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***MĀORI ATTITUDES TO
ASSISTED HUMAN REPRODUCTION:
AN EXPLORATORY STUDY.***

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E kore au e ngaro, te kākano i ruia mai i Rangīātea.

**I will never be lost,
the seed which was sown from Rangīātea.**

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CONTENTS

1.0 INTRODUCTION	1
1.1 The Māori Fertility Rate	3
1.2 Historical Responses to Infertility	4
1.3 Māori and Assisted Human Reproduction (AHR)	5
2. METHOD	7
2.1 Kaupapa Māori	7
2.2 Research Design	7
2.3 Demographics – Key Informants	8
2.4 Demographics – Hui Participants	10
2.5 Data Analysis	11
3. RESULTS	12
3.1 Seeking the Māori View	13
3.2 He Puta Tatou / We Must Survive	14
3.2.1 Ensuring the Survival of The Māori.....	14
3.2.2 Sustaining the People.....	16
3.2.3 He Mokokopuna, He Taonga.....	16
3.2.4 He Māori, He Mātua.....	17
3.2.5 He Wahine Māori Ahau, He Mama Ahau Hoki / Fertility and Māori Women’s Identity.....	23
3.2.6 Fertility, Sexuality and Gender.....	23
3.3 Historical Māori Views on Fertility and Responses to Infertility	24
3.3.1 What Did Māori Think About Infertility?.....	24
3.3.2 Some People Have Children and Some Don’t.....	24
3.3.3 Mākutu.....	25
3.3.4 Tohunga and Rongoa.....	25
3.3.5 He Puna Rua.....	26
3.3.6 Within Whānau Solutions.....	27
3.3.7 Whāngai.....	28
3.3.8 Co-Parenting.....	33
3.3.9 God Willing.....	33
3.4 Infertility	34
3.4.1 Infertility: A Phenomenon of the Times.....	35
3.4.2 You’ve Got to Own Your Own Home, Own Your Own Baby... ..	41
3.4.3 Infertility – How It’s Defined Today.....	42
3.4.4 Infertility – The Causes.....	43
3.4.5 The Contribution of STIs to Infertility.....	46
3.4.6 Infertility – Te Mamae.....	46
3.4.7 Infertility – An Emerging Issue for Māori?.....	49

3.5	Attitudes to Assisted Human Reproduction	51
3.5.1	Potato, nail, musket, AHR	51
3.5.2	It's a Right, Right?	52
3.5.3	Nature's Way or No Way	54
3.5.4	Concern for the Integrity of Whakapapa	56
3.5.5	When Does Life Begin?	59
3.6	Access to AHR	60
3.6.1	Fertility a Low Priority for Māori	61
3.6.2	Māori Don't Have a Problem with Fertility Anyway – Do They?	62
3.6.3	Lack of Awareness of Infertility	65
3.6.4	Lack of Knowledge about Fertility Services	67
3.6.5	Inability to Articulate Need Directly	69
3.6.6	Men's Reluctance	72
3.6.7	Differential Diagnosis	74
3.6.8	Lack of Whānau Support	76
3.6.9	Lack of Māori Fertility Services	77
3.6.10	Cost	77
3.6.11	The Exclusion Criteria	79
3.6.12	Other Responsibilities	81
3.7	AHR – Procedures and Practices	81
3.7.1	Assessing Infertility	83
3.7.2	Gamete Donation	86
3.7.3	The Obligations and Responsibilities of Whakapapa	88
3.7.4	The Tapu Nature of the Body	89
3.7.5	Embryo Donation: Early Whāngai?	89
3.7.6	The Ideal Donor	90
3.7.7	Māori Sperm Like Gold	90
3.7.8	Cross-Cultural Donation	92
3.7.9	Within Whānau Donation	92
3.7.10	Gamete Storage	95
3.7.11	Artificial Insemination	99
3.7.12	Ovulation Induction	101
3.7.13	In Vitro Fertilisation (IVF)	102
3.7.14	Intra Cytoplasmic Sperm Injection (ICSI)	104
3.7.15	Surrogacy	105
3.7.16	Pre-Implantation Genetic Diagnosis (PGD)	111
4.	FERTILE GROUND FOR MĀORI INVOLVEMENT	116
4.1	Primary Prevention	116
4.2	Increase Public Provision of Sexual Health Services	119
4.3	Māori Friendly AHR	119
4.4	Addressing the Effects of Colonisation	123
4.5	Where Are the Māori Providers?	125
4.6	Workforce Development	129
4.7	Māori Involvement in AHR Policy	131
4.8	He Aha Te Kaupapa?	132

5.	RESEARCH AND INFORMATION NEEDS	135
6.	DISCUSSION	137
6.1	A Māori View	137
6.2	Ensuring the Survival of Māori	137
6.3	Historically-held Māori Views on Fertility and Responses to Infertility	138
6.4	Infertility	139
6.4.1	Infertility – How It’s Defined	139
6.4.2	Infertility – The Causes	140
6.4.3	Infertility – Te Mamae	140
6.4.4	Infertility – An Emerging Issue For Māori?.....	140
6.5	Māori Attitudes to AHR	141
6.5.1	It’s a Right, Right?	141
6.5.2	Treaty of Waitangi	141
6.5.3	The Right to Medical Treatment.....	141
6.5.4	Nature’s Way or No Way.....	141
6.5.5	Concern for the Integrity of Whakapapa.....	142
6.5.6	When Does Life Begin?	142
6.6	Access to AHR	142
6.6.1	Fertility a Low Priority for Māori	143
6.6.2	Māori Don’t Have a Problem with Fertility	143
6.6.3	Lack of Awareness of Infertility	143
6.6.4	Lack of Knowledge about Fertility Services.....	144
6.6.5	Inability to Articulate Need Directly.....	144
6.6.6	Men’s Reluctance.....	145
6.7	Māori Attitudes to AHR Procedures and Practices	147
6.7.1	Assessing Infertility	147
6.7.2	Gamete Donation	148
6.7.3	Gamete Storage	150
6.7.4	Artificial Insemination	151
6.7.5	In Vitro Fertilisation (IVF).....	152
6.7.6	Intra Cytoplasmic Sperm Injection (ICSI)	153
6.7.7	Surrogacy	153
6.7.8	Pre-Implantation Genetic Diagnosis (PGD).....	154
6.8	Fertile Ground for Māori Involvement	155
6.8.1	Māori-friendly AHR	156
7.0	SUMMARY OF THE RECOMMENDATIONS	158
9.	REFERENCES	161
10.	GLOSSARY	163

11. APPENDICES

165

- A. Participant information sheet
- B. Participant consent sheet
- C. Participant demographic sheet
- D. Key informant interview schedule
- E. Flipchart/PowerPoint presentation for Interviews/Hui
- F. Hui Pānui: Health workers

List of Tables and Figures

Table 1.	Viewpoints represented	8
Table 2.	Demographic Information by Hui	10
Table 3.	Hui Participants Fertility Experience	11
Figure 1.	Framework for the presentation of results	12

1.0 INTRODUCTION

“Māori leadership seems to deny that Māori kids having kids is a problem.” Said Judy Turner (United Future New Zealand Party family and social services spokesperson) when commenting on a parliamentary report on teen pregnancy rates (United Future NZ Party, 2007). In her press release she picked out something Tariana Turia (Co-leader of The Māori Party) said in a speech to the 1st National Māori Sexual and Reproductive Health Conference, in November 2004:

I am intolerant of the excessive focus on controlling our fertility... When Cabinet Ministers sat around tut-tutting the fact that the fertility rate for Māori females aged 13-17 years was 26.2 per 1000, more than five times that of non-Māori, I objected to their analysis of our fertility as a problem.

This quote was of course taken out of context. Māori see a very different picture when we think about fertility as illustrated below in this fuller excerpt from Tariana’s speech:

...our origins emerged out of te kore from which came ira atua. In tikanga Māori terms, ira tangata came from ira atua. So when we look at the faces of our babies, we recognise the imprints of those before us. I think of the concept of kawai whakaheke: we are what our ancestors were. I think of my nannies who would hold my face in their hands, and mihi to our tūpuna. Tēnā koe e te hunga mokopuna. It’s more than DNA.

In looking to reflect the dreams and aspirations of our people, the Māori Party has looked to such concepts as our guiding kaupapa. Kaupapa such as manaakitanga, whanaungatanga, kaitiakitanga, mana tūpuna, and the tikanga that emanate from them. Concepts that our nannies and koroua lived, concepts we can restore to ourselves to set our futures.

It’s in cherishing the special status that befalls you when you move into the Nanny category. When I sit with our kuia and koroua at hui, they don’t ask me how much I paid my cleaner, or what’s the size of my pay packet? Their interest is in how many mokopuna we have. And similarly, my heart just bursts when I disclose we have 6 children, 24 mokopuna, 5 mokopuna tuarua.

It’s not a numbers game ...but then again, it is disappointing to read that statisticians state the annual growth rate of the Māori population is projected to slow from 1.4% in 2002 to 1.2% in 2021. The statisticians tell us that the age structure of the Māori population will undergo change reflecting, amongst other factors, our reduced fertility. What this will mean for instance, is that the demographics of our population start creeping upwards. The number of Māori children aged between 0-14 years as a proportion of the total Māori population will fall from 37% to 30% over the next twenty years.

Maybe one of our policy goals in the Māori Party should be to go forth and multiply! I want to return to this issue of our ‘reduced fertility’ as a population.

I often think when I read through the statistics telling me that Māori experience gonorrhoea in higher numbers at a younger age than do non-Māori; Māori and especially rangatahi Māori are at greater risk of sexually transmitted infections; the rate of Chlamydia for Māori (at 10.5%) is over two times higher than non-Māori (4.6%); that the tragedy of these statistics is lost when seen only in the context of epidemiological data.

Similarly as new developments in biotechnology occur I question how any discussion of such technologies can be appreciated without guidance from tikanga and matauranga Māori. Our whakapapa must be the context in which all such discussions sit. Our whakapapa is the bridge which links us to our ancestors, which defines our heritage, gives us the stories which define our place in the world.

We are te kakano i ruia mai i Rangiatea. Mana tūpuna helps us know who we are, from whom we descend, and what our obligations are to those who come after us. And we must celebrate that whakapapa in every heartbeat, every birth and in the lives we have lost.

The expression of our rights defined by mana atua, by mana tūpuna, is best reflected in our drive for rangatiratanga, our self-determined destinies. The survival and the prosperity of our people is determined by the protection of our whakapapa. And I have chosen those words deliberately. Protection, not control.

I am intolerant of the excessive focus on controlling our fertility. When I used to sit around the Cabinet table with colleagues, one of the many hot topics I got into strife about was discussion around the 'problem' of teenage pregnancy. My objection was to the problematization of conception. Professor Sidney Hirini Mead has discussed how our cosmological beginning as a people, are mirrored in the processes of conception. From the kākano (seed) develops the koi ora hou (a new life), which - while within the whare tangata (womb) - possesses mauri, whakapapa, wairua, hau and pūmanawa (natural talents). It is then born into the world of light. So when Cabinet Ministers sat around tut-tutting the fact that the fertility rate for Māori females aged 13-17 years was 26.2 per 1000, more than five times that of non-Māori, (4.9% per 1000), I objected to their analysis of our fertility as a problem.

If there was respect for our existence as based on kaupapa, the foundation principles of the Māori world, these Ministers may have thought more carefully about the interventions they were seeking to impose. Indeed, their guidance might have been sourced in these words: Ma ratau anake ratau e korero, ma tatau anake tatau e korero, ehara ma tetahi ake (We will be our own assessors, they in turn will be theirs, it is not for others to judge) I am not saying that we should not be concerned about the impact of STIs, or that indeed that I am opening the doors to a sexual explosion. Quite the opposite.

If we are to actively demonstrate rangatiratanga, to respect wairuatanga, our connections must be affirmed through promoting knowledge and understanding of atua Māori; and they must be maintained and nourished towards the achievement of wellness. Tikanga Māori gives us clear cultural guidelines about how we treat one another and how the human body is regarded.

Whether it's medical intervention that is considered such as hormonal replacement therapy or hysterectomy, or some other form of intervention such as depo-provera, inter-uterine devices, or some other form of contraception, there are guiding principles to understand our obligations to respect all attributes of human life as tapu.

It's not a textbook science, but it is in understanding our responsibilities for protection, for nourishment, for respect for te whare tangata. Implicit in our kaupapa is the reality that we are all children of our ancestors entering this world through the whare tangata that is woman. Such a precious gift is not meant to be the responsibility of one person, alone.

In the matter of pregnancy, manaakitanga will tell us that care must be placed on the life within – but also conscious of the need to ensure the mother's health is not placed in jeopardy. The expertise and support of inter and intra whānau, hāpū and iwi relationships must be called on for support. As descendants of ira atua, we are part of an inter-related universe. Our strength is collective. As part of this the concepts of vertical and horizontal care that include the roles of grandparents and siblings may need to be actively restored.

Tino rangatiratanga is about revitalising and reminding ourselves of the rights, the responsibilities and obligations that exist within whānau. We need to retain the essence of who we are, to celebrate that, and to focus on promoting the importance of oranga wairua for Māori well-being. If we nourish and nurture respect for whanaungatanga, if we ensure protection of te whare tangata, we will truly be demonstrating our belief that our people are our wealth (Turia, 2004).

Tariana's speech is a fitting introduction to this report as she touches on a number of the different topics that make up the background context for thinking about Māori attitudes towards and use of Assisted Human Reproductive procedures and technologies. Firstly, she expresses disappointment that the growth rate of the Māori population is falling. One indicator of this is the fertility rate, which is based on the number of children Māori women are having.

1.1 The Māori Fertility Rate

The Māori fertility rate is 2.87 (Statistics New Zealand, 2007) which is higher than the national average of 2.11. This is one health statistic where the disparity between Māori and non-Māori non-Pacific goes the other way with the Pākeha fertility rate sitting just below replacement level at 1.9 (Statistics New Zealand 2006). But the gap is predicted to close up a bit with Māori total fertility rate declining to 2.40 births per Māori woman by 2011.

Māori fertility has seen some dramatic peaks and troughs, with the Māori population dropping off from over 500,000 prior to colonization down to 42,000 after European contact. As Durie (2003) intimated Māori fertility rates seemed to rise as if in response to the threat of genocide. By 1960, the fertility rate was as high as 6.6 children per Māori woman. The drop to 2.8 represents a dramatic decline. We have however, replenished our number to 565,326 (15% of the total New Zealand population) (Statistics New Zealand, 2007) although this has taken over 150 years to achieve. Perhaps it is true, as Durie (ibid) concludes that our population's survival is

now secure enough not to require high fertility and higher fertility rates may only occur again if some future depopulation trend coupled with a new threat to survival occurs.

Tariana attributes the drop in our population growth to our “reduced fertility.” Māori women might be having fewer children on average, but is this due to reduced fertility?

There are no statistics on the prevalence of infertility among Māori or Māori use of fertility services. Fertility New Zealand’s 2005 study of 1000 New Zealand women interviewed in the course of other phone surveys found that 1 in 5 of them had been in the past or were currently affected by infertility. Experience of infertility appeared to be consistent across the ages suggesting that experience of infertility has been consistent over the last 30 years rather than a picture emerging of reducing fertility. The study did determine however, that women are having their first child much later than they used to. For example, 90% of the women over 60 years old had their first child when they were less than 30 years old, whereas only 36% of the under 30 year olds women in the study had given birth. Despite 84% of the women believing that the ideal age for childbirth is in a woman’s 20s, most of the women in their 20s and half of the women in their 30s said they were not ready to have children. Wanting a stable relationship, good incomes and having a partner with sufficient income were the top three influences on when to have children.

There are other indicators that suggest Māori could be experiencing reduced fertility. As Tariana mentioned in her speech, Māori have higher rates of gonorrhoea (Azariah & Perkins 2007), up to twice the rates of chlamydia (Sparrow et al 2007) and 1.4 times the rate of ectopic pregnancies, a rough indicator of the burden of sexually transmitted diseases (Ministry of Health, 1998).

There are other conditions and behaviours that undermine fertility, such as smoking. About 11% of infertility can be attributed to reduced fertility due to tobacco smoking (Norman 2007). About 60% of Māori women of child-bearing age smoke (Glover 2004) and 40% of Māori men aged over 15 smoke and Māori are significantly more likely to be overweight and obese than non-Māori non-Pacific women (Ministry of Health 2006).

1.2 Historical Responses to Infertility

It is beyond the scope of this project to examine historical documents, moteatea, waiata and whakataukī for references to fertility and infertility. Certainly research with that intent should be undertaken. For example, just in one of Best’s (1929) texts there are a number of accounts of Māori practices aimed at assisting conception.

Best described *te whakatō tamariki*, a rite performed by tohunga to assist conception. The child-bearing powers of Hine-ahu-one were invoked. Hine-ahu-one being “the first of all mortal women, the Earth-formed Maid” (1929 p.10). Best also explains that Māori believed that the seed of life which emanates from Io (the supreme God):

...is with the man, and that woman represents the sheltering and nurturing bed or receptacle for that seed, and so result conception and growth (Best, 1929, p.11).

Other methods and mediums that possessed “the strange powers of causing women to conceive” such as “a famed stone” or a certain tree are also mentioned in Best’s book.

There were also rites used to induce infertility.

In cases where women desired to forgo the pains and pleasures of bringing children into the world, a peculiar rite known as taupā, whakapā, and kokoti-uru was performed over them. In this ceremony symbolism again appeared in the introduction of a stone; the trend of the meaning of the charm employed was that the woman should become as barren and unproductive as the stone (Best, 1929, p.13).

A well known tikanga that has carried through to today is whāngai, the ‘gifting’ of a child to a couple or whānau in order that whakapapa might be preserved (Mead 2003). Families who were unable to conceive or who birthed children who did not grow to adulthood “were known as whare ngaro (lost houses), that is in terms of whakapapa and of continuing a family line” (Mead, 2003, p.291).

1.3 Māori and Assisted Human Reproduction (AHR)

Today, concern is often expressed about young teenage Māori women having babies at much higher rates than non-Māori non-Pacific as Tariana observes in her speech. The focus on problematising Māori pregnancies has perhaps contributed to the apparent lack of interest in declining fertility rates among Māori. For example, policy documents, such as, *Access to infertility services: development of priority criteria* (Gillett & Peek 1997) omit any consideration of the prevalence of infertility among Māori, Māori access to AHR or unique Māori concerns re AHR. Yet, the document acknowledges regional differences in public funding for infertility services. The authors propose a set of exclusion criteria to be used when assessing eligibility for publicly funded AHR. Excessive body mass index (BMI), female smoking, previous sterilization and having had multiple children, most of which Māori women will be over-represented in are proposed. Therefore, if Māori women do seek to use AHR, they could possibly find it harder to access public funding for their treatments.

There is a dearth of literature on Māori attitudes towards and uptake of AHR. The Committee on Assisted Reproductive Technologies, of which Dr Papāangi Reid was a member, published a report in July 1994. *Assisted human reproduction: Navigating our future* refers to implications for Māori. The appendices show that few Māori contributed views throughout the process, though Lorna Dyll was involved in the analysis of submissions to the Committee. Dyll was later instrumental in having this kaupapa discussed at *Hui Whai Māramatanga Whai Oranga*, a hui on Māori reproductive health and HIV/AIDS held at Papakura Marae in March 1995 (Te Puni Kokiri 1995).

