neutral’ toward the subjects of their research, I subscribe to an interpretivist approach. Such an approach argues that research must focus on understanding the world through the eyes of participants, and searches for meaning (Wagenaar, 2011; Yanow, 2000). This requires considering the relative positions of power of the interviewer and participants, as well as the levels of knowledge and access to information. The ‘biography’ of the interviewer, in terms of gender, age, ethnicity, and personal experience may also be a consideration. The interpretivist framework also allows the rational/emotional dichotomy that places rational considerations as legitimate knowledge and emotions as irrelevant ‘noise’ to be broken. By considering the lived experience of research participants (not subjects) as an essential component of the research, I was able to display an attitude of respect and empathy towards those involved. This was modelled impressively by many of the doctors and research scientists involved, who displayed genuine empathy for the patients in their care.

### **Ethics and Public Engagement**

The ethical considerations that were relevant to my research are instructive when we consider public engagement on the topic of ARTs. The adoption of an ethical framework by researchers is crucial for both the presentation of information and the design of public engagement spaces. The low level of public knowledge around ARTs makes education a priority as any part of public engagement. Information that provides clarity around the scientific, social, and legal issues is crucial to informed discussion. Care must be taken to provide information that demonstrates different perspectives and illustrates areas of divergent opinion. This is an area where the initiators of the engagement must act ethically, as the presentation and framing of such information can have a significant impact. Such issues include how the ‘problem’ that ARTs address is framed, the type of expertise that included, and how conflicts and dichotomies are presented. For instance, sex selection at the individual level is often framed in terms of rights and choice, and a distinction is often made

between social and medical reasons for selection. However the societal pressure that may dictate selection one way and the potential population-level effect of skewed gender ratios must also be included. There are a number of areas where such framing is crucial for the educational portion of engagement to be ethical. This commitment to ethical principles must also apply to all members of the research team. This includes selecting moderators who act appropriately, and in accordance with the ethical principles of the research.

Considering ethical issues during the design of the space for public engagement is important. Having available multiple spaces delineated by factors such as gender, culture, age, ethnicity, or experience may be important. This can allow participants to learn about a topic and develop ideas comfortably, before being required to defend them. It can allow a chance for them to ask the 'stupid' question, or pose controversial hypotheticals without fear of immediate attack. This practice is currently used on many issues, with examples including ACART-led hui and fono (meetings based in Maori and Pacifica cultures), and youth hui on a number of issues. Public engagement that draws on deliberative democracy will ultimately require that these spaces be merged and competing perspectives given a chance to be debated, but giving participants an initial space will allow stronger deliberation. It is important to note that diversity can still exist within delineated groups, and can sometimes be enhanced by it. My citizen jury was limited to women (partly due to the internal ethics committee<sup>1</sup>) and this allowed me to focus on having a group that was diverse in ethnicity and age, and included lesbian and trans women. This was a successful group, and there was a range of opinions and experiences represented. However the participants all felt comfortable enough to participate in the deliberations.

Forms of engagement that leverage the benefits of the internet and social media have great potential. Toi te Taiao: The Bioethics Council carried out an internet-based public consultation in 2007 and 2008 on sex selection for social (non-medical) reasons (Toi te Taiao: The Bioethics Council (N.Z.), 2007a, 2008). Information that displayed different approaches and perspectives was presented to any interested parties, then discussed over a period of several weeks through internet forums (Toi te Taiao: The Bioethics Council (N.Z.), 2007b) This helped overcome resource constraints

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<sup>1</sup> The initial intention of the research was to focus the citizen jury on traditionally marginalised groups, specifically women from ethnic minorities, single parents from lower socioeconomic groups, and those marginalised by their gender identity and or sexuality. This was an attempt to overcome existing systematic and structural imbalances that mean these groups are significantly less involved in public discussion and policy making. The internal committee responsible for research ethics approval were dubious about limiting the jury in this way, and were concerned about the protection of the emotional and psychological wellbeing of participants in a group discussion setting. After some negotiation, a compromise was reached. The group was limited to women; participants were recruited from a wide variety of community groups including those that represent single mothers, the gay and lesbian community, and recent migrants. Any future research would require significant work on the ethical aspects of participation of this nature.

as not all participants had to be in the same place, and timing was not an issue. The internet also helped people preserve a measure of anonymity as discussions were not face to face. It should be noted that such spaces are not mutually respectful or safe by default, but do allow for very careful moderation to be implemented, as well as the option for participants to opt out very easily. While some were critical of the lack of clarity around Toi te Taiao's final recommendations, the consultation was widely acknowledged as a useful and innovative way to approach a sensitive topic (Jones, King, & Whitaker, 2009). Unfortunately this model has not been developed further, as Toi te Taiao was disbanded without substantive replacement in 2009. The Advisory Committee on Assisted Reproductive Technology (ACART) was nominated by the Government as a similar body that could carry on the work, but has a different and significantly narrower mandate (McCabe, 2009).

### **Conclusion**

While the ethical issues involved in social research on ART use and regulation are significant, these should not prevent public engagement on the issue. Acknowledging the relevance of anonymity and maintaining empathy and respect for participants are key issues in the conduct of ethical research. Participant engagement brings about specific challenges for the ethical researcher, and requires a commitment to ethics by the researchers and moderators involved. However, there are opportunities in the design of deliberative spaces, both in terms of participant selection and physical construction, to reap benefits from ethically sound choices.

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