More general texts, such as, Donna Hall and Joan Metge’s (2002) paper on Māori aspirations and family law contribute another angle in which AHR impacts upon Māori. A New Zealand Law Commission discussion report on AHR published in 2004 outlined a number of contradictions in terms of how New Zealand laws provide for Māori beliefs and tikanga leading Ruru (2005) to conclude that the implications for Māori of the Human Assisted Reproductive Technology Act (2004) needs further examination.

Few published academic discussions regarding a specific Māori framework or theoretical base for consideration of new scientific developments with regard to human reproduction exist. Mead's 2003 book covers a broad range of contemporary challenges for Māori. In it he proposes a tikanga Māori framework for assessing new issues, such as, in vitro fertilisation (IVF) and surrogacy, and arriving at a Māori position. The framework involves the application of five 'tests':

1. Will tapu be breached?
2. Is any person's mauri put at risk?
3. Take-utu-ea. If tapu has been breached or mauri has been damaged, the reasons for doing so must be considered. For example, was the intention behind the offending action, to harm or benefit? Was adequate consideration given to the impacts prior to proceeding with the action? Can a state of satisfaction be reached, wherein peaceful interrelationships can be secured and the matter closed.
4. Is there precedent within the culture? Is there some event in our traditions that might help with understanding? Is there a whakapapa to which the new event can be linked?
5. Principles (whanaungatanga, manaakitanga, mana, noa, tika) (Mead, 2003).

Mead uses surrogacy as an exemplar issue for application of the mauri test.

Surrogacy aims at creating a new mauri in a way that does not follow the accepted norm. Is the mauri of the child put at risk? It is not at all clear what the risks might be, if any, in such cases... The concern would be for the life of the new being and for the long-term prospects (Mead, 2003, p.341).

He concludes that most of the concerns are probably focused on moral and social issues rather than on risks to the mauri.

Recent advancements in AHR technology have seen the NECAHR approve embryo donation (National Ethics Committee on Assisted Human Reproduction 2005) and egg freezing and the Minister of Health approve a second IVF cycle for eligible couples. The latest controversial developments in AHR include Preimplantation Genetic Diagnosis (PGD) (National Ethics Committee on Assisted Human Reproduction 2004) and stem cell research (Advisory Committee on Assisted Reproductive Technology 2007). Any developments in AHR technology, practice or the laws governing them have considerable significance to and for Māori, but developments in AHR outstrip existing Māori commentary on the topic.

The aims of this research were:

- To explore/examine the thinking of Māori regarding developments in AHR;
- To explore the contribution, actual and potential, of Māori to policy development in AHR;
- To examine issues associated with Māori access to AHR services;
- To make recommendations for policy and/or future research.

2. METHOD

2.1 Kaupapa Māori

The research was conducted in accordance with the principles of a kaupapa Māori approach to Māori health research. That is:

- primacy will be given to Māori paradigms,
- Māori kaumātua/kuia will be consulted and will continue to provide guidance,
- the investigators are Māori,
- communities are entered into only after appropriate mana whenua consent has been obtained,
- interviews will be conducted in accordance with the kawa of the interviewer and participant,
- the research intends to support Māori knowledge and development,
- is of direct relevance to Māori health and is a priority identified by Māori,
- will be emancipatory in intent,
- there is an ongoing commitment to share the results of the research with participating communities and key stakeholders,
- so that Māori benefit from the research (Glover 2002).

2.2 Research Design

Given the dearth of existing literature or previous research on this topic for Māori, a qualitative exploratory study was conducted to scope the field of inquiry. In the first Phase of the study, key informants were interviewed. Phase II involved the conduct of six hui/focus groups to elicit the views of particular sub-groups of Māori.

Ethical approval for both phases of the study was obtained from the University of Auckland Human Participants Ethics Committee.

Phase I

A series of semi-structured interviews were conducted with people identified as key informants. Key informants were chosen for their involvement in Māori health policy, ethics or research, provision of Māori health or welfare services, provision of fertility services, and or knowledge of tikanga and mātauranga Māori. It was known or expected that key informants had at some time in their career, been involved in discussions related to AHR and or they would have had to consider AHR. All informants were over 16 years old.

Key informants were sent a letter and participant information sheet (Appendix A) inviting them to take part in the research. The principal investigator then contacted the key informants by phone and or email to arrange an interview time. Informants were interviewed at a time and place suitable to them, e.g. their home or workplace. Two informants were interviewed by phone as they lived in distant towns. All face to face interviews were conducted within Auckland/Northland or Wellington. Consent forms (Appendix B) were provided to informants at beginning of interviews, and were emailed to the phone interviewees for completion and return by mail.

A short self-complete questionnaire (Appendix C) was used to collect demographic information, such as, gender, age, income source, occupation and eligibility for a Community Services Card. Informants were also asked to rate the extent of their knowledge on AHR and to stipulate their experience of fertility or infertility and AHR.

A semi-structured interview schedule (Appendix D) was used to collect data on informants' personal or professional experience with infertility and fertility services. Informants were asked for their personal view of infertility and what they thought Māori views might be. They were asked if they thought it important that Māori have good fertility and why and if it was important for Māori to have access to AHR. A flipchart (Appendix E) was then used to trigger opinion on the various AHR interventions that were available in New Zealand at the time of interview. Informants were asked if there were any 'issues' for Māori with regards to the development of policy on AHR and the formulation or changing of legislation and what, if any, changes to current policy or legislation were needed? Finally, key informants were asked to comment on the proposal to run six hui on AHR to gather opinion from kaumātua/kuia, rangatahi, Māori health workers, Māori who may have used or wanted to use fertility services and takatāpui (non-heterosexuals) and they were asked if there was anything further about the topic they wanted to add.

All but one interview was tape recorded. Informants were given a retail voucher in recognition of their contribution. Two informants requested copies of their transcript to check, which resulted in some minor changes, for instance to grammar.

2.3 Demographics – Key Informants

Eleven female and four male key informants were interviewed during late 2005. Two women attended one interview. Informants ranged in age from 30 to 73, with the average age being 51. All the informants worked, though two were officially retired. Many of the informants were able to represent a number of different viewpoints given their wide range of experience across health policy, research and practice as shown in Table 1.

Table 1. Viewpoints represented	
Number able to speak from experience	
Māori health research	5
Policy	4
Ethics Committee	4
Fertility Services	3
Kaumātua	2
Women	2
Men	2
Māori Provider	1
General Practice	1
Religion	1
Takatāpui	1

Nine of the informants rated their knowledge of the topic as extensive and four informants rated their knowledge as less than extensive but informed. Two informants did not answer the question.

Nine of the informants had had children of their own. Four informants had had personal difficulties conceiving or hanging on to a pregnancy at some time and two of them had tried various methods to improve their chances of conceiving/carrying to term. One participant had assisted others to have a child through donation. Data was missing for three people.

Most of the key informants resided in either the Auckland or Wellington regions. Two informants lived outside of major centers.

Phase II

Community groups or organisations were approached to support recruitment for the study and potentially to provide a venue. As a result, four of the hui were hosted by a group/organisation. Pānui (notices) were made up for each hui (Appendix F) advertising the date, time and venue. The pānui stipulated that participants must be over 16 years old and they were asked to RSVP for catering purposes. The pānui were sent via email to Māori health workers, sexual health workers and takatāpui people known to the researchers with a request that the notice be forwarded to others who the recipients thought might be interested in knowing about the hui. Pānui were also posted to Auckland based fertility services for posting on their notice boards or distribution throughout their organisation. Fertility NZ was asked to distribute the notice to its Auckland membership, some women's social organisations and gay and lesbian organisations were also sent the appropriate notice/s. An advertisement about the takatāpui hui was posted on Māori TV's community notice board and read out during Radio Wātea's community news service. The principal investigator was interviewed on Radio Wātea and National Radio about the research to support recruitment.

People phoned or emailed the principal investigator to find out more about the hui or to RSVP. During the phone call they were asked if they wanted to receive a copy of the participant information sheet by mail. This was sent by return email to people who enquired via that medium.

Pōwhiri, whakatau or mihi were conducted at the beginning of each hui depending on the venue. One hui was held on a marae in the wharenuī requiring the tikanga of a full pōwhiri to be conducted. Two hui were held on a marae in service buildings. Two hui were held in health organisation offices and one hui was held on campus. Opening protocols were followed by mihimihi and cup of tea.

Participant information sheets, consent forms and the demographics questionnaire were handed out at the beginning of hui. The principal investigator verbally explained the research and reiterated the contents of the consent form. These were collected from participants at the beginning of the hui.

The same self-complete questionnaire used in Phase I, was used to collect demographic information.

A slide presentation (using PowerPoint or overhead transparencies) (Appendix E) was used to prompt discussion of Māori views on infertility. Participants were asked if they thought it important that Māori have good fertility and why and if it was important for Māori to have access to AHR. The various AHR interventions that were available in New Zealand were explained and participants were asked if they had any questions or comments. Participants were asked if there were any ‘issues’ for Māori with regards to the development of policy on AHR and the formulation or changing of legislation and what, if any, changes to current policy or legislation were needed?

The hui were tape-recorded. Participants were given a retail voucher in recognition of their contribution.

2.4 Demographics – Hui Participants

Fifty-two participants attended six hui held during early 2006, as shown in Table 2. There were 34 women and 18 men. They ranged in age from 16 to 81. The median age was 42.5. Twenty-eight of the participants worked in paid employment, six of whom were part-time. Thirteen participants were eligible for a Community Services Card. Their primary income came from the Domestic Purposes Benefit (1), Invalids Benefit (4) or other type of benefit (9). One person said they received both an Invalids Benefit and another type of benefit. Forty seven participants lived in Auckland, one lived in Wellington and two said they lived rurally. Two participants did not answer this question.

Hui	N	Age Range	Female	Male
Takatāpui	6	38-58	4	2
Health Workers	11	32-58	8	3
Kaumātua	17	38-81	15	2
Consumers	4	33-40	2	2
Rangatahi	7	16-24	5	2
Men	7	21-42	0	7
Total	52	16-81	34	18

Four of the participants rated their knowledge of the topic as extensive, 10 participants had read pamphlets, books or other information on the topic and 14 participants ticked that what they knew about AHR came from the general media. Twenty-two participants thought they knew “very little” about the topic. Two participants did not answer the question.

Table 3. Hui Participants' Fertility Experience.

I/We haven't tried to get pregnant and have children yet, but intend to do so in the future	8
I never had the opportunity to have children but I would have liked to have had children	1
I/We have had personal difficulties conceiving or hanging on to a pregnancy	8
I/We have tried different methods to improve my/our chances of conceiving/carrying to term	4
I/We have used fertility services	2
I/We have had a child/children without assistance	30
I/We have had a child/children with assistance	4
I/We have assisted others (as a donor/surrogate) to have a child/children	3
Other	3
Missing data	5

Hui participants' experience of fertility is summarized in Table 3. A few participants marked multiple options; for example, participants who had experienced infertility, may have ticked that they had tried to increase their chances of conceiving and that they had used fertility services and/or had a child with assistance.

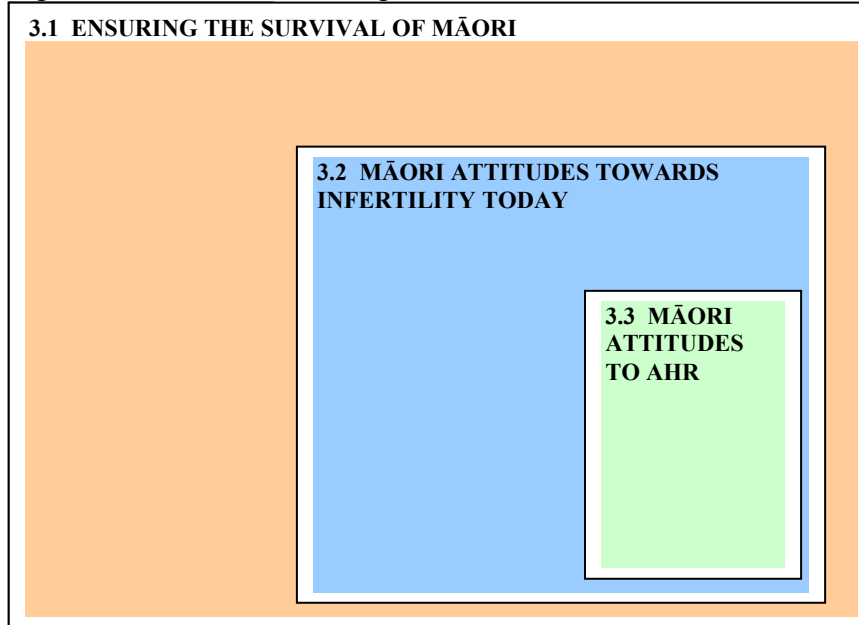
2.5 Data Analysis

The informant interview and hui tapes were transcribed into a Word document and demographic data was entered into Excel to organize the data for convenient access and frequency counts. A general inductive approach was used to analyse the qualitative data. An inductive approach allows research findings to emerge from the common, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies (Pope et al, 2000; Thomas, 2006). The transcripts were read to identify phrases, sentences or paragraphs with a single meaning and these were then assigned a label. Each group of meaning-similar text units was then assigned to a category determined by the objectives of the study or arising from the data. All transcribed interviews were merged grouping participant responses to the question areas provided in the interview schedule. The hui transcripts were merged and treated in a similar way. Transcribed text was then paraphrased in to text giving note to the frequency with which meaning-similar statements occurred. Results from the informant interviews and the hui are presented separately in the results section.

3. RESULTS

The results are presented in several parts as depicted in Figure 1.

Figure 1. Framework for the presentation of the results.



The first section of the results reports on Māori beliefs and practices that existed and/or exist to ensure the survival of Māori as a unique people.

The second results section introduces some of the beliefs and practices that Māori believe are impacting on Māori fertility bringing about the emergence of infertility as an issue for Māori.

The third results section presents the views on the actual AHR processes, procedures and technologies.

Throughout the results, key informants are referred to as “informants” and hui participants are referred to as “participants.” The views of informants are differentiated using numbers 1-14. Hui results are presented following informant results and are boxed for ease of reference. Quotes or views of hui participants are identified using the first letter of the hui group as follows:

C = Consumers
H = Health Workers
K = Kaumātua
M = Men
R = Rangatahi
T = Takatāpui

3.1 Seeking the Māori View

Informants were asked for their personal views and what they thought would be Māori views on infertility and AHR. One response was that we don't know what the Māori views are, hence the need for this research. One informant distinguished between fertility and infertility, saying that he'd picked up views on Māori fertility but not necessarily on infertility. (6) The predominant response was that there is not one Māori view but a range of views on each of the topics and that these views could be expected to change over time.

Seeking the Māori view was seen to be problematic. As one key informant said "some people have volunteered to me what they considered to be aspects of traditional views. I don't think any of them are free from colonial constructs, influences." (14)

We can't be romantic about our views about this because we live in a contemporary world and we're Māori in a contemporary world. (4)

Another participant recommended adherence to the principle "ngā mahi ā ngā tūpuna" which guards against rewriting "the ancestral story to fit your purpose." Instead he said to ask the question, "What are the actions of our ancestors that inform us in the present?" (9)

Informants identified that there would be for example, pre-colonial tribal religious beliefs, traditional and contemporary Māori views, the Māori Catholic view, urban Māori views and community versus individual views.

A takatāpui hui participant thought that seeking the Māori view was problematic. She said that even whānau members, though they come from the same community, could have completely different views on what Māori is. This is because their experiences have been different, especially for example, between a takatāpui whānau member and a straight whānau member.

I think we'd all describe what a Māori community is completely differently from each other. (T)

Most of the informants had a personal view, though a few said they hadn't really thought about the topic before. Their personal view, they acknowledged, was based on their own experience. Thus, key informants ranged from having deep feelings about the topic to having "superficial" thoughts. They thought that generally people's views on infertility and AHR are tempered by their own experience. Thus, one informant said:

I suppose because you don't have that experience, you can be slightly intolerant of people who ... appear to have their whole lives tied up into the notion that they're infertile and what can they do about it? (4)

In addition to the participants who attended the consumers' hui for people who had experienced infertility, some of the participants in the other 5 hui attended because they had "a personal interest" in the topic. One woman saw the hui as a way of getting information on AHR without having to spend money. A few of the hui participants had or were experiencing infertility or had a whānau member who was experiencing infertility. (H)

Another informant thought that “attitudes and perhaps fears come from positions of not understanding the whole process.” (12) Those without infertility see it strangely. One informant estimated that 40% of society would still be perturbed by IVF even though it’s been around for 25 years. They would say it “sounds artificial, it’s playing God, it’s interfering with nature.” One of the most significant determinants of attitudes towards IVF, he believed was “accessibility to IVF of your whānau and friends.” If people have access to it, then the number objecting would come down to perhaps 20%. “But if you have not had” any friends or family use it then the number objecting would probably continue to be 50-60%.” (8)

It’s quite a difficult one in the sense that I haven’t been in that position myself. And I also haven’t had close family that have been in that position so I think that always kind of changes the way you think about it. (4)

As one informant said, those people and whānau affected are likely to have a pragmatic view. As happened with Māori resistance to donating and transplanting organs, when it’s actually someone you know facing the alternative of a life sitting on a dialysis machine or potentially dying from heart problems then you might change your mind about organ donation. (4)

Thus, with time as the Māori knowledge base about infertility and fertility practices changes, acceptance of fertility procedures will grow. (8)

If you were either someone who was unable to have children or someone who was very close to someone who was unable to have children and wanted to then I think you’d see the true cost of that issue in that it can be silent because it’s not killing our people but effectively it could be killing our potential as a people. (2)

3.2 He Puta Tatou / We Must Survive

This section presents a selection of the findings that point to the way Māori might have thought about fertility and or the way that Māori think about fertility in contemporary times. For instance, one theme throughout the results was that fertility serves a greater kaupapa, that is, it is a means by which a greater goal is achieved. The ultimate goal expressed by informants and participants, was to ensure the survival of Māori.

3.2.1 Ensuring the Survival of The Māori

Many of the informants talked about fertility being important for carrying on “whakapapa and lineage and future generations.” A few informants specified that good fertility was about ensuring the preservation of Māori as a unique people and culture. (6) For example, one informant said we need to have good fertility “to survive.” They thought “it could be quite easy for us to lose our whakapapa.” (3)

One hui participant said that Māori stories inherent in whakapapa tell of “our survival.” Having good fertility is part of that story which, he said, “is all about adapting well and developing new ways of doing things that promote our wellness.” (T)

A kaumātua hui participant calculated that if there were 400,000 Māori when the Pākehā arrived here, only 40,000 when the Treaty of Waitangi was signed and it's taken almost 200 years to reach 400,000 again, then without good fertility, "we simply will not exist as Māori people within a 100 years." (K)

It's again around whakapapa and around continuing whakapapa, of our whānau, your line. Your tamariki, your tamariki's tamariki, and so on and so on. The next generations. (C)

A variation on this theme was that Māori need to have good fertility to keep up our numbers in the population. As one informant said, "there are so many other cultures coming here now and we will be kind of outnumbered." (1)

One participant thought that it was too late to preserve the uniqueness of Māori genetically, as "we've already been watered down." (H) The kaumātua hui discussed the impracticality of trying to direct partnerships to preserve Māori. They recalled how in the past, in some whānau it was made a rule that you were to find a Pākehā partner and not to marry back in to Māori blood. Others were directed to marry Māori. And others were brought up to believe that "when you met your soul mate, it just happens." (K) As the following participant implied, if her daughter had children with a Pākehā, the children would be more likely to identify as Pākehā.

That's what I'm saying, our children are half breeds and then if say if one of my daughters goes off on to a Pākehā, well it's going to run to the Pākehā side. (K)

Identification as Māori was seen to be more a psychological state. The uniqueness of Māori could now only be preserved through the preservation of the language and culture and having people identify as Māori. (H) A kaumātua disagreed with this position. As he said:

As long as they got Māori blood in them, they're Māori... I remember having this talk to my mokopunas. I said to them, because I'm a Māori you're a Māori, end of story. No other story. (K)

The men's hui thought it wasn't enough to know you have whakapapa. One participant thought people needed to identify as Māori for their whakapapa to work for them. (M)

If you don't identify as being a Māori then you don't care what the whakapapa is. (M)

One of the implications of people choosing not to identify as Māori was that statistics would not be accurate. For example, one man thought that maybe only 50% of the Māori children at a school he knew of identified as Māori. Therefore, statistics on Māori would not reflect the true picture for Māori. (M)

One participant said "it's up to the parents, or whoever is the Māori, to inject those Māori values into the children." Where children have Māori and other whakapapa, they should be "brought up in the sense that they don't have to choose between one or the other. They can have both and know that they're Māori." (M)

3.2.2 Sustaining the People

Historically, good fertility was the expectation for many cultures. It was a necessity. In addition to replenishing the people, fertility had other uses and functions for the community group living and supporting each other.

The modern-day version was put forward by one informant. She pointed out that at the national level, New Zealand has an aging population; thus, “it’s really important that we keep our fertility rates up so that we continue to have a workforce of a size that can support the older generation.” (2)

During the kaumātua hui it was proposed that one of the reasons why it is important for Māori to have good fertility is that:

We need to produce lots more Māori so that we can take back our land. (K)

3.2.3 He Mokopuna, He Taonga

Traditionally, one informant believed that many Māori values enshrined the importance of being fertile. (5)

The importance of children is very much there within our culture. (2)

Having children to ensure the survival of Māori in and of itself is not enough. It is important also that the children are looked after and provided for. “That they’ll have good health and all the other things that go with good health.”

Good fertility, or rather, having children was important for whānau, hapū and iwi at a number of pragmatic levels. Children, and thus whakapapa, created links between whānau, hapū and iwi. As one informant said, it was once very important to have “culturally safe strategic alliances.” (2) Children were a way of mending “broken relationships between hapū and iwi; between families.” Children were a way “of tying yourself to the land.”

Your child is your whakapapa. (3)

Children are important “for reasons such as being able to pass on talents and values and history... so that the culture is alive, a living one.” (12) In these ways children bring status, not just to individuals, but to whole groups; to iwi.

Children (and thus good fertility) were essential also for whānau ora, that is, the wellbeing of the whānau as a structure. Good fertility and being able to have children impacts directly on individual wellbeing also.

It’s quite a great thing to have a child. (3)

The importance of children within Māori culture is enshrined in whakatauki. Hence, the common reference to children as taonga (treasures).

3.2.4 He Māori, He Mātua

One informant believed that some Māori, particularly some Māori women, were conscious of the threat to the survival of Māori and that “the absolute importance of continuing or being able to assist in the continuity of Māori ancestry/whakapapa” became integral to their identity and role as Māori women.

Having children was seen to be integral to a Māori identity. Being Māori is about having whānau, extended whānau and mokopuna (grandchildren). (7)

Children are such an ingrained and absolute part of being a family, being a Māori family. (2)

One informant explained how she was taught about the importance of children.

Children are an awesome thing that I wanted to have... I have a background where I have always identified as Māori and it's something that I see as a real cultural thing. (2)

Being able to have children was so essential it was talked about as if it was almost the reason for living.

I would severely question my purpose on earth if I wasn't able to be a mother, just because it's so why I'm here. (2)

It's what life's all about, having children and being able to have children. (1)

Whilst many heterosexual people perhaps take their fertility and their role in continuing whakapapa for granted, takatāpui who have to take extra steps to have children may be more conscious of the reasons and import of having children. As one takatāpui informant said:

In terms of continuing our whakapapa, that's been something that's been quite overwhelming for me. (6)

One of the takatāpui hui participants thought that having children is “vital in terms of how we consider ourselves to be Māori” and “in terms of how we construct ourselves.”

Within my whānau, fertility, well, producing children is the number one job to do. (T)
This informant said, “We are here to propagate the next generation, your whakapapa.” The first thing whānau ask when they haven't seen you for a while is, “got any kids yet?” The second question is “are you married yet?” This line of questioning, she said, was typical, even when they know you are takatāpui.

You could introduce your partner and they still ask you... I come from a very rural community. (T)

For gay men, children may not be as integral to their identity as Māori. For instance, one takatāpui man explained that his sisters have children and are therefore continuing the whakapapa, so he doesn't have to.

I don't think the mana of my whānau is dependent on me It's dependent on the whole family.

He admitted though that he occasionally wonders about having his own children. To which another participant responded that at least it's "never too late for a man."

There was some discussion of how iwi views differ. One of the other participants thought it was common for Tuhoe men to think that it is not their destiny to have children, that "they are not on this planet to have children. If it doesn't turn out that they have children well that's fine, it doesn't make them less or more a person or impact their standing in the family." She believed that elders, however, thought that it was the woman's job to carry on the whakapapa.

Women are produced to have children... to keep the whakapapa going.

The irony for her was that if you believe "that it's all about whakapapa" and you use your whakapapa, then she said she had to "support what my elder is saying." Though it was quite "another thing to actually work with it, to live that reality." (T)

Several informants believed that having children is a cultural norm. A few informants believed that the cultural norm was particularly that Māori women have children when they are younger, for example, before they are 20.

For example, one participant said "we are a family who get pregnant at 16, if not 14." (T)

One informant asserted that "life is about having children in the late twenties not having children in the late thirties." (8)

This cultural norm of having children when you are a young woman was said to mitigate the shock of early unplanned pregnancies among young women. One informant said there was "certainly less of an aversion to fertility in some of our young women." He acknowledged that they "might be a bit upset maybe initially but they tend to get over it quite quickly." (5)

This cultural norm also supported unmarried women to have children (2). As one woman explained, having a child is an important desire in and of itself that is not moderated by the existence of a relationship between the mother and father or by the quality of that relationship.

I chose to have a child when I was 24 because I desperately wanted to have one and that was like a desire that was really not related at all to the fact that I was in a relationship... wanting to have a baby wasn't about an extension of a fulfilling and wonderful relationship it was about me wanting to have a baby. (2)

The rangatahi hui discussed this idea of there being a right age. One participant said that she had heard someone saying “that the best time for a woman to have a baby is between eighteen and twenty two or three.” That is, that would be the best age to have children physically. The hui then looked at how old their own parents and great grandparents had been when they had children, for instance one participant’s great grandmother had reportedly had seventeen children. So, they concluded that there was no right age, but that you should at least start having children by 23.

So I was like, oh I better hurry up. (R)

But, one of the problems with starting to have children between 18 and 23 was that society’s not supportive of young mothers, “especially young Māori mothers.” One participant said they’re basically seen to be “using the benefit.” (R)

One woman who was experiencing infertility said she could remember her general practitioner (GP) saying to her, that 23 years old is when a woman’s fertility peaks and then it starts falling off. At the time she thought he was “an idiot.”

Now I look back and think he was right. It’s not the case for everybody, that’s the hard thing. (C)

Several informants said that good fertility was assumed and that you would have children and grandchildren was also assumed.

The rangatahi confirmed that they just assumed that they would be able to have kids. The participant who already had a child said that she thought “sweet, I’ve got a baby now so I can have more if I want to.” For her, infertility was not something she ever expected to experience. (R)

We all think about having children, and having grandchildren. (1)

One informant said it was “quite a socially acceptable thing” to “hear grandmothers saying things like I want my moko or I want a moko. (2) Which could add to the pressure women might feel to have children, although as one informant said that pressure is likely to be put on the eldest children.

A kaumātua hui participant said that “we as parents are probably one of the worst because once our kids grow up we say we want mokos and we try and encourage it.” But, this participant thought it wrong to do that “unless we help out financially.” (K)

The younger rangatahi did not think that any of their grandparents were encouraging them to have children. Instead, they were being told to “go do this and go do that” for example, “finish school.” The 24 year old, however, thought that once in to your early twenties people started to encourage having children and asking ‘when are you going to have babies?’ As if it was being monitored within whānau. (R)

One of the men’s hui participants recalled that his parents had thought he was sterile.

They thought I was taking too long. Especially at my age. And I was young, thirteen, when I first had a girlfriend. They would say, come on, and we'd go, no we're too young. (M)

But, the hui agreed “that whakaaro’s changed.” Now “it’s about not wanting our babies to have babies.” Young men and women were encouraged to “go out and see the world” and “use protection” to prevent them from becoming parents too young. (M)

They're trying to get away from young mothers. They're getting right into promoting education, careers and stuff. You know, get that first. (M)

Biology Is Destiny

Being able to reproduce was considered “an innate function,” (4) a human instinct. As one informant said, “there’s something within us that just expects things to go on, the whakapapa to go.” (1)

I think we as humans just want to have children (1)

You take for granted that you have the ability to have children. (4)

One informant said “it’s alright if you don’t want to have children” (2) but mostly informants spoke of the assumption being that everyone wants to have children. As one informant said she hadn’t met anyone who just deliberately didn’t want any children. (1)

A hui participant also thought that the majority of women wanted to have children.

I think it is good for our women to have good fertility, because most of us do want children. Well the majority of us do want children and it is important for us to have that. (K)

The consumers’ hui participants talked about the popular notion of the biological clock. One woman said that up until about the age of about 35 she hadn’t had the desire to have children. When she did start to think about having a child, she thought it was “just the biological clock.” She said it felt like it was some kind of genetic programme, or hormonal thing that was making her think “you have to have a child. Got to have a child. And so I think I probably fought it for a while, thinking no this is just programming, a biological thing. But it got stronger.”

She used to think that it only happened to women who hadn’t had children, but had changed her mind. As she said:

The genetic drive to reproduce, which is really, very innate - I thought that once you have a child it would stop. So, women who have had at least one child wouldn't feel driven to have another one. But I don't think that's true.

Another woman who had four children confirmed that she still wanted to have more.

I know practically that I can't look after any more children if I still want to do the mahi that I do and have a life and hold on to my husband and all that. But there's not a month that goes by that I don't think oh, I wish I had another baby... I think that's quite common. I fight it on a regular basis.

She added that she had “the privilege of being able to fight it” implying acknowledgment that some women do not have the ability to make it a choice. The hui then talked about how you go from wanting to have more children to wanting mokopuna.

Of course, if you can't have any children then the focus is very different, they said.

The focus is I just want one. Just give me one.

The hui then discussed whether or not men felt the same compulsion to reproduce. One difference that was acknowledged was that men didn't run out of time and they cited Michael Douglas as an example who was still having children with Catherine Zita Jones when he was 68, 70 years old. Someone joked that men felt “a compulsion to do something else!” (C)

A few informants spoke about the negative pressure that these expectations and assumptions create for people who haven't had or who can't have children. One of the negative experiences reported by one informant was hearing a doctor at a hui say “you're not real people 'til you have children.” (14)

To be a real woman you have to have babies. (14)

The stigma attached to not having children came up at the Māori health workers' hui also. One participant thought there was “a strong stigma” attached to infertility, “especially amongst Māori men. The expectation is, especially if you come from a Māori whānau, is that you're going to be giving birth to lots of babies and if you don't what's wrong with you?”

One woman said that even if you have children her whānau, and especially the old people, always ask “when are you gonna have more kids?” and “that's been happening for 15 years.” She said that even if it was done with humour, it creates a pressure. She also said that “whānau can be quite cruel” about it. For example, she recalled an incident at a whānau gathering, when a younger male cousin asked in a “smarmy sarcastic” tone “what are you doing wrong?” He told her she should trade in “your model and get another one.” She took this as a slur on her partner. Now she felt that aunties and uncles were saying “there's no point in having any more” because the age gap between her 15 year old son and a new baby would be too big.

Another woman said she had experienced “this pressure” also. She didn't have children, but had had two miscarriages. She explained how she just kept trying and saying to herself that if it hadn't happened by 35 then she'd seek help. But she got to 40 and said to herself if it hadn't happened by 45 she'd do something about it. Meanwhile, her aunties put “a lot of pressure” on her, saying she was “being selfish.”

I was trying my hardest to get pregnant. They don't see that. They couldn't understand why I wasn't having children and didn't, you know, infertility didn't even enter their heads.

She was told that in traditional times, “barren” women were considered “no good” and they would have been assigned to tasks like “cleaning the toilets.”

A kuia recalled that her husband’s father wrote a very stinging letter which upset her. In the letter her father-in-law said “his son was a seedless raisin” because at the time he was the only son and they had not had any children. They later adopted a child and three years later got pregnant with their daughter who was followed by a brother 3 years after that. Her last baby was born a further 10 years after that. She concluded that it didn’t matter how often you have sex, some factor, unknown to her, determined whether or not you get pregnant. (H)

An informant believed that a woman without children would not be viewed, by some Māori, as being of the same status as women with children. She also thought that some Māori men without children would view themselves as not as powerful as someone who has children. (12) When it comes to expressing opinions on children, one informant said, if you haven’t had children yourself your view on children would not be accepted. She had experienced this especially in regards to her step-children. It was as if she had “no rights” to talk about parenting. (14)

I felt that my voice was secondary because I hadn't had kids. (14)

Even a kuia’s status can be downgraded if she doesn’t have grandchildren, as the following quote illustrates:

I would feel lost without grandchildren... in Māoridom you're a nothing. You could have done all sorts of things in the world but you go back to the hui and they go “E hia mokopuna...?” The first thing they say to me, “E hia mokopuna?” And I'd go “Oh kāore au he mokopuna” and you can see... down on the totem pole... It doesn't matter what you've done in your life, if you have no mokopuna... (1)

The men’s hui put forward that one of the reasons why it is important for all Māori to have good fertility is because “if you have good fertility you have more mana.” (M)

One informant was concerned that Government health and social policies reinforced the expectations. As she said, “at the moment we’re saying that whānau is, you’ve got to have children. You’ve got to have children and grandchildren. You are not normal if you don’t.” (10) The focus on whānau, she felt, left people without children wondering “where am I in this society?” (10) Another informant wondered how much this positioning had been influenced by colonial versus Māori views.

It's not accepted that some people have infertility issues. (14)

3.2.5 He Wahine Māori Ahau, He Mama Ahau Hoki / Fertility and Māori Women's Identity

As some of the preceding kōrero suggests, having children is thought to be essential to Māori women's identity and sexuality.

One key informant reported that Māori women look to their culture, their whakapapa and their roles in Māori society to understand who they are in terms of their sexuality. (6) Continuing or being able to assist in the continuity of Māori whakapapa is of absolute importance to Māori women and central to their role as Māori women. Unlike Māori men who, the informant said, see themselves as studs.

They're the ones who do it and they don't actually think about it in context... women do tend to be more nurturing than men and maybe it's to do with that, but Māori women place it in the context of what it means to be a Māori woman, whereas Māori men just see themselves as, you know, doers. (6)

Another informant said that "fertility and having children is something that many women value highly." To not be able to have children, she believed would be detrimental to women's well-being. (2)

We're put on this earth for a reason and it's to carry on whakapapa, and a lot of us take it very, very seriously. (H)

One of the men's hui participants believed that women want to have babies. He said "it just develops that way. They get clucky when they see all their nieces and nephews and all that. My girl's clucky, she's only fourteen. Somewhere down the line she's going to want to have, you know, because they're brought up around that. Little kids everywhere." Whereas men, "just run around and roam like a ram out there" without worrying that somebody's going to knock on their door 21 years later. (M)

3.2.6 Fertility, Sexuality and Gender

Two informants thought that fertility needed to be talked about within the context of sexuality, in that, having children is just one of the by-products of having sex. And that historically, sexuality was about relationships and connections. (6)

Thus, one informant said "the far more important thing we should be talking about is sex, sexuality and sexual relationships and sexual beings and our, the Māori way of sexually being." (14) She said there was a need to look at what it is to be male. "How do we bring our boys up? How do we bring our girls up?" That sexuality and consequently fertility was also about "the policing of manhood. The policing of womanhood." As alluded to above, there are some quite strict gender-associated expectations, that can give rise to notions of compulsory heterosexuality and heterosexism. Thus, it was recommended that when thinking about fertility, and infertility, these constructs need to be factored in to the analysis. (14)

3.3 Historical Māori Views on Fertility and Responses to Infertility

In this section, we present a set of beliefs about fertility that informants reported as being views held by Māori in the past. Some practices, such as whāngai are included here. The informants did not claim that these beliefs and practices reflect traditional Māori knowledge. Their reservations about the origin of such beliefs are expressed where relevant.

3.3.1 What Did Māori Think About Infertility?

None of the informants claimed to know what Māori would have thought about fertility or infertility in the past.

The rangatahi had not heard anything about traditional Māori views on fertility or infertility.

Generations back you never really heard of infertility. What happened in those days if they wasn't able to have children they just whāngai children. (K)

The few informants that commented specifically said they were not “aware of any cultural or traditional taboos around infertility.” (4) They were not aware of any attitudes that considered infertility as “bad”. Neither did they think there was any “great moral judgement” (9) against someone or “slight on that family or that person” (11) if they were infertile. Having no children was just recorded historically in whakapapa as “no issue.”

A participant introduced the term “whare ngaro” which she said referred to a whakapapa line having ended as a result of some tragedy. The term was used in a very respectful way rather than in a derogatory way. (T) Another takatāpui participant told a story that exemplifies this term. Her brother was the last male from the male line and his only child had been diagnosed with bone cancer and was unlikely to have any children before her imminent death. “So that’s it,” she said. (T)

Another participant thought that infertility was known about, if not discussed. This knowledge is alluded to in the use of terms such as, kāore he hua (to bear no fruit, barren).

A few participants believed that there was probably a range of traditional responses to infertility, such as, whāngai. (T, H)

They had ways of ensuring that people play a full part in the community even though 'kāore he hua ai'. (T)

3.3.2 Some People Have Children and Some Don't

Infertility could potentially have been thought about differently in a culture that accepted, as one informant said, that “some people have children and some people don't.”

She said that this belief was commonly applied to thinking about fertility. A sort of “if it happens, it happens” (11) attitude. When talking about the past, a kuia had reportedly told her “if you have babies you just have babies and that’s all there is to it... you just coped with it as they come along.” (11) But, this way of thinking was believed to be still common today.

...some of our people if they don’t have children they just take it as, they don’t have them. (11)

Further support for the idea that Māori culture did not engender a focus on infertility as problematic is suggested by the following comments. One informant said it was “all right for women not to have babies because then they helped out with other people’s babies and they were involved in other things in the community.” (7) One woman, who had not had children of her own, had indeed had some of her brother’s many children live with her for periods of time. (10)

I think it was my mother’s brother that couldn’t have the children but it was never said as a negative thing it was just something that was. (T)

Finally, te reo Māori gives some clues as to Māori beliefs about whānau. As another informant said, “we have the same word for our first cousins as we do for brothers and sisters. So, it’s a broader version of reality to have nieces and nephews as the same as having children.” (14)

A hui also discussed how in te reo Māori there were no distinct words for aunties, just whaea and matua. Thus, the language implied the idea that within the whānau “the child or children are the responsibility of everyone in the whānau.” Whilst individuals may have still wanted children of their own, participants thought that there “wouldn’t have been that terrible need to have your own child” and infertility wouldn’t have been “quite noticed back then where you had all of the children to look after, and they were all our mokopuna” (C)

3.3.3 Mākutu

One informant recounted that “there was the whole kind of notion of there being some other cause whether spiritual or something else that made a woman infertile.” (5) For instance, another informant recalled kōrero about different families only having girls or boys and that the belief was that they didn’t “get the other because somebody’s put a mākutu on the whānau.” (11) But, this informant did not believe that there was much observance of that value base any more, especially amongst young people, unless “they know their tikanga or they’ve been pretty immersed in it or they’ve been bought up as Māori.” (11)

3.3.4 Tohunga and Rongoa

One informant talked about the work of Tohunga Hohepa Delamere who had featured in a television documentary *No Ordinary Joe* (TV3). He had been working with couples who’d been having infertility problems locally and overseas. The key informant believed that ‘treatment’ had a number of elements to it including mirimiri and deep massage, discussion about the effects of stress, activity levels, diet and other lifestyle choices on the reproductive organs. (5)

Participants in the kaumātua hui had heard of the use of massage.

In those days, everybody in all those areas had someone who could come and mirimiri. (K)

The kaumātua's hui and the takatāpui hui talked about there being "tohungas around." People received healing to balance the physical with the wairua. They also believed the people used rongoa, diet and other natural products to improve and to prevent fertility, and to induce terminations. Some participants believed they were still being used today.

I would actually suggest to my whānaunga that they go not only to the tohunga but they go do rongoa and they do a whole lot of the traditional knowledge stuff. That would be my first port of call... so there's a fusion literally of both traditional knowledge and any new stuff that's come on board. So you have the best of both. So my first port of call would be go home.

A kuia in attendance at the health hui did not believe there was any rongoa that could assist conception because if there was any then it would have been employed to help a whānau member she talked about. The woman had been cured of a venereal disease with "the herbs" but never had any children. The kuia concluded that "something must have to happen for Māori to get pregnant." (H)

The men's hui also believed that some iwi still have traditional ways of assisting conception. One man said that people who go and see the tohunga who "do their thing for three days and three nights" and a month later the woman is hapū.

In Māori, there's a lot of magic in us. (M)

3.3.5 He Puna Rua

A few informants talked about a practice that one informant named "Puna Rua." The practice was enacted in response to infertility in a couple. That is, if a couple didn't have children within a certain timeframe, even though they wanted to stay with their partner, they could have another relationship to see if they could have offspring. (14)

Another informant said that "in pre-Christian times certain rangatira might have three, four or five wives." But it was known that the male rangatira's affection for his first wife was not necessarily lessened by this. (9)

A third informant believed "that there were probably some people that really knew what they were doing in that era." They would have put two and two together when, for instance, people changed partners and suddenly they're having children. Changing partners, he thought, was and still is one response to infertility. This informant also, recalled hearing of cases where another person was brought into the relationship in order to create a child if the man was sterile. (5) He believed that even in contemporary times a man and a woman might arrange to have sexual intercourse in order for her to get pregnant.

I'm sure that within Māori communities, there are ways of doing it without having to go to fertility services. (6)

The informant who had had the practice of Puna Rua promoted to her, recalled that it was proposed by a male and that he had also said “that’s why people didn’t necessarily have so much problems with monogamy.” (14) There is, she suggested, “a level of sexism associated with it.” For instance, ‘Puna Rua’ could be interpreted to mean ‘two springs.’ “It meant a second wife as opposed to necessarily a second husband.” (14) She was not sure whether the term was associated with a pre-colonial practice, or whether it was a post-colonial term. (14)

Some hui participants had heard of this practice also which they believe demonstrated how important it was to the continuation of whakapapa.

One participant had heard that “way way back” if a couple couldn’t conceive the man took on another wife “and usually the second one had lots of babies.” This was allowed to happen and it was usually done with whānau knowing exactly what was happening. The first wife, “depending on how strong she was, was usually stigmatized” and pushed away because she couldn’t have children. (H)

Another participant told the story of a chieftainess, who married a chief and she could not give him children. In this story the chieftainess brought in another woman to have the children who were then raised as her own. The children continued the chief’s whakapapa and continued his name. (H)

The kaumātua hui talked about how in the old days “the old koros” might have taken on another wife. They believed that back then this practice worked for them and it built a whānau feeling where everybody was very close knit. (K) Participants wondered at how things had changed. They thought it was the done thing in the past to have different partners, but now it’s not the done thing. For instance, one participant said “my grandfather had different women, not that there was only one mother, but had different women.” (K)

3.3.6 Within Whānau Solutions

A few informants were of the opinion that “whānau should be able to meet the need for a child” (11) and that Māori would prefer to use existing cultural networks and “go back and see uncles and aunties and the family.” (9) Whāngai was the main process informants referred to as the appropriate whānau response.

Hui participants introduced another practice that was organized within whānau: that is, tomo or arranged marriages. “That’s where our people came and they tomo’d them right up to another one.” (K)

One participant said there had been a lot of tomo and “a lot of that manipulation” done in their family with arranged marriages. (T)

Another participant talked about a time when widowed women would marry one of her deceased husbands’ brothers. This was done not only to ensure the continuation of the whakapapa, but also to preserve whānau land holdings. (T)

3.3.7 Whāngai

Most of the informants talked about whāngai. In the context of this research, whāngai was mainly talked about as a way “of allowing a person to have a family and maintain their kind of family links.” (5)

Whāngai as a concept and a practice is one of the Māori mechanisms for addressing infertility in families. (4)

But, whāngai has been practiced by Māori mai ra no for many different reasons and parents with children of their own have also raised whāngai children. Whāngai was not only a way of addressing infertility.

The existence of whāngai as a living cultural practice was offered as explanation for why infertility has not become a public and talked-about issue for Māori. For instance, one key informant, reflecting back to the sixties and seventies believed that “infertility wasn’t seen as an issue because you always had access to other potential children, so the counselling we were doing was related to, ‘you want children? Here’s how you go and get them.’” (9) His recollection was that it was assumed people could adopt. Of course, back then “AHR wasn’t available so it wasn’t seen as an issue.” And, “infertility wasn’t a public issue, no one talked about it.”

Infertility might not have been a public issue, but knowledge of someone’s inability to have children was known about within the whānau. As one informant said, “it’s carried on in the whānau, the whānau knows around them and they have raised children through being, through whāngai, having whāngai children and it’s not really spoken about.” (10)

Another key informant said that because “many of us were whāngai by our grandparents as an example,” it was common to suggest “that our women should try and whāngai” if they were “unable to have children.” (3)

Informants believed that traditionally if someone couldn’t have a child, “then people would say oh well, here. It was an offering. People wouldn’t have to ask necessarily.” (5)

The experience of one informant diagnosed infertile in the 80s reflected this process, as she said:

Being without children was never presented to me as an option. So it wasn’t like looking at a long bleak road ahead... I was offered a child within about a year. (10)

Another informant thought it was culturally acceptable to “go and just take them.” (9)

But, the reliance on whāngai is predicated on the belief that “we have the opportunity to whāngai” (3) and that children will be available to whāngai. As one informant said, in the late sixties and seventies it was easy to adopt because “there was always children around, children for adopting” (9)

Some stories indicate that it is not as easy to adopt as it once was. One informant recounted how she had helped a woman to adopt a child. The woman reportedly knew she couldn't physically have children and had consequently accepted that she wasn't ever going to have children. When asked if she wanted a child, she responded "yeah but where am I going to get one from?" (11)

Another informant could see a number of reasons why whāngai would be less of an option. Firstly, he said, nowadays, "if you can't have a child, how many people are likely to know about that? And then how many people are likely to actually want to do something to help you with it?" Trying to apply the predicament of infertility to himself he acknowledged, that whilst he might think he would choose whāngai over AHR, "there's all likelihood that that wouldn't be an option. I mean I can't think of anyone in my close family, I don't think any of them would give me a baby. Just because they don't have the same number of babies as they used to, they don't kind of have extra children now. If I went out to my more extended family I could probably find one of my cousins that would be happy to give me one of their children." (5)

There's gonna be scarcity. (9)

One informant said she'd heard of people saying "we'll give you a baby if you haven't got one. So-and-so's got heaps and they'll give them to you and you know it'll be fine, don't worry about it." But, she said "that doesn't happen." (1)

Attitudes to whāngai may be very different now as indicated by one informant's kōrero who said the only person she could give a child to would be her sister.

The only person I could give a baby to would be my sister, which isn't an issue because she has two lovely children of her own, but right from a very young age I have always been aware that people do this and right from I think when I was at school I made a decision that if my sister couldn't have children and if she wanted a baby, I could give her a child. (2)

For all intents and purposes, whāngai appears to work well as a mechanism one informant said. (4) But she and other informants warned against romanticizing the concept of whāngai. It was different when, for example, the child was a whāngai to a whānau member who lived at a farm adjacent to their mother's farm "and they went backwards and forwards, like it must have been when we used to have this wonderful idea of whāngai children." (1)

Sometimes whāngai hasn't been a good thing, for example, one informant told of a boy she knew who "resented it all his life." "Why me? Why did they give me?" He would ask. (1) She also said there were occurrences of children being given as whāngai and then not being looked after. (1) Or there's the story of a couple seeking a child, getting one through a Māori woman and then having to go to court when it was eighteen months old because it was taken back by one of his sisters. (1)

Thus, some informants were doubtful about the relevance of whāngai today. As one informant said, it "is quite difficult to work out unless you're in that position." (5)

All the hui talked about whāngai.

Some participants believed that where “a whānau member was unable to have a child or children” then “a child would be whāngai to that whānau so that they could have a child that they could bring up” and this would be arranged by whānau members. (C)

One takatāpui participant thought of whāngai more as a support system that same sex couples could fall back on if they hadn’t got hapū themselves by the time they reached their 40’s. As she said, “then you approach your family and extended group for whāngai.”

Participants knew of people or couples in their whānau or communities who had not had children of their own, “but they had a family nonetheless.” The children were usually gathered from or “taken from” various members in the community, for various reasons. For example, children were adopted because whānau couldn’t support them, because the birth parents didn’t want to marry, because there were so many children, or children came early when the mother was young. (T)

The rangatahi thought that whāngai was how Māori used to respond to infertility and that whāngai would still be the initial option that Māori would consider if they couldn’t have a child. One participant said that they had heard people having conversations about having a baby for someone else. Another participant said her cousin had found out that she couldn’t have babies so her sister was planning on having a baby for her. One of the rangatahi said that she had told her friend “if this happens to me you have to have a baby for me.” (R)

The whāngai children, these hui participants knew of, received all the benefits of natural born children. (T)

One of the words used to describe family was paharakeke, he paharakeke. This was another way of saying “anei taku paharakeke tuatahi, he tuarua wera” (this is my first family and that is my second family). The participant explained that this terminology came from the term harakeke, referring to flax and implying the weaving together. The existence of such terms implied for this participant that Māori in the past “understood” that they were resolving infertility issues.

Often these children grew up knowing not just that that was their mother and father but where they actually came from and that was a fairly common way of whāngai. (T)

Whāngai was also a way of cementing families, or the community and bringing it together.

It was about sort of bringing people in to make the community look whole and share the burden and maintain whakapapa. (T)

Some participants were whāngai themselves. One takatāpui participant considered himself both a whāngai and adopted, because he was both whāngai in the Māori sense and legally adopted “the Pākehā way.” Within his whānau there were numerous examples of whāngai done for various reasons. An uncle and auntie had adopted

children because they couldn't have children. Another relation who wasn't married at the time was given a child to bring up. He knew of another aunty who was to whāngai two children but she died before the adoption took place. The children's whānau "forced the adoption to go through" so that the children would be born with her name, even though the children were to be 'given back' to their "tūturu families."

Part of that was because she didn't have any children, part was because she had land and so the land was spread back to the family again through those two children.

The kaumātua hui discussed the issue of inheritance to land. One participant said they had heard that adopted children "i te wa ka pakeke" that is, "should go back to their natural roots." This was because "i te wa ka wawahingia ngā whenua me hoki ano ngā whenua ki runga." In times past, the land was passed to the grandchildren of the whānau, "i ngā mokopuna i runga i te whānau." To help with translation, they went on to say: "Because quite often some adopted parents will have the one and only child and that child will take the majority of the shares in it. I mean, that's one of the reasons. Ka riro ngā whenua." This could potentially be a conflict that children resulting from AHR might have to face in the future.

One participant thought it was "terrible" that some iwi don't recognise whāngai as members if they cannot biologically whakapapa to the iwi. She said she would "fight them tooth and nail" if she was ever put in that position. (K)

Whāngai was also "a way of bringing the family together so that we would never separate as a whole family." Whāngai served to fulfill obligations to reciprocate, especially where one whānau had raised children for another.

Otherwise it's one family doing all the work for another one. (T)

People adopted sons "to carry on the line." (T) As one of the participants of the men's hui explained, "in the former generations... not as many men were being born." If people only had girls then there was "no-one to carry on their name."

All the boys would be whāngai'd out to cousins and stuff. To keep their families going. (M)

It's about whakapapa. (T)

The men's hui thought that the ones that were carrying on the traditional practice of whāngai were the grandparents that take the moko's. "That's about the closest to the staunch whāngai back then." (M) But, other hui participants stories showed that grandparents came by moko for various reasons. For instance, one kuia said moko were just wrapped up and brought to her, because the father was very sick. (K) Another kuia said she had stepped in to save her mokopuna from being adopted outside of the whānau. She raised two of her mokopuna until they were 5 and 6 at which time their mother decided she wanted them back, which she said was "hard."

I said, they're your children take them... I just looked after them being my blood and everything, eh? (K)

Another kuia who had brought up a grandchild said she “was also frightened” that her daughter “was going to come and take that child from me... I was scared she wasn’t going to give him back to me. It’s the legal thing that I used to be frightened of.” (K) Another participant said he had been whāngai’d by his grandparents.

I was passed around quite a bit... I loved it, actually I loved it yeah and you know every now and then my parents would miss me and want me back. (H)

One of the men’s hui participants said he was supposed to be whāngai, but his mother had “just straight out said no.” Her generation, he said were more independent and had more of a “Western New Zealand type attitude rather than a Māori focused one.” (M)

The kids of the sixties, that’s where it started to stop. (M)

In my generation we just don’t have the number of children that are coming through. (T)

One participant was saying that “whāngai is just what we do” to which another participant responded “you’ve got a surplus of babies down there.” He agreed that in the rural area where he was from there was a surplus. Thereby, suggesting that whāngai was still happening and may be more usual in rural areas. (H)

The men’s hui said “you very rarely hear of whāngai now.” People “just have a kid upon the ten other kids” they’ve got. Or, as another participant said “it’s happening less now with us because families are getting smaller... and the kids aren’t as young as they used to be.” They also thought that the range of services available to help people helped them to keep their kids. (M)

...they had six children and didn’t want the seventh one because they couldn’t afford it they used to whāngai them out. Whereas now they don’t because they’ve got a place called WINZ [Work and Income New Zealand] that helps them financially, so they don’t have to. They can manage... The whāngai business has stopped. So now our people who cannot have babies they going to have to look to something... go somewhere else. (K)

A further reason for whāngai occurring less now was that “people are more aware” about life. (M)

It was acknowledged that whilst there are examples of whāngai working well, there’s also going to be examples of some whāngai arrangements going bad too. (T) For instance, one participant said they had seen people use Pākehā law to take whāngai children back. “You do have that” they said, “we always live between these two worlds.” (C)

3.3.8 Co-Parenting

One of the informants believed that if there are people that haven't got children, "then we have to share that responsibility if they want to share that responsibility." (11) She spoke of, what is perhaps a contemporary arrangement, whereby a friend who was not going to have children approached her and asked if she could coparent the child that she was expecting.

I agreed. I said that was fine with me and I asked her if she wanted to go through any formal procedure and she said no, she just wanted it to be our, an arrangement between the parents and herself... I think it's great that others can contribute to your children's life. (11)

Her experience had led her to conclude that children should have more than two parents if possible.

3.3.9 God Willing

Some statements implied that an individual's fertility was spiritually determined. For example, informants both perceived that other Māori "think that if you're not meant to have them you're not going to have them anyway... it doesn't matter how hard you try" (11) and expressed similar beliefs themselves.

If we don't have them – well, c'est la vie, maybe we're not meant to have any. Maybe it's not our journey. (11)

Infertility was seen as "part of the human condition for whatever reasons." (9)

One informant suggested that people going through AHR might have to at some stage, just accept their fate. As she said, "once you get to a particular stage then it's time to stand back and you sort of get what you're given, and I mean it's really sad and horrible and hard but that's just what happens." (2)

One informant who had encountered this "that's-just-how-it-is" view of infertility said it was like people thought that "God made it that way sort of and that there was a reason for it." (5)

Thus, one way of thinking about children that shapes people's attitudes towards infertility is to believe that children are a gift, for instance, from God.

It is a product that a human has helped to create but the potential that grows from that action is actually a gift... if I strongly believed in God then I could say it was a gift from God. For me it's a gift from a higher being. (2)

Others used the term gift without specific reference to God. About a woman who conceived naturally after using AHR, an informant said "it was a real gift." (7) A key informant who became a father via artificial insemination (AI) said "it's a wonderful gift." (6)

I think a baby is a gift and it's a gift that is very special. (2)

An allied spiritual belief is that children don't belong to their parents, for example, one informant said.

I don't believe that they're ours, that they belong to us as an individual. I believe that, that they're gifted to us to support. (11)

The resulting belief that impacts on thinking about infertility is thus that:

Some of us are blessed with them and some of us aren't. (11)

A few participants at hui promoted that "every child that comes into our whānau is a gift from God" and "our ancestors." (H)

One participant, had been taught that "as Māori we whakapapa back to Rangī and Papa." Her understanding of tikanga Māori was that if a couple couldn't have a child, then "you're not always talking about a couple that belong together as a couple. (K) A participant at the consumers' hui had come across this attitude that if you can't have a child then "it wasn't supposed to happen." (C)

3.4 Infertility

This section presents a range of beliefs that are described by the informants and participants as contemporary and foreign. Some of the changes that are outlined have occurred at a philosophical level and there are new ways of doing things.

Most of the informants thought it was important "for all people to have good fertility" for various reasons.

The ability to have children is important. (2)

Hui participants thought fertility was "absolutely important" especially if Māori fertility rates were poor. (T)

Everyone should be able to have good fertility and be able to turn it off when they want. Or to turn it on. (4)

One hui participant wondered what 'good' means? (T) Another participant asked "what's good health and what's good well-being?" For her, "good well-being can and does incorporate that I can have a child." She went on to say that it was important that the child carried their whakapapa. Thus, fertility was "an important component to well-being, of our well-being as a people." (C)

The Māori men's hui thought fertility is important for "most Māori men... who are looking to continue their line."

I think they always think that it's an important thing to be fertile. (M)

3.4.1 Infertility: A Phenomenon of the Times

One theme that arose out of the kōrero is that infertility is a contemporary issue, “a phenomenon of the times” as one informant put it. There were a number of reasons for seeing it this way.

Firstly, Māori now live longer. Historically, for instance, in the 1830’s and before, people were considered old at twenty-seven, twenty-eight. Women were physically worn out by 24. They had pelvic and other problems from having large numbers of children under extremely difficult circumstances, whilst also having to work in their commune. (9) Infant mortality rates have come down as “quality of life” has improved. So, “unlike our ancestors of 1833... you don’t have to have six now to get two, you can have two to have two. So why have more?” (9)

Secondly, modern medicine has increased access to contraception and abortion enabling people to choose and manage if and when they have children. This had created what one informant saw as an ironic situation whereby on the one hand it was easier “for people to make a moral decision about whether they’re going to have a child or not and on the other hand you’ve got” people wanting to have children and finding they are unable to. (9)

Now we’ve got more choice around not being pregnant... the dynamic of it has changed. (H)

Attitudes are a lot different now... They tend more to plan whether they’re going to have 2 or 1 or 3 or whatever. Not like in the old days, one after the other, sixteen in my family. (K)

Some participants talked about the changes in attitudes towards young people being sexually active. One participant said that when she grew up the worst thing you could possibly do as a girl was to get pregnant when you’re at school. Now she said, we live in “a whole different society” in which the media actively encouraged and promoted sexual activity as the norm. She was particularly worried about the increased incidence of STIs among young people. Her generation, she said, received constant messages to look after themselves. (H)

We are exposing ourselves to others - putting our well-being at risk. (H)

The role of contraception was talked about at the kaumātua hui also. They said that mothers are introducing contraceptive use to their children “from the time they are 14” to prevent STIs. (K)

Another medical intervention that could be contributing to reduced fertility rates among Māori was tubal ligation. One participant said she had had her tubes tied even though “I didn’t mean for myself to get my tubes tied.” But her social circumstances made it a viable solution. She expressed sadness that she’d done it and after hearing the presentation at the hui, regretted it even more so as she realized that “this is something that I could have given back to other people.” (K)

Thirdly, for various reasons people are delaying having children. “We’re getting a growing middle class who will put off having children, so we will start to replicate the non-Māori experience” (4) and this mirrors a trend occurring internationally (7) in developed nations.

It’s a trend. The changing of age of delivery for Māori...reflects social change, socio-economic change anywhere. And as a nation gets richer then the age of their childbearing mums gets older. (8)

One participant said, “my family’s not really a family of getting pregnant as soon as you get to sixteen... it’s not really been like that... there’s always been a delay.” (T)

A takatāpui participant saw the delay as characteristic of women of her early 40s generation.

One woman explained that she stopped at one child because she was so put off by her experience of birth. She was 20 years old, “scared as” and had no idea of what was happening. She was in labour for two days, her partner “was so scared about becoming a father that he got himself stoned and was sitting at the end of the bed in a lazy-boy chair fast asleep.” The only way she got through it, she believed, “was because I had whānau support.” Her mother and father were with her and encouraged her through it. Psychologically, she said, it put her off having another baby. It was seven years before she felt ready to do it again “but of course it hasn’t happened.” (H)

Sex stereotyping had also changed. For instance, one participant explained that when he was growing up, “the girls had a job to do. They looked after the kids.” Boys did a lot of work around the marae. (H)

Too Old to Keep Up with Kids

Another participant suggested that you get to a point where you feel you’re “so damn old you don’t have the energy. You want to put your energy into something else rather than change nappies.” (T)

A male participant said he would decide over the next 10 years whether he wanted to have children or not. But he had had non-Māori friends say that he was too old (at 40) to have children. They said to him that he wouldn’t physically have the strength to bring up the child, and that “when you’re 60 the child would be 20 and he or she wouldn’t want to introduce you to their friends because you’re too old.” This was a surprise to him because he had “always thought that maybe the older you are, you’ve got your career behind you, you’re financially set, and you’ve got a bit more experience about the world, it might be actually more helpful for the child.” Others at the hui thought this was “a real Western” perspective. The participants then recalled examples from their own whānau of women having their last child at 54, and men still having children, albeit to younger second wives, at the age of 72.

We weren’t just having babies at the predicted time... They were having them in the middle years as well as the later years as well... all of our whakapapa is a contestation to that, with both genders. (T)

One of the women who was experiencing infertility was concerned about the kōrero “don’t push a pram before your time.” But, she said, “we are not telling them when is their time. And the prime time when to have your children is in your 20s... Sure don’t have a baby at 14 but don’t wait until you’re 40 either is the message we need to be saying.”

Given her experience, she now believed that women need to start thinking about having children when they’re in their 20s. As an example of what is being promoted, she referred to an advertisement that was currently playing on television. It depicted success at the different stages in life. Having children is not shown until age 35. A man and pregnant woman walk into their newly acquired first home at age 35.

“That’s the common myth that is put out there isn’t it? That that’s a good time, in your 30’s is a good time.” (C) But, this participant said “that’s too late.” (C)

Informants proposed that people were delaying having children until they had secured an acceptable standard of living so that they could provide the best quality of care for their children as possible. As one informant said:

When you have these children you want to be good parents for them... you should be able to look after them and provide a good home for them. (I)

Towards this end some women may find themselves delaying childbirth while they wait for the right partner.

Multiple Influences on Fertility

The men added that fertility was being affected by all the problems “you see in the news all the time. Sex education of young Māori – they’re having sex earlier and not using protection; the social issues; less money for families in different areas... smoking, the drinking...” (M) The health workers’ hui added that “we’re an aging population.” (H)

Other changes in the world over time were seen to contribute, such as, people spending more time watching television or on other recreational pursuits.

The Cost of Living

Several participants mentioned that the cost of raising children was now so expensive, particularly in Auckland, and that having fewer children was just “economic reality.”

I’ve got two. I don’t need any more quite simply cause it’s too bloody expensive you know ’cos I live in Auckland. (H)

Since I’ve had my son, I’ve said that I won’t have another baby until I’m financially secure. Or if I win Lotto I’ll start popping kids out. (R)

As another participant said “if you want to work in Auckland you’ve got to both work” and “if you’ve gotta both work whose got the time to have children... whose gonna look after them.” Another participant said that this had led to a situation where grandparents were living with their children to help with raising their grandchildren because the parents have to work. But a further participant said this wasn’t always possible because the grandparents were also working. (H)

We're made to work until we're 65. (H)

A kuia said that back “in our days” it was feasible to have nine children, whereas now even with both parents working they can still only afford to have two to three children.

I look at some of my mokos and unfortunately I'm on a benefit, but we try and help as much as we can but it's very very hard for them to live.(K)

A takatāpui participant was all for her nephews and nieces to all go and have children, but, she said, “Who’s going to bring them up?” It’s all right, she said, if you’ve the support systems in place and a good nurturing space for the child. (T)

The rangatahi confirmed that they had been discouraged from staying at home with kids. People would ask “why aren’t you out working?” One young woman said that when she has kids, she’d “love to stay home” and send her partner out to work, if she had a partner. The rangatahi thought that being a full-time mother at home should be seen as equally worthy as having “a job.” (R)

The kaumātua hui also talked about how “the make up of our woman are a lot different now than what they were in the past.” For instance, women in the past were “strong” because they would go home 10 minutes after having the baby. “They had to ride a horse to get to the hospital. If there was a hospital.” But, as another participant said, “they didn’t work in the old days. They stayed home and they looked after the children and they looked after the house. And they kept the gardens and everything while the husband was out at work. Whereas now they can’t.” (K)

One participant compared his urban lifestyle with the less costly rural community environment where he was from. There, he said, “you don’t even have to feed them half the time, just pass them around... send a couple down the road at tea time, or they’ll call into their Nan’s and get a feed and come back after.” This pointed out a further difference which was that back home “there’s a lot of support.”(H)

Finding Mr or Mrs Right

The men’s hui also discussed the importance of “finding a good partner first” and “building a foundation”. (M)

The health workers’ hui pointed out that not having a partner was a barrier to having children. (H) One barrier to finding a partner was that 50% of the prison population is Māori, thus as one participant said, “a large number of our men have been taken out... they’re not available.” Thus, some women who would like to have children may have trouble finding someone to establish a relationship with. (H)

Another participant said that having fewer children was sometimes due to men choosing partners who were older than themselves. (T)

The Professional Lifestyle

A takatāpui hui participant suggested that the takatāpui lifestyle, especially that of the “takatāpui professional” was such, that women could get all the way to 40 without having seriously considered having children. She also referred to the clubbing lifestyle as being a barrier to takatāpui becoming parents.

Some of us don't want to compromise our lifestyle. That's how we get to that age. (T)

One participant thought there was a gender difference in terms of how many children women versus men wanted to have. Women might still have “lots of kids ‘cos they’re used to working hard, whereas men tend to have 2 maybe 3.” He compared himself with his sister who had 10 children. He said he enjoyed “the contemporary trap” and “the trappings of modern day living.” (H)

I like to do different things that cost a lot of money and if I've got a lot of kids... I can't do it. (H)

For example, he said he liked to travel and he liked to take his children, but if he had 5 or 6 he wouldn't be able to afford to take them. His sister, he said “doesn't care... having ten kids is just what she does.” (H)

Takatāpui who have only same-sex sexual partners are not going to accidentally fall pregnant; thus, one participant stressed, having a problem with your fertility is not the only way to be infertile. (T) Even heterosexuals, it seems, could be having trouble getting it on. One participant said she had read that in Britain, “everyone was working so hard, a lot of young couples don't bother having sex anymore they just go straight to AHR.” (H)

Finally, if and when Māori have children they have fewer children. Over the preceding generations, the number of children per family had significantly dropped. Several informants had noticed this within their own family. Their grandparents had children in the double digits, their parents had had six to seven and they had only had two or three and their children were talking about only having one or two. (10)

Just looking at our five children, they're all marrying late, they're all having their children late. (9)

One participant said he had talked a lot to the next generation and “none of them want to have a lot of kids.” He believed this was because they're colonized.

They're colonised, they're urbanized. (H)

For instance, he said one of his nieces said she didn't want the stretch marks. Another participant said that the role models for younger people and the lifestyle that is modeled for them is not Māori. She thought they were being heavily influenced by the American way of life.

Our young women today, they're not talking family, they're not talking mokopuna. They're talking about getting higher education, they're talking about building a house first. (K)

The younger generations are more focused on education, sport and travel. One woman's 35 year old daughter "reckons she makes a better aunty than she would a mother." She apparently had plans to travel. (K)

It's the evolving lifestyles.

The men's hui also believed people are putting more time into their careers and "are planning out their lives" more.

Because people want to have all the things like everybody else has got. Stability, money in the bank. So you've got something there for your children to work on for their education. (M)

Wanting to build a home before having children added to the financial pressures. (K)

The rangatahi hui confirmed that young people today are more focused on their goals to travel and their enjoyment of "partying." (R) When they finish school, they're "supposed to go to uni, get a job, do your OE [overseas experience], come back and do whatever you want to do. And then you start having babies. And by that time you might be 26. That's what I want to do. But that's what's been instilled in me." (R)

People I know don't want kids because they feel that they're too selfish at the moment, they want to do things for themselves before they go and have kids. (R)

The rangatahi believed that the "society we live in today is like money and your status." (R)

A kuia said her generation "was lucky." In the 1950s "it was taken for granted that you got married, you had babies." She stopped playing sport the day she got married and went back to work after she'd raised her children. But now, she said, "it's accepted that you get a career and a house with everything in it" before you marry.

One participant said that to understand why there had been such a rapid drop in Māori fertility rates, it was necessary to look at what policies may have triggered the drop. For instance, the men's hui talked about how "a lot of men weren't around with the war. A lot of our kaumātuas died, our rangatira died in the war, second World War, so that was a big loss for us in the stats aye? Maybe, I don't know, rough figures, sixty percent of Māori didn't come home. That's right. That's why most iwīs during the war, they stopped their men from going. Especially Waikato where I'm from, it was stopped. It was, no, why should we go there and fight? You're needed here." But, the men concluded that they thought Māori had made up for the loss through the 1940s and 50s, "then they made their babies." (M)

Another participant recalled that Family Planning was introduced in the 1960s.

We were told if you had probably more than 2 kids it was too big a family. This is the right size of family and we were encouraged to model basically Pākehā of what size their families were. (H)

What had not helped also, was that “our whānau behaviour is also decreasing.” (H) For instance, the men’s hui talked about how whānau had been “split into nuclear family groups”. Whānau were separated, which broke down the supports provided by community living. The resulting “mentality” was that you have “the two parents plus another two and a half kids.” (M) So, “there’s less and less tendency to have heaps of kids.” It had become the norm.

3.4.2 You’ve Got to Own Your Own Home, Own Your Own Baby...

Contrary to the downward trend in the Māori fertility rate, a few informants thought there was a new pressure that pushed the importance of having your own biological children, although they identified it as a Pākehā thing.

There’s a lot of this drive and you’ve got to have babies and you’ve got to do it. That’s really a Pākehā thing isn’t it? (7)

One informant thought that increased availability of AHR technology contributed to this drive also. (7) Another informant alluded to the possibility that increased effectiveness of AHR technology could be impacting on this drive and changing the attractiveness of AHR as over time it improved. She said that when she and her partner faced infertility in the early 1980s, IVF was new on the scene “but we didn’t pick it up as an option.” One reason was that “we didn’t think it was a big deal to have to have our own child. It wasn’t a big thing for us.” Another reason was that at that time IVF “wasn’t anywhere near as precise as it is now” and the possibilities of conceiving were that much lower. (10)

Another informant believed stories in the media about people having a baby as a result of AHR has been changing people’s expectations of AHR and encouraging people to think in terms of fixing their infertility as opposed to considering adoption.

Within fertility treatment there’s also an expectation now that things need to be tested... the expectation that that’s created as well maybe channels people to go down that route as opposed to adoption. (5)

He also talked about the new emphasis on having your own biological child. Which he believed partly fed the demand for surrogacy.

I can’t carry it, but it’s still mine... It’s that people expect that they can have their own. They see it as their ownership about it. (5)

He wondered why it had become so difficult to accept adopting another woman’s baby instead.

Two informants reflected the preference for a child of your own blood in their kōrero. One informant, who appeared to support the concept and practice of whāngai, also said:

When you whāngai someone else’s child you raise them like your own child... but there’s always something missing and that’s whakapapa. You only have whakapapa by blood. Being able to conceive a child of your own blood is quite important. (3)

Another younger informant stated that it was preferable to have your own child.

If you can do something which enables a couple to have a child from the woman's egg and from the man's sperm without a third person being involved then I would see that as being preferable. (2)

One informant said she found it quite hard to deal with the application of individual ownership to the argument for having a child. (11) Another informant's kōrero partly helps to explain why this might be so. She had personally experienced pressure to have her own biological child, as opposed to a whāngai. She suggested this was a new pressure for Māori, "related to the fact that we've narrowed down families so much in Pākehā terms." (14) This resulted in the predominance of the colonisers' views rather than mātauranga Māori views. As she said:

There's a level of colonisation that occurs when you feel that you've got to own your own home, own your own baby. (14)

Participants in the consumers' hui talked about how under the older, broader view of whānau, children were "shared around the whānau and there is a shared responsibility too." But, today they believed that to be "an impossibility." It was impractical now given people's work and the way "whare's are set up" for instance "how we've shifted from those marae-based homes." (C)

3.4.3 Infertility – How It's Defined Today

Infertility is currently defined as the inability to conceive after a year of trying, or not being able to carry a baby to term. As one key informant explained, "many people who experience infertility will go on successfully to have children and some of them will do it without medical help and some will need minor medical help and some will need more extensive medical help." (13)

This is potentially not the way the general Māori population view infertility. The "historical view" was that "Māori would view infertility more in the line of sterility... "It's not a transitional thing but a state of being." (5) A few of the key informants used the term sterile and or thought infertility equated to sterility.

I would've said infertility maybe a number of years ago related to sterility, you know just not being able to have a child. But now, you can be infertile while you still have kids. (5)

Thus, the definitions and terms used for infertility have and or are changing over time. For instance, in the field of AHR the term 'fertility' is now preferred to 'infertility.' One example, provided, was that *fertility NZ* changed their name from *New Zealand Infertility Society* because people didn't like the word infertility. (13)

Another informant said that trying to conceive for one year, before applying the diagnosis of infertility has also changed over time. He said, "It used to be two years of trying because the population generally trying, say two decades ago, was younger." (8)

How infertility is defined affects whether or not, and when, a person or a couple might seek help. For example, one informant said that infertility has been “medicalised as a problem.” (5) He and a few other informants challenged the way in which infertility is being defined or conceptualised

They saw infertility as a “very complex personal thing that’s not neutral, it’s overlaid with so many different human and social and cultural, political, economic constructs and it’s very hard to tease out what it is.” (14) Thus, one informant argued for a more holistic way of thinking about infertility. She said it’s “part of the bigger picture of people being sexual beings so there’s more to it than just sex and at the end you have a baby or you’re not able to have a baby” and it needed to be thought about within the context of “a whole life course.” (4)

Another informant argued for a focus on “constructs of reproduction” (14) so as to take in to account the broader social context within which people have children. This would provide for the belief that infertility is socially determined (4) and the opinion held by a few informants, that infertility is a social issue “not a health issue.” Although, one informant thought it was “peripheral” to health. (8).

Thinking that infertility is the same as sterility came up in the takatāpui hui, the health workers’ hui and the men’s hui. Infertility, or being sterile, was seen “in the community” as “a permanent situation.” The notion that fertility waxes and wanes was a new concept that some participants struggled to understand. They wondered what people had to go through to maintain their status as infertile. (T)

The rangatahi hui thought that the term sterile only applied to infertility in men. (R) One young woman, who already had a child, was surprised to learn that she could experience infertility at some later time. “That’s pretty scary.” She said, because she had just assumed she would be able to have more kids later on whenever she wanted to. (R)

The health workers’ hui questioned the notion of “regular sex” what is considered to be “regular sex?” They asked. They suggested that there could be relationship problems and a lack of intimacy and that people shouldn’t assume that just because there’s been this length of time without a pregnancy that the couple are infertile. (H)

It was proposed at the health workers’ hui that it would be inappropriate to settle on one definition of Māori fertility. (H)

3.4.4 Infertility – The Causes

Whether people see infertility as a medical problem or a social problem determines their approach to understanding the causes of infertility. As kōrero outlined above shows, many of the informants saw infertility as a contemporary issue arising from a number of social changes. As one informant said, “a lot of the infertility these days is due to ...is social.”

Good fertility needs good environment. (K)

Some hui participants used the term “environment” when suggesting a more holistic view be taken of the causes of infertility.

The environment we are living in now plays a big big factor in our lives and decisions.

Thus, this participant suggested that we look at changing the environmental factors in order to improve fertility, rather than “having to interfere” with medical interventions. (K)

One woman said infertility was not just a biological condition, but “a state of mind and it’s also a state of behaviour and choice.” From a holistic Māori perspective, she said that in order to have good fertility, your health has to be up to scratch, “you’ve gotta live healthy... save more more money than going out... it’s got to start from the home inside... like when you got food on the table, proper food... if that doesn’t build enough inside you... it’s that eye contact that you make.” It’s “whether or not the woman is taking care of herself in all the areas of her life and whether the male is as well taking care of himself in all the areas of his life.” For example, she said that when she had her child, she was 20 years old, playing netball, working, going to church and “a lot healthier than what I am now. But my partner was also a lot healthier than what he is now.” She said that, “when I was 20 I thought I was pretty alright, you know I thought I was OK.” She was now 36 and had not had any more children, despite her desire to do so.

I’ve had a long time now to sit and think why I’m not falling pregnant.

She had applied the Whare Tapa Wha model to try and understand why she and her partner had not had another pregnancy. She said that “over the last 16 years life has been a real struggle. I’ve had mental health issues... I obviously am not in the best of health... my partner has alcohol and drug issues, so you know it all begins to add up.” (H)

Another hui participant thought there is a fundamental difference between Māori and mainstream thought about fertility, in that the Māori perspective does take the social and psychological factors into account. This participant even thought that Te Whare Tapa Wha was not holistic enough “because I think it’s more than just wha.” (H)

Part of the presentation used to guide the interviews with informants included a statement about half of infertility being female based and half male based. One key informant said it would be more correct to say that a third of infertility is female-based, a third is male-based and a third is due to unknown causes. Another informant asked why it was not considered a couple’s problem? Especially, for instance, when a lot of tubal damage was “male-based anyway.”

Two informants thought “that there is a presumption that most of the reason why couples don’t get pregnant is because it’s the female.” (4)

Women were always blamed. (1)

One informant thought that historically, Māori probably did assume that infertility was the woman’s fault because “it was the woman that had the baby.” (5) As another informant said, she’d heard anecdotal stories within her own whānau “of different

things that women have gone to do when they've found that they couldn't have children." She had not heard similar stories about men. (10)

One informant said that if 'no issue' was recorded in a man's whakapapa "then it could be assumed that it was his fault." (5)

One informant said he had heard stories about increasing rates of male infertility. (6)

Hui participants were interested to know what causes infertility. At the kaumātua hui they wanted to know what "male-based" infertility meant.

The takatāpui hui knew that older women "can't have children as easily" and the men's hui had heard it was "old eggs." Another participant talked about a woman he knew who was infertile. "That's 'cause she was an exercise buff," he said. (M)

Some participants had heard of people becoming infertile "through different diseases." (T) For instance, a whānau member of a participant had reportedly contracted syphilis during the war from her husband and as a result repeatedly miscarried. (T)

The health workers' hui talked about research that said it was important to have good health prior to conception. If this was true, they said, then the poor health status of Māori would predict a higher prevalence of infertility among Māori.

One kuia thought that her granddaughter was infertile because when the granddaughter was 3 years old she came in to the kuia's room during radiation treatment. (K)

Another participant recounted a story of an uncle and aunty who never had children despite their 5 years together. But as soon as they went off with other people they had children. Thus, she said:

Sometimes it's actually a couple together problem. (H)

Infertility Causes – Woman's Fault

The kaumātua hui thought that in the past women were always blamed for infertility. (K)

At the health workers' hui, one man said two of his cousins, who had never had children, "both blame their wives." The woman at the hui who had not had another child despite trying said her husband "said to me, it's all your fault." But, she believed he said this to take the focus off him.

A lot of women get blamed but I suspect there's a very high level of Māori male impotency because of diabetes, alcohol and drug abuse, the things that we don't talk about. (H)

At the men's hui they had only heard of men being infertile "through drinking and drug abuse I suppose. Self inflicted. Can't get it up anymore." (M)

3.4.5 The Contribution of STIs to Infertility

Several informants were aware that infertility is one of the more severe consequences of untreated STIs, in particular, tubal failure following chlamydia. This was a concern for Māori because as one informant explained “young Māori have much higher rates of chlamydia than non-Māori.”(6) Another informant thought that there were increasing numbers of Māori presenting with chlamydia and gonorrhoea in both the younger age brackets and in the late 30s, early 40s age bracket as well. (2)

A few informants questioned the validity of current prevalence statistics. One informant believed that “the figures that we actually do have are actually under reported.” Another informant confirmed that this would be the case as some tests are not reported. She added that there is a range of statistics produced on STIs and that they vary in what information is recorded depending on where the testing is done.

Two informants were concerned about the way in which this negative statistic can be used to portray Māori as dirty and promiscuous. (14) But, there are systematic factors that contribute to the prevalence and disparity. For example, one informant recalled that World Health Organisation reports had showed that there’s an increase in STIs occurring globally. (10) Another informant referred to “work in Australia with aboriginal groups that do have a high chlamydia rate. But the rate is high because of no treatment not because of promiscuous behaviour.” (8) Untreated STIs could be an issue for Māori because, as another informant said, “a huge number of people who have chlamydia don’t even know they’ve got it.”

On a positive note, one informant believed that there was less pelvic inflammatory disease and infective causes of infertility as there used to be. (7)

Infertility Causes – STIs

A health worker expressed concern about sexual activity occurring among very young people and the higher prevalence of STIs among Māori. She said that “a lot of people don’t know what chlamydia is. They don’t when they’ve got it and the scary thing about that is... it’s a silent disease and left unchecked for too long can actually render both male and female infertile.”

She worked for an organization that was trying to increase awareness of STIs among young people and encourage them to have tests so that they can find out if they have chlamydia or any other STI. One problem they had found, she said, was that some men are too scared to come forward. (H)

3.4.6 Infertility – Te Mamae

The informants expressed a great deal of empathy and recognition of the deep hurt that can be experienced by people who have found themselves infertile. Informants who had not experienced infertility themselves said that they could only imagine how they would have felt if they couldn’t have had children.

Had I never had a child I would have felt let down and I would have tried whatever there was that was going. (1)

A few participants at the kaumātua hui said that “you’ve got to stand at the decision road” and face infertility yourself before you can really know whether or not you would use AHR.

We can only be there to support them. (K)

Informants expressed sadness for people who wanted but were unable to “create another child or a child in their likeness” (6) and they thought it sad that they would miss out on looking forward to and having mokopuna. (7) They imagined it would be “devastating” and “heartbreaking on a whole number of levels.” For example, to not be able to say “I’ve got a direct line back because for whatever reason there’s been a break... would be really devastating.” (2)

It’s having ‘no issue’. When you do your whakapapa and you come across all these people – ‘no issue’... I looked at the whakapapa and thought ‘Oh how sad.’ ‘No issue’. The whakapapa for you stops there. (1)

This informant felt sad also for the “famous people like Te Puea who never had children, but they raised many. But I wonder if, how they must have wanted children.” Although she conceded the whakapapa of Te Puea was carried on in her sister’s children, that is, “if you believe in the proper whakapapa... ’cause in Māoridom it must be like that because we have no other word there for all our mokopuna.” (1)

Another informant recounted how people within his whānau expressed pity that an uncle had not had children.

People always used to say what a great pity that they never had children, because my uncle would have been a great father... He was a neat uncle and he would have been a neat father... they both would have been great parents. (6)

One informant had observed the heartbreak of a woman trying to conceive using AHR and not succeeding after two cycles. (7) Another informant knew of a couple who decided not to be together because they couldn’t have children. (3)

In reality, as an informant with experience of infertility explained, there is a scale of individual response to infertility.

For most people infertility isn’t a breeze or a walk in the park emotionally... For most people it brings some pain... (12)

Unfortunately, she said, that pain is often compounded by society’s “lack of understanding” of “how intensely emotionally painful infertility” can be. She said that people’s feelings are minimised by comments such as, “it’s not actually fatal, and there could be worse things that happen to you.” (12)

She also talked about “that whole stigma thing.” (12) That is, the negative stigma people perceive as attached to being infertile.

The negative psychological impact on mental well-being was one of the reasons why infertility needed to be recognized as a concern according to one informant. (2)
Infertility is also important for whānau, as one informant said.

It's not the end of the world, but it's quite important for the family/whānau. (7)

One of the women who had been unable to have another child said:

I'd love to have another baby... in fact it's all I've been thinking about since I turned 30. (H)

She spent a lot of time thinking about why she had not fallen pregnant again. She blamed herself for “16 years of basically abusing my body in terms of my weight fluctuation and really not being in a good space.” She said she wondered about what she could do to improve her fertility but didn't actually do anything, because “it's a scary place to be.” She was now 36 years old and had never wanted to be an older mother. Then there was her partner who she believed had “issues” as well.

She now considered it a miracle that she ever got pregnant in the first place 15 years previous, and she had been saying to herself if it's meant to be then she's going to need another miracle. But, learning about infertility at the hui had caused her to reconsider. She said, “it's actually quite scary, because does that then mean if I really really really want to have another baby, what's the next step in the journey for me? Especially if my partner... if that could mean that I have to subject him to some testing... Where do I go now?” (H)

She was asked if she would consider AHR? To which she replied, “Already the price has put me off. And at the end of the day I still have the belief that if I'm meant to be pregnant I'll be pregnant. If I'm not, you know, then I won't have another pregnancy, but there's also that part of me that thinks, well, you know, maybe we can just go to Family Planning and I'll try to get a couple of things out of my partner.” She said that if she didn't go somewhere for help she would always wonder “what if?”

Another participant who was experiencing infertility and using AHR explained how hard it was to get to the point of accepting you're infertile.

Accepting that I was infertile was hard, because a woman is born and they think that it's their given right to be able to have children... There is that assumption there that you will be able to have your own children.

Another thing that was hard was that everyone else assumed it is easy to get pregnant and that all you have to do is relax and have sex. She said that some whānau, probably the ones who don't know that they have sought fertility help are saying “Just relax. Go away on a holiday” and “it will happen one day.” But the hardest thing to hear is other women moaning about not falling pregnant after 2 months of trying or moaning about being pregnant.

You're sitting at the clinic and you hear other people talk and say, I've been off the pill for 2 months and I'm not pregnant yet, I guess we will have to try again and see what happens next month. And you just sit there and think, oh god, 2 months is

nothing when you've been 5 years, or it's not just as simple as taking your partner to bed and you're pregnant. For some of us, it's not that easy. So yeah, that's probably the hardest thing that I've had to sit through, women who do that. Or women that, oh god, it's morning sickness again. It's like oh jeez if only I could have morning sickness. Yeah, I'd give anything to be feeling sick right now. (C)

Two other participants talked about being affected by people's comments about their not having children. One woman concluded that "the effect that it had on me overall was that I became really tough, I became staunch and it, I think it built my determination up, made me a strong person." The other woman said "we already know that we're not falling pregnant, we don't need to be told and you don't need to be reminded." She said you'll be okay if "you're pretty staunch" and "you stand up to your whānau" but "if you're not it plays in your head" and it can "really mess you up." (H)

One of the sad consequences of infertility was that some couples split up because of it. The men's hui had heard of this happening.

Especially when they go out to the doctors and they find out that one of them can't have them, they split. You know they'll go off and try again. It's a bit sad. You know it's a bit pouri. (M)

3.4.7 Infertility – An Emerging Issue for Māori?

Several of the informants believed that infertility was going to be of increasing importance to Māori. Especially if the downward trend in fertility rates outlined above continues (9) and if nothing is done about the disproportionately higher STI rates amongst youth now. (6; 4)

Further, as one informant pointed out, we have a growing middle class who will put off having children. Then, she said, "we will start to replicate the non-Māori experience, and I don't think it's anywhere on our radar screen to address that." (4)

If infertility is connected to women delaying trying to have children until they are in their thirties, then one informant saw fertility testing becoming normal practice. (9)

This sounds to me like the time has arrived where assessing one's fertility is now a necessary component of normal life especially if you're later on maybe late twenties, thirties. (9)

One informant fully expected to see "more and more cases of Māori wanting to use fertility services, and use whatever services are becoming available... that's going to increasingly become an issue." (5)

Hui participants differed in their own estimates of infertility prevalence among Māori. They based it on how many people they knew who had difficulties. Whilst, some knew few people who had had trouble, a lot of the kaumātua hui participants knew people. (K)

The men's hui were sure that infertility is a problem for some Māori especially "now that whāngai happens less and less." (M)

The rangatahi hui had not heard anything about Māori fertility rates. They had heard about teenage pregnancies but did not relate that to Māori fertility rates. They just thought based on their observations that Māori women had five to ten children, as illustrated by this snippet of the conversation:

Five. Ten. I know one lady that's got about that much kids. Our family has. All of our aunties have got like four kids. Yeah, I know a family that's got like thirteen kids. (R)

They said they would be surprised if they heard that Māori fertility rates were nearly the same as Pākehā rates.

The woman who was currently using AHR said she'd only ever seen one other couple that were clearly Māori in at the clinic over the last four years, and even then they might not have been there for fertility and could have been waiting to go in to one of the other clinics on the same floor. (C)

The kaumātua, takatāpui and consumers' hui questioned the validity of applying prevalence statistics based on other ethnic groups, especially European, to Māori. One participant said he knew there was a lack of fertility statistics for Māori or any indigenous people.

That our population is young perhaps masks the problem somewhat. It would be easy to under-report infertility among Māori because those who already had children wouldn't consider themselves infertile, but as one of the men pointed out, there could be people who had kids when they were younger, who are having trouble conceiving later in life. (M)

Hui participants said we need studies to determine the prevalence of infertility among Māori and to look at the reasons for the infertility.

Fertility Prevalence

Most hui participants were surprised to hear that Māori fertility rates were so low. When faced with the possibility of our rates dropping lower, dropping to equal that of Pākehā or lower than Pākehā to the point where we might not be replacing ourselves they were shocked.

That would mean that "someone else is replacing us." (H)

This caused one kaumātua to reverse his attitude to AHR

I've got to tell you when I first came in here, as far as I was concerned there was only one way. Boy meets girl. They get together, have child, end of story. No other way. But then you and... threatened me about me losing my whakapapa... So from the extreme I started coming back and now I'm in the middle somewhere. (K)

The rangatahi said they would feel "gutted" if that happened. One young man said "Māori would respond by trying to find ways to increase their fertility. To increase the population." Another rangatahi added, "To keep their identity nice and strong."

That's what Māori people do. I don't know. But Māori are known to stand up and do stuff if something happens. And I think the big thing there with Māori is the whakapapa. You know they worry about our whakapapa. So they'll do something about it, but I don't know what they'll do. (R)

One of the young women had heard about infertility in everyday conversations and on television and as a result wondered what she would do if she found she couldn't have children. The rest had not started to think about it or, for the rangatahi who already had a child, it wasn't an issue because she assumed she would never have any trouble. (R)

3.5 Attitudes to Assisted Human Reproduction

Different beliefs and experiences underpin attitudes towards fertility, infertility and AHR. This section outlines some of the beliefs and ways of thinking about AHR that informants either expressed themselves or talked about.

3.5.1 Potato, nail, musket, AHR...

Informants supported Māori use of AHR for a number of reasons which somewhat arose from their beliefs or the frameworks that they use to assess and judge topics such as AHR. For instance, one informant proposed that we should look at AHR as a new technology and thus approach it as Māori have approached all new and introduced things, that is, with an open mind.

Māori thinking pre-1840 - how did they address or question new technologies? Well the historical evidence is one, keep an open mind about it, whether it's a white potato or a nail, a musket, a ship – from a canoe to a schooner, you know all those kind of new technologies, whether they be food technologies or whatever, clothing, housings. All the evidence is our people would keep an open mind on the matter. And then if for some reason they concluded that this was going to be useful, then they adopted it. (9)

What would be driving Māori, he said, is the need for a sustainable population. He thought that if we look at a tribal level at the little one-year-olds running around, “well, at the moment you'd be having to look hard.” This perception of a diminished number of children, led him to conclude that AHR “is a technology that culturally speaking we would need to look at, in order to sustain ourselves as a people.”(9)

Another informant said we have to “get over this idea that medical intervention is against nature or unnatural” because we're going to need to see AHR as a legitimate way “of continuing our whakapapa and ensuring the preservation of the Māori race.” (6)

Some informants spoke about the benefits of AHR for the individuals affected by infertility. For one informant, being able to help others was a foremost consideration when thinking about AHR. As she said:

If we can contribute to anybody else's children or anybody else's lives then that's what we should do in our lives. (11)

Another informant believed that there's no good reason why "people who want to be parents shouldn't be parents" and if there is a "medical process that enables that to happen then it's fantastic because you're continuing bloodlines, you're providing those people basically with what they want." She acknowledged that there are people who have strong negative views of AHR, but for her it's about looking after the emotional, mental, and spiritual wellbeing of the parent, acknowledging whakapapa and being respectful. (2)

One informant said that she personally wasn't against AHR. But she also said that "as long as it doesn't hurt anybody else" AHR is up to the people involved. (1)

One of the takatāpui participants suggested that the kūmara could be used as a metaphor for thinking about AHR. That AHR could be thought of "as a 21st century version of the kūmara" that sustained us. She said it was about "sustainability. Sustaining who we are."

Our ancestors brought the kūmara here, which you can think of as life, life sustaining. That travelled great distances. It was successful and it wasn't all around the country. Thinking of this idea is this thing life or is it not life? I guess anything that is connected to our existence is life... I'm all for being pragmatic in support of any form of technology that provides... for the future.

Because AHR is "going to affect and impact the future more than our present" she said that "it's how we respond to this idea that I think has the biggest impact on our communities?"

What mattered the most, she said, was the goal. What was AHR technology being used for? What are people trying to achieve? "Not the details." The details of how AHR works and is implemented were "just details" and of secondary importance to the kaupapa. (T)

3.5.2 It's a Right, Right?

Believing that fertility is a right leads to certain ways of thinking about infertility and thus AHR. Just more than half of the informants backed their support for AHR with some talk about rights. For instance, that people have the right to found a family, they have the right to equitable access to whatever medical treatments are available, or as is the case for Māori, they have Treaty of Waitangi rights. A few informants did not support a rights-based argument for AHR. These different views are presented below.

The Human Right to Found a Family

Firstly, there is the view that being able to conceive, carry and birth a child is a human right. (8) One informant referred to the Universal Declaration of Human Rights 1948, Article 16 which establishes it as the right to found a family. Which she felt inferred "the right to be able to have the chance to found a family." (13) Certainly, one informant thought no individual "has a right to deny women the access to the information and opportunity" to undertake AHR. (3)

Contrary to her saying that, she also said that people have "the right to have children in a natural way." (3) Whilst another informant was unsure if this particular human right could be extended and applied to the different procedures now available. For

instance, they said, “I’m not sure how far down that track remains a human right... how far down the track of intervention should one expect to have that kind of management.” (8)

One informant thought that thinking that “it’s a woman’s right or a couple’s right to be fertile and to have a baby” sets up expectations in people that they will be able to have children of their own and what follows is that “they’ll do whatever they can to make it happen.” (5) Further, he thinks this line of thinking implies “that you have a right to be fertile all the time. So if you’re not fertile for a period of time then you’re infertile.” If the social expectation is that you will be able to have your own children and then you can’t, then infertility will be seen as “strange” (5) “and that’s why we have all this kind of technology around helping couples with infertility issues.” (5) He saw this line of thinking as a Western argument, rather than a Māori culturally based argument, that Māori are adopting, “because we’re a part of society.”

Another informant offered that acceptance of the claim that “it’s a human right now that you can have a child” logically leads to “the proposition that the State should fund AHR.” She queried the impact of this and concluded that the matter was complicated.” (11) One of those impacts is the focus on public funding or lack of funding for AHR. For instance, another informant argued that people experiencing infertility are discriminated against. For example, the Government fully funds maternity services, spending in “excess of three hundred million per annum on delivering babies in our public system... in excess of twenty million on terminations” but only 9.7 million on fertility treatments. (13)

AHR as a Treaty Right

One informant said that we shouldn’t be looking at Māori needs with regards to AHR. Instead we should be talking in terms of our Treaty of Waitangi right to AHR. A focus on needs bypasses and risks ignoring the more fundamental rights enshrined in the Treaty.

As she explained, a Māori ‘need’ for AHR arises from a breach of those rights. That is, the Crown has failed to provide the protection assured in the Treaty and breaches of the Treaty have undermined Māori women’s capacity to protect their fertility. For instance, breaches of the Treaty have led to “the imposition of all the things that give us the risk factors: the chlamydia... the low socio-economic, educational failure, low self-esteem, being caught, being labeled... having so many relationships... and long abuse, intergenerational abuse... and that leads to the needs.” The ‘needs’ have come about “through an abuse of our rights as an indigenous [people], as tāngata whenua.” (14)

AHR therefore should be considered using a Treaty framework. As for individuals, she said it was up to each individual to “decide what aspects of the new technologies you’re taking on as your Treaty right.” (14)

The Right to Medical Treatment

The other rights-based argument that came through the informants’ kōrero was the right to medical treatment. If infertility is considered a medical condition, then people who experience infertility could rightly expect to be able to access medical treatment for it.

Following on from the above kōrero about rights enshrined in the Treaty, those rights also promised that Māori would have the right to access all treatments available, “even treatments some people in our culture would say are not culturally sound.” What this informant was pointing out was that quite apart from what a Māori collective view might be about AHR, as individuals Māori have the right to access any new treatment they want. They have the right, as individuals, to participate in research also. But viewing Māori solely as individuals risks overlooking or ignoring the effects of belonging to the collective; for example, institutional racism. Thus she added that:

We also have a right to a health system without prejudice. (14)

Whilst some informants said that the ability to have children is a right, others disagreed, saying “it’s not our right to have children, it’s a gift.” (11)

3.5.3 Nature’s Way or No Way

Informants talked about beliefs that led people, if not themselves, to be against AHR or resistant to the idea of AHR. Alluded to above there is the preference for children to be conceived ‘naturally.’ For instance one informant said, “I’ve never believed in assistance.” (3) Another informant pointed out that some religions, such as Catholicism, have big issues with AHR. (9)

There are people who will be against “all these things that are outside the natural, our understanding of the natural world.” (9) They may question the point of even discussing or considering AHR. But, as this informant said, this viewpoint raises the question, “What’s natural?” What’s natural, he said, is that conception is “like the lotto isn’t it? It’ll work sometimes...” (9) One perception is that AHR removes that uncertainty. Particularly, procedures like Intra Cytoplasmic Sperm Injection (ICSI) are seen to remove the uncertainty of conception. (9)

One informant explained that some of the hesitancy or resistance among Māori towards AHR and particularly the new technologies involved, is due to the effects of colonisation. That is, the poorly implemented colonisation process disconnected Māori from traditional values, structures and practices leaving contemporary Māori struggling to “engage with our traditional past” whilst being confronted in rapid succession with new technology. Thus, Māori appear to be struggling with new technology. What this informant believed was that if Māori had retained more of the traditional values, structures and processes they would have been better placed to consider the implications and participate in the adoption of new technology. (5) As another informant explained, historically it can be seen that in time Māori developed tikanga appropriate to new technologies, whether it was the white potato or a nail. As yet there has not been sufficient discussion among Māori on AHR to allow for this to occur. (9) Further, development and introduction of new technology is occurring “faster than anyone can make decisions on them.” (7)

Compounding the problem is the fact that new technologies are introduced “way ahead of people’s actual awareness that the technologies exist.” (10) This other informant explained that for Māori, the experience of surprise or bewilderment is “even more acute” because Māori “are behind the eight ball” in that they are less

likely to have accessed and used the existing technologies or procedures that have been around for a while and are therefore less likely to know about them. (10) As one informant said, when he heard about the range of procedures now available:

I just didn't know that this is how far the science has gone. (9)

As the presentation of information on AHR progressed, some participants expressed increasing levels of discomfort and concern. For example, one person said “this whole thing for me is becoming increasingly problematic.” She said it was like “playing God.” For instance, she was uncomfortable with the idea that sperm could be cleaned and with the “whole vision of cleansing everything.” (T) Another participant said being able to pick which gametes are used was contrary to her understanding of tikanga. As she said:

It's getting to the stage where you can go and pick it out of a dish and say this is the criteria. 'I will have that sperm. Thank you.' And to me, that negates the divine spark between a man and woman, that links our whakapapa back to the beginnings of time. (K)

She believed that some aspects of AHR will have serious impacts “on our tikanga and the things that our tūpuna taught us.” She said it was important to implement a step in the process that provided the opportunity for prospective parents to talk through the implications with “somebody who has experience in that area. Because there are all sorts of things within tikanga Māori that infertility treatment cuts right across and I liken that to taking rongoa Māori without doing the karakia.” For these reasons, AHR was not an option, as she explained.

I have been myself to an infertility clinic... I made a choice for myself, in the end, not to go down that road... I felt it was a conflict in my belief of what I understand the tikanga I've been taught. (K)

Another participant was opposed to AHR for similar reasons. She said that if her only daughter ever wanted to use AHR she would disallow it.

I will say no, you're not to do that. Because there is only one person that will allow you to give the baby. If you are blessed with a baby, he will give you it... If you're not to have a baby well there is a reason why the Lord is not giving you one.

“It's also te tapu” she said. “Engari, ka hoki atu ki o tātou atua kia rongō ki a papātuanuku ki ā ranginui, well then, tino tapu tēnā, i ngā taonga kua homai te atua kia mātou.” (K)

One of the kaumātua said that “when I talk about tapu, I am only talking about the matenga. Te matenga o te tangata. Ko ēnā te mea tapu o ngā tapu katoa. Te matenga o te tangata. Ahakoa he tapu anō te whare tangata, he tapu anō tō te tāne me te wahine engari he tino tapu o ngā tapu.” [The head of the person. That is the most sacred of all the tapu. Even though the womb is sacred (women), and the act of conceiving a child is tapu and men and women have their own tapu. But the most sacred of all is the head.] (K)

A rangatahi participant thought that “tūturu Māori” and Māori who “see birth as a real in-depth, serious thing” would be more likely to reject “artificial” unnatural AHR processes and technologies. The rangatahi hui also suggested that there would be some Māori who will think, “I don’t want some Pākehā thing to help me to have kids. So then they’ll divert to the whāngai thing.”

Some Māori are like, oh no, I don’t want to do that because it might have diseases on it. Totally nuh. It’s not natural. That’s it mate. Artificial. (R)

3.5.4 Concern for the Integrity of Whakapapa

The attitude that AHR is ‘unnatural’ has to do with the integrity of whakapapa also. (10) One informant believed that some people will see the use of technologies and medical intervention to assist human reproduction as “manipulating” the natural course of whakapapa. (4)

Whakapapa’s important to us because it’s our identity... (3)

No Hea Koe?

Most informants expressed support for absolute transparency and openness about genetic origins, that is, the whakapapa of the child. The following section outlines why informants believed every Māori needed to be able to answer the question “Ko wai koe?” Informants said that not only must people know which iwi they belong to, they should know who their genetic parents were and even the means by which they were conceived if, for instance, they were conceived using AHR. Further, this information should be available to the parents of the child and to the child from birth.

On this matter, some informants spoke about the need to acknowledge the feelings and desires of the parents. For instance, one informant knew that in the past some women might not have wanted people to know, or the child to know, that they had had difficulties having a child. She said it was “only in latter years where a lot of our people have allowed adopted children to find out or find their biological parents.” (3)

Most of the informants however, believed priority needed to be given to the child’s need to know their whakapapa. Or rather, as several informants said, their right to know their whakapapa. (6, 14)

A break in whakapapa is generally not seen as good (9), or worse is if whakapapa is lost. (8) “There’s implications there in terms of identity.” As an informant explained, “traditional thinking has it that the nature of the person is in the mauri and that mauri comes down through the two parents.” If the identity of a parent was unknown, then questions are raised about “whose tapu? Whose mana? Whose mauri? Whose wairua? Whose hau? All those ingredients make up that tinana. That’s the Māori notion of life – all those things together.” (9) Being able to recount your whakapapa is a significant tikanga. (9)

Our whakapapa’s always based on you know your father, you know your mother or you know your grandmother or you know your grandfather. (9)

One informant recommended Hirini Moko Mead's tikanga test (see Section 1.3) because it provides a way for whānau who are concerned to sort through and discuss the affects on the mauri of the child, whakapapa, everyone's rights to know what's happening? (10)

The process of applying for ethics approval for the use of some procedures arose from the parent/s' desires and as one informant said they sometimes had to ask themselves "am I looking at the safety of this child for the future?" (11) One informant wondered what the issues would be for children born via AHR. She believed that these would be different from the issues that their parents had to deal with. She wanted the potential implications for the children to be considered over and above the parent/s' desire to have a child. For example, she wanted thought to be given to how the child would feel about what's happened, that is, where they've come from. (2) "Openness and honesty between parents and children" was important, she believed, to avoid consequences such as an "identity crisis, feelings of rejection, feeling that people who have loved you haven't told you the true story and then you also get issues then of people feeling rejected by their birth mothers." (2)

I'm thinking back to people who I know who were whāngai but didn't know that until later and then seeing the consequences of needing to deal with that at a later stage... just feeling like questioning the whole history of your life as you knew it. (2)

A further consideration is that AHR provides the possibility for the child to be genetically from a different ethnic group to their parents. (7)

Openness was supported not only because of the child's, as mentioned above, or the parents' rights, but as one informant said, "there is also a collective right." (10) This informant also said that "we've got a traditional basis of having been very open around knowledge and information relating to where children are raised" and she couldn't see any reason why that shouldn't continue. (10)

Another reason for maintaining transparency around whakapapa is the relatively small size of the Māori population. One informant recalled how an uncle of hers was able to see a whānau resemblance in a woman he didn't know. When he asked her how she was related to him, she revealed she was an illegitimate child of one of his whānau. As she said, "sometimes you just end up with family traits, family faces, family looks that you can't deny and so if you're moving in Māori circles with people who know people from around the place situations like that will arise." (2)

Thus, some informants were relieved that the law now requires donors to at least register their identity with the Registrar of Births, Deaths and Marriages and it disallows anonymity of donors.

Some participants believed that children should know "right from the start" if they were conceived with AHR and that it should have to be part of the criteria for using AHR that parents were willing to tell their child the truth.

Once children get to school and they hear things at home from mum or dad about another couple, then they go to school and go, ooh he wasn't conceived from his

father. And children can be so nasty. And that could have repercussions on that child. (K)

As another participant explained, “you have a responsibility ki te mau ki te whakapapa o te ra mokopuna.” If parents are honest and open with the child from their beginning, the child will carry the knowledge, or will carry both their whakapapa, without reservations.

If you make them feel safe and comfortable, right from birth, they’ll carry both, no sweat. It’s us that has the hang-up, not them. (K)

Whāngai or some AHR children have what one informant called a dual whakapapa, both from the parents who raise them and their blood whakapapa acknowledging any other people involved. This effectively, she said, provides the child with a dual citizenship. (2) The child would know their whakapapa but as one informant said it wouldn’t be “a lived one.”

Some problems that whāngai children have experienced could potentially arise for some children conceived via AHR. For instance, some iwi refuse to recognize whāngai who, though raised within the iwi area by members of the iwi, biologically whakapapa to a different iwi or even to non-Māori. One informant thought this was “quite harsh.”

It’s harsh in the sense of... you may be living in an iwi area and have whāngai’d a child from another iwi area and that child can never, even though they may have been raised all their lives, learnt the dialect of the area, all of their knowledge and information has come from that iwi, we’re actually excluding them from being full participants, in the iwi. (10)

How iwi determine who is a valid member is an important issue coming up for Māori because of Treaty settlements. One informant thought that most iwi are blocking the idea that any descendant of an iwi can be non-blood. (10) Thus, for example, if a child is not related to their parents genetically they may have no claim to their parents’ iwi. (7) How whakapapa relates to genetic information is one topic needing further exploration. (10)

Another participant had a niece who was given to an aunty and uncle, making her both the participants’ first cousin and niece. She was thus recorded twice in their whakapapa. (H)

To be recognized by one’s iwi some participants said people needed to know more than which iwi their donor came from, “the iwi, will only respond if you know the line.” You have to know “which whānau.” (T)

A rangatahi participant balked at the idea of using unknown donor gametes, saying “I just think it’s weird.”

The rangatahi wondered if the biological donor would have to accept the child was their offspring if the child wanted to access iwi grants. They worried that children born this way “could run into difficulties when it comes to getting education grants...”

Because in our corporate office... all the beneficiaries have to know their whakapapa back to a certain person... if they said 'I was born from an anonymous donor. I know my iwi, but I don't know the whānau or the hapū.' I know for a fact they'll go, no... We don't accept whāngai." (R)

3.5.5 When Does Life Begin?

One informant suggested that talking about AHR raises questions about "contemporary Māori views on life itself" and how life comes into being. This informant said he was "not aware of that discussion taking place within Māori society" or "of any kind of cultural practice that informs us on this discussion." (9)

A number of informants foresaw that arguments about "when is a person a person?" could arise when thinking about the different AHR procedures. (2) For instance, following on from the kōrero above, even a stored embryo has its mauri, tapu, mana and genealogy "and it's waiting for the time when it will be called up to become a living thing." (9) This wasn't seen as problematic by this informant, however, as he said "it fits the cultural story. An embryo... is a potential being that has to be expressed somewhere along the lines." He was quite clear that:

Sperm in itself is not life. An egg is not a life. The embryo is a life. (9)

Another informant referred to stored embryos as "little potential human beings." (6)

Some informants had experience of debates about abortion. One of them didn't think anyone is ambivalent about life's start. "It's at conception," he said, then added, "Or, at the confirmation the conception has occurred I guess." (8) Another informant concluded that once you knew you were expecting a child, then it is being considered as a person. (2) Conversely, another informant thought that "even an egg is a beginning of a human form" or as another informant said sperm and eggs "have the potentiality of life within them." She thought this area of discussion raised some tough questions and that it came down to the "value" that we give to that potentiality. (10) One informant didn't think we could afford to give an 8 cell being "the same respect and treatment as if it was a person." (2)

Some informants were not as definitive about when life starts. As one of them said, it "depends on whether you believe the sperm or the egg is the whakapapa, or the embryo?" (7)

One informant challenged this whole line of thinking. For her, a person is a person "when you say it is." For example, if people wanted to, she said, they could say a person is a person "when it's got a name." (14) She questioned the rationale behind even asking when life begins. "What do we want to know that for?" she asked, when as she said Māori, like many pre-developed cultures, practiced infanticide. The problem with this line of questioning, she said, is that it about one group trying to control another group. For instance, the belief that life starts at conception is used against people who support abortion. (14) The real issue is that "there's always a level of social rights and responsibilities and children of whatever age might have less of them than adults."

3.6 Access to AHR

One theme inherent in discussions of Treaty rights – which also arises from comparisons of services available for people experiencing infertility versus, for example, those provided to people getting pregnant without assistance – is the question of equitable access. Do all people who might want to access AHR have the same opportunity to do so?

Certainly, some of the informants believed that people who want to have access to AHR should find the services to be “freely available.” (6) All the informants thought it was important that Māori should have equitable access to AHR. But several informants believed there is or would be a disparity between Māori and non-Māori non-Pacific people’s access to and use of AHR; that is, they suspected that Māori aren’t accessing AHR services. (7, 10) These are outlined in the following section.

The takatāpui, men’s and rangatahi hui all agreed “it’s important for Māori to have access to” AHR.

Many participants said they would support people who want to do this. (T) As one of the kaumātua hui participants said she understood “the emotional need that a lot of people have to have a baby and how infertility treatment would help them.” (K)

Whilst some of the kaumātua hui participants were against AHR, others agreed that we “need to know our tikanga” but argued that “we should as Māori have a choice.”

If our children want to go and have these things done because they can’t have babies, I think, it’s their choice. (K)

Another participant who had many children herself, said she had not had to “worry about anything like this.” But, she still said “we’ve got to support our children in their new life and the new way people are living today.” Thus, she said “our tikanga has to change with the times.” (K)

A takatāpui and a rangatahi participant both saw AHR as useful for ensuring the survival of Māori.

If a technology is available and its going to help Māori continue to maintain a reasonable level of identity for itself, and fulfill all those things round keeping the communities together, making robust whakapapa, I don’t think its any different than it was sort of a hundred years ago... the concept is the same, the process for achieving it is slightly different. (T)

Especially if the Māori fertility rate dropped dramatically the rangatahi participants believed Māori would “turn to” AHR. (R)

One of the consumers’ hui participants also said, “When it comes to fertility you have got to look for help from situations not within the Māori world. We have got to take advantage of technological stuff in the world.” (C)

I think these kinds of fertility opportunities are probably one of the important things that we need to discover. (T)

One of the men's hui participants had recently been thinking about AHR because he and his partner were thinking of having children. He and a rangatahi participant were pleased to learn about AHR. As the rangatahi participant said:

It's good to know that it's there. (R)

Informants identified a wide range of possible barriers to Māori access of AHR services many of which mirror barriers to access typical of many healthcare services, such as, cost. The full range of barriers identified is outlined below.

3.6.1 Fertility a Low Priority for Māori

Informants were asked if they thought fertility was an important issue for Māori and if so, how did it rate against all the other issues Māori are grappling with?

Several (1,3,4,5,6,9,14) informants did not think that fertility was a significant health issue for Māori. They said it was either not “on the radar screen” (4) or only “right on the edge of the radar screen” (6). One informant, included for his extensive experience in Māoridom and mātauranga Māori, said infertility had “never come up in the Māori circles that I've mixed in.” (9)

An informant with recent experience in the health sector said it was not viewed as a high priority for the Government.

Sexual and reproductive health is starting to get there but if you had to list them it wouldn't be in the top ten. (2)

One informant suggested that AHR was not prioritised partly because only small numbers of people are affected by infertility and the perception that AHR success rates are low. (11) Further, against other issues infertility just could not compete. As one informant explained, if infertility was made a priority then it would be necessary to make funding for it available. “But, then the money wouldn't be there for something else.” (6) Support for “competing issues that people say are far more important” such as, diabetes would make it difficult “to attract sufficient interest in infertility to succeed at having an impact.” (6)

It may sound harsh, but I don't think it's as significant an issue to warrant, you know to take priority over some of our other Māori health needs. (5)

One informant believed fertility was only on the health agenda because Pākehā wanted it on the agenda. It wasn't on the agenda for Māori communally. It was an issue for individual Māori couples however. (14)

A few informants said it was important to them and that fertility should be a priority “because it's our whakapapa and identity.”

For me it's number one -- that we have the ability to have children. (3)

Ki ahau, i te mea nui tēnā. (1) [To me it is the greatest thing.]

One of the kaumātua hui participants thought that fertility was a priority issue for Māori.

It is a first thing for Māori. (K)

But, as one of the consumers' hui participants said, "I don't think it's been identified as a problem" for Māori. (C)

The takatāpui hui debated whether infertility was a health issue. They said "it's a whānau issue" and "a social issue" and a health issue. Because the relatively poorer health status of Māori contributed towards infertility and undermined the success of AHR, one participant said therefore, fertility was a health issue for Māori. (T)

The health workers' hui thought that fertility was particularly a woman's health issue, but at the moment fertility was "not on the agenda." They identified a number of barriers to getting fertility recognized as a health issue for Māori. Firstly, Māori have so many health issues to deal with.

Māori actually get sick of being at the top of the heap, high statistics in everything.

They said that even if we ever got funding to run a training hui for tamariki ora kaimahi, turn out would be poor because there's so many other issues and "this is not an issue that people have been thinking about." Further, "managers would be thinking where does this fit." (H)

They thought that whānau who have been affected by infertility and are interested would be more likely to attend hui on this topic. But then, as the hui had learned from its own participants, one difficulty with getting attention for the issue was that some people don't know they are infertile and others might think they are sterile and have given up any thought of having children.

Trying to raise awareness for infertility would also be seen to be contradictory to the focus that has been placed on "telling us not to have babies."

Lastly, Māori health priorities are largely driven by Government dictates to reduce disparities. "This is one area where we do not have that disparity." Therefore, fertility is not an issue. But, as one participant asked, "what are we doing about preventing the future disparity?" (H)

3.6.2 Māori Don't Have a Problem with Fertility Anyway – Do They?

A few informants proposed that there is a view or myth that Māori are prolific breeders and this perception was one of the reasons why Māori input into AHR policy development has been less than it could be. (4) The stereotype is that "we don't have a problem" – that Māori are "very fertile." (2)

This perception was a lived one for some people. For example, one informant said her only experience of infertility had been "in a positive way i.e. having unprotected sex and not getting pregnant. You think, oh thank goodness for that." (2)

Further, one informant thought the statistics showed Māori to be twice as fertile as, or at least more fertile than, Pākehā women. And if that is changing, if the gap is closing, she hadn't "seen much discussion around whether we used to have four and now we're only having two." (2)

The view of Māori as hyper-fertile is encouraged and subsequently a focus on Māori fertility is discouraged by the emphasis that is placed on problematising of issues, such as teenage pregnancies. As one informant explained, the statistics showing young Māori women to have fertility rates "far higher than any other young women in terms of like pregnancies under the age of 20" (2) had been problematised. So everyone gets to hear "tut tut sigh sigh so you need contraception... oh teenage pregnancy rates so high." This informant said this negative talk about Māori echoed the old "colonial discourse of the promiscuous native... the promiscuous savage – can't help themselves, bonk all day, all night..." (14).

Further, the focus is on making young Māori women wrong. For instance, the statistics might be reported as '500 teenage girls got pregnant last year.' As this same informant pointed out, what's not said is that up to "500 men were involved in that pregnancy" but, the discourse is "those bloody bloody teenage girls are out of control... Men are not mentioned. Men are privileged by being not named." (14) Nothing is said about the men who are sexually abusing teenage girls.

Another informant believed that among Māori it was "more acceptable that once you've got pregnant that you will have the pepi." (2) Thus, young Māori women were less likely to terminate an unplanned pregnancy which helped to bump up the statistics. Further, she didn't think it was necessarily bad that Māori women have children young. They could, after all be 19, married and have planned to have the baby. What is bad, she said, was that having a baby young was "an indicator that you will have other bad outcomes as well or, increased chances of bad outcomes." (2)

Many hui participants had not experienced any trouble getting pregnant themselves and thus many had never thought about infertility.

We had children like drinking cold water. (K)

My niece was just saying she just had to look at her husband and she got pregnant. (K)

One participant had only heard about infertility in a documentary about a Māori woman... "I'd never thought about it before or after it. ...I never thought about it after that. I thought about it but not open thoughts." (C)

The overall perception among hui participants was that Māori had a high fertility rate. As one of the consumer hui participants said, people think that "we breed like rabbits. That's all you ever hear about... you never hear" about infertility. (C)

The men said that they thought "we were doing well." Because in their community, they knew people who had "heaps" of kids. So it was more than just what they heard it was what they saw on a day to day basis as well. Plus, infertility was not spoken

about, “because we’re always into breeding anyway. The more Māori the better. And the younger you are, the better.” (M)

The health workers’ hui acknowledged that infertility “could be more of an issue than we realise” because there were whānau and places that had higher rates of fertility. For instance, they thought that fertility rates differed by socio-economic group, and beneficiaries tended to have more babies. (H)

From the media, the men had gathered “that we’re one of the highest growing populations.” They believed that Māori having big families was framed as problematic.

I don’t think you hear anything about infertility, there’s always complaints about having too many babies. (M)

The rangatahi also got the impression “that we have good fertility.”

Because so many Māori are having babies. Teenagers. Yeah, hearing teenagers are having babies at like the age of 15 and stuff.

As one rangatahi said they were always hearing about “the down-point of it” that is the negatives. For instance they said that the media focus’ on Māori in the lower socio-economic category and young teenage mums “popping babies out” and questions why they are bringing children into the world and “what kind of life are you going to be able to give it?” (R)

A consumers’ hui participant also said “it sounds as if we” have “the highest rate in the world or something for teenage pregnancies.” She recalled hearing that “they only get pregnant because they get money from the DPB to live on instead of a job.” (C)

This perception of all these young girls having babies led one participant to assume that there were similarly high rates of abortion among Māori girls. (C)

One health workers’ hui participant said she had in the past tried to challenge health ministers and the Ministry of Health about the way they were labeling the births to young teenage girls as “unplanned” and “unwanted” and how they were implying that this automatically meant “they were bad girls.” She tried to advocate for an approach that looked instead at what support could be put in place for these young women and their families, such as, family support or income support or additional health services. (H)

The rangatahi talked about the impact on them of this negative stereotyping.

It’s quite annoying. Like me being a teenage mum, I’d love to know the figures on teenage mums that have been successful. Like I mean I’ve got a good job and I’m still with my family and my partner and got a car and living at home and stuff. But that’s to help me further myself in the future, start saving for a house and things like that. You only hear about the ones who are living in scummy places... coming from a Māori family, I had so much awahi from my whānau and so much support, which is why I think I’ve got where I am today. (R)

One of the other young women said, “it kind of makes you feel, oh maybe I shouldn’t have babies.” (R)

The men’s hui said that “most of us around here had them early. Yeah, very early.” (M)

3.6.3 Lack of Awareness of Infertility

Key informants were of the general opinion that awareness of infertility among Māori was low. One reason for this was that people, particularly young Māori, wouldn’t know what infertility meant. (6,9) Several informants said that even they had not really thought much about infertility. (2) Even an informant who had personally helped a lesbian couple have a child said he had not thought about infertility. (6) Another informant said she didn’t think about it until late in her childbearing years. (11) The perception was that Māori generally would be the same. Some would have thought about infertility and some wouldn’t. (5)

Informants thought that infertility was “one of those things that’s quite sort of hidden” (2) and not talked about. As another informant said, people “might say that they want children” but it’s not generally talked about in normal conversations, unless “you actually know them or, and you can bring it up or you can raise it or ask them if they’re gonna have children.” She thought “it’s a bit rude” to ask these questions if you don’t know them very well. (11) Another informant thought that infertility was probably known about within whānau. (10)

The informants believed there was “minimal information out there” about infertility and thus “most people don’t think of this as an issue for them.” (6) Compounding lack of information as a “major barrier” to access is “lack of information about when you should ask for help.” (7)

It was often said throughout the hui at different times that infertility is not talked about, that “it’s not something that pops up in the conversation.” One consumers’ hui participant said she’d “never heard it being brought up in conversation or around friends.” She thought people probably don’t think about it unless it happens to them.

I think it’s lack of knowledge, or it could even be ignorance.(C)

It’s not spoken about. No one knows. (C)

The men’s hui also said it’s not a topic that comes up.

Especially around here because there’s always a lot of kids around... So even if you don’t have any of your own, the subject never comes up. Yeah it never comes up ‘cause there’s other tamariki there for you. (M)

What they heard about infertility was that it was “like people going and getting eggs implanted in them. That’s about it.” (M)

Nobody wants to talk about it. (M)

But when the men tried to think of people who hadn't had children, they could think of two ("two out of, what, thirty years"). (M)

The health workers' hui said that a lot of young mums don't know what ovulation is, let alone when they're ovulating?

They just think it could happen any time within that month. (H)

They don't know where a cervical smear is taken from and the participants said, they don't know that the baby comes down through the cervix. Which led the hui to wonder: "What are they teaching them at school?" (H)

People didn't know that fertility drops off with age. One of the men asked "when does it kick in exactly for women, that their fertility rate actually drops?" He also wanted to know how much it drops, because his partner was approaching 35 and they still wanted to have children. (M) The rangatahi hui, also were surprised to learn that eggs age.

I thought your eggs just stayed as they are. I thought you'd get more eggs. (R)

What is the right way to have a baby, because half the time we weren't thinking about having a baby we were just thinking about sex? (H)

Throughout the hui, participants recounted tips they'd heard for improving the chances of conceiving a child. Some of the information indicates that lack of accurate knowledge about human reproduction could be a forerunner to lack of knowledge about infertility. For instance, to improve the chance of conception occurring, participants said they had been told or they had heard that:

It's best to hold off so you get a big build up of sperm. (H)

You should just relax.... and get married. (K)

Turn around and put your legs up on the on the wall and... don't go to the toilet, don't go get out of bed, try and stay there for as long as you can ...don't go on top because that's a sure way of not getting pregnant... my partner was told, don't let her come because if she comes then it's going to quickly push away the sperm... I used to sit there thinking 'oh... this is all about you.' ...He must have been talking to someone because when he came home he said, '...it's your fault because you like to come... I asked doctors, 'well what happens if the woman wants to come as well' and of course the doctor looked at me and she just said to me... that's nothing to do with it. (H)

Another participant said she had been told the opposite, that she should orgasm.

I was told no you've got to, so there was pressure on me because when you do, it encourages the sperm to get sucked in.

Both women said that when you're trying to get pregnant you try to do everything right. So, when nothing happens "you come away thinking oh I didn't come and that's why I'm not pregnant." (H)

Another participant sought advice from “professionals.” She said a male doctor said “well maybe you’re not doing it right, maybe just change positions and maybe after sex what you could try is” to “lift your hips up and put a pillow underneath so the sperm can run down.” She said:

It just got too much in the end. I mean just just visualising it was enough to think oh for goodness sake I’m tired and then I’ve got to raise the legs.(H)

A few hui participants had heard of or knew of people who only were able to have their own children some time after adopting a child or taking on a whāngai baby. (K)

The hui revealed that some people don’t know they don’t have good fertility. As one woman said she thought she was okay. And another who had been trying to have another baby for 15 years, as a result of the hui said “for the first time I actually class myself as being infertile.” This raises the question, how many other Māori think they’re fertile when they’re not, or think they’re sterile and beyond help? (H)

Some participants thought that Māori are not even talking to their GP’s about it. (H) One of the health workers’ hui participants who worked for a Māori health provider, said they had “never touched on anything to do with infertility.” (H)

At my own GP’s there’s no pamphlets, there is nothing on the wall about infertility. (C)

Another participant said they had never seen any pamphlets about infertility and she said that “it’s actually quite overwhelming... seeing exactly what’s out there for us, because it’s not an every day thing... you don’t see it in the media.” (H)

People also didn’t necessarily know when to seek help. One of the consumers’ hui participants thought that the message used to be that if you haven’t had a baby by the time you’re 35 then go to a fertility clinic. Now, she thought it was “if you haven’t had one by 27 then go to the fertility clinics.” But because people often try everything else before they decide to try IVF, many years could go by with fertility dropping off. (C)

3.6.4 Lack of Knowledge about Fertility Services

Even if people think they might be infertile, or know that they are, informants believed that there is a lack of information about what services are available (7) and “what it’s all about.” (6) Lack of information about fertility services was believed to be a barrier to access. (13)

One participant said she didn’t know where to go to get help for infertility. She thought, probably Family Planning could refer people to an infertility service, although she suspected “you probably have to ask for it and and say you want to go.” Others at the health workers’ hui thought that “most people out there” would think of going to Family Planning, if they were wanting to have a baby or were having trouble having a baby. But, then it was said that Family Planning is somewhere women go “when they think they’re pregnant; not when they’re thinking, when do I want to have

my baby.” Family Planning was also the place to go for STIs, cervical smears and advice on contraception. It was not providing any information on infertility, although participants thought that it should incorporate that. A participant added that Family Planning was not providing anything for Māori and others agreed that it was “very mainstream.” (H)

Because the information about infertility and AHR was such “foreign stuff” in that it was “not everyday information that is out there” participants believed it would be hard for people to access and understand. Especially if they “already have issues around the fact that you haven’t conceived for x amount of years and you’re a little bit scared to get into maybe the real nitty gritty of why you haven’t conceived.” (H)

Participants thought people would need to have a “certain degree of understanding to even be bothered with the bureaucracy stuff.” That is, they would need “some degree of self-understanding” and probably be of middle to high socio-economic status to understand the language, bureaucratic procedures and to know how to find out what’s free and what you have to pay for. (T) The men and rangatahi hui participants particularly wanted a lot of the terms and procedures explained, such as, egg donor, sperm donors, hysterosalpingogram, gamete donation and embryo. The rangatahi did not know that embryos could be frozen. (R)

One participant wanted to know what the process was if people wanted to be egg donors. She had not heard about egg donation before and she had never seen advertisements in magazines for donors. But, as she said, “I don’t know what I’m looking for.” (C)

The men thought that it would be easier for younger generations to access AHR because they are “getting brought up along with other nationalities and stuff, so they’re getting opened up to a lot more technology.” Whereas, older women probably wouldn’t even know this technology was available. (M)

At the end of the hui the men wanted to know where they could tell people to go for information. (M)

The woman who was still going through AHR was disappointed that she had not been referred to a fertility service earlier. She had an operation in 2001, after which the gynaecologist said she would probably need to be referred to a fertility clinic. But, she was not actually referred for another 18 months, despite 2 monthly check ups. It wasn’t until after a second operation in 2002 that she got the referral. As she said:

I wouldn’t have known where to look to find fertility help. (C)

“Apart from the odd magazine story” that she had seen, she had only heard of one fertility clinic and she didn’t know if there was public funding or not. The other woman who had used AHR said she just assumed there was no public funding.

Participants asked a lot of questions about AHR and how the fertility clinics work. One participant wanted to know if you get to call the shots if you go to a private fertility clinic or did they have rules and regulations that dictated what they would do?

Participants wondered if being able to pay for AHR meant you could “go to the top of the list” or have “a better chance” of getting pregnant.

Participants who had used AHR seemed to be heavily dependent upon the advice of the fertility specialists as to what would happen. For example, one woman who had used AHR said that she went in at 40 and had to have a laparoscopy. She was sure there was nothing wrong with her and she wondered what would have happened if she’d said that she didn’t want to have the laparoscopy.

That could’ve been the end of it for me. If I really didn’t want to go ahead with an operation. (C)

Then there is the policy about trying for a year to determine infertility. So this participant found her own donor and tried to get pregnant using the least invasive procedure, which was AI. It wasn’t until after a year of that that she asked to do IVF. She now believed that the specialist should have intervened earlier because of her age and recommended going straight to IVF. That’s what she said she would now tell people if they’re old.

If they’re over 35 then my advice to others would be don’t muck around, go straight for IVF. Even go for ICSI. I feel that they’re the experts and they should have known that and they should have advised that in the first place. Me walking in there at 40, they should have said, well at your age, we recommend that you go straight to IVF. Instead of leaving it for a year. (C)

3.6.5 Inability to Articulate Need Directly

One of the first ports of call for a person or couple concerned about their not being able to have children is probably a GP. Though some informants thought that Māori probably don’t raise it with their doctors, others thought that plenty of Māori do raise it with their doctors. (8) Even so, the barriers to access, lack of knowledge about infertility and fertility services, would be compounded by some people’s inability to articulate clearly or directly what they need.

Informants referred to this as “what the person brings with them, in terms of how they address those issues.” (12) One clinician described her experience of Māori women not being able to talk about it, as follows.

A Pākehā woman will come and say, ‘I wanna have babies. I can’t have them, help me.’ Whereas with Māori, you have to go round and talk about lots of other things, to come to that realisation that there is a problem. (7)

Another informant wondered if people who were pushier and more able to communicate their needs and desires strongly to a specialist, might find their access to AHR occurred easier, faster and therefore earlier. (2)

Whakamā

Most of the informants identified a range of feelings, grouped here under whakamā, as a major barrier to clearly and directly articulating infertility as a problem someone wants help with. For instance, people experiencing infertility could be feeling “upset about it.” (7) They could be feeling shame - that being infertile is shameful and bad. (7)

I suspect that they feel more hōhā about it and a bit more embarrassed. (8)

And, because it’s about sperm and eggs, it’s brought closer to sex and “there’s a stigma associated with that.” (13) “It’s very intimate and personal.” (13) Two informants said these are barriers that come up regardless of culture. (13,12)

Speaking about matters that are inherently sexual or to do with sexuality and things is difficult. (12)

The whole process, right from the beginning of having to assess for infertility onwards is “quite frightening for people.” (11)

As one informant explained, the whakamā starts when they recognise that they’re not able to get pregnant and they start thinking about having to talk to someone about it. They know that it’s going to lead to having an examination “down below the waist.” She thought this would be a major barrier for some women and as a result they would never get to use AHR. (7) Four informants drew a parallel with whakamā as a barrier to Māori women having cervical smears. As this informant said, “our women feel kinda shy... even when we have our periods.” (3) Another informant also believed that lots of women don’t like having cervical smears “because they don’t like having to take their trousers off, and put their legs up and have people feeling around inside them.”

We’ve got great respect for Te Whare Tangata. I’m not saying that other women do not have the same type of respect, but we’ve got great respect. (3)

At each step in the process of seeking help for infertility, Māori women or couples could drop out. For instance, one informant said there is a big difference between “going to see somebody for a talk about something and then joining a programme for fertility.” (8) Thus, even if a woman or couple was to get to the point of being referred to a fertility service, another informant believed that only some people would actually take up the referral. (12)

Many of the health worker participants drew parallels between the whakamā that women might experience having to go for cervical smears. “We have women who are whakamā,” they said. Whakamā was experienced because women were scared.

The kaimahi said to help overcome whakamā the women needed to be told what’s going to happen, and why, in a way that ensures that they’re comprehending. With cervical screening, the kaimahi had to initially “walk alongside these women” going with them to their smear appointments and supporting them through “pre-ops” or they wouldn’t go to the appointments.

They, for whatever reasons, don't like going into hospital. They don't like having to open themselves up... a lot of the doctors that do these procedures are male.

Once “they understand what’s actually happening, so that education actually is really important, and just understanding the whole screening pathway” the women would take over booking or rescheduling their own appointments and getting themselves there. (H)

Another participant reflected back on times when she had felt whakamā because “different culture things” happened and “you shrivel” she said. “I just wanted to die... I just cried. I was so embarrassed.” And little things, could have been done to avoid this, for instance one GP she had “always when he had to do things, would give you a sheet, just giving you a sheet, to cover you.” She agreed that it would be good to have services “where you don’t have to explain ourselves. Where people know that you’re whakamā in places like that and they come and do things.” (C)

The women who had used fertility services talked about the things that had caused or increased their whakamā. For instance, one woman found it hard having so many people present for some procedures, what she referred to as “the whole rugby team thing, having different people every time. The lack of awareness of that kind of modesty, of whakamā. They don’t seem to acknowledge it. And yet I know that it’s not an issue just for Māori women.”

She wondered how it would be for Māori women who were “tūturu Māori” and who wanted to observe certain tikanga and say karakia. She thought that “unless you were a staunch, radical Māori and really strong in yourself about asserting your tikanga, there is not a place in clinics for that. I think they could make it more comfortable... they could allow it to happen.”

The other woman who had used fertility services believed that the clinics would allow clients to take whānau or an advocate or even a Māori health worker in with them because they currently offered that either your partner or someone else could accompany you. She believed that they would be okay about tikanga and karakia because they understood about people wanting to use “other medicines or relaxing things.” For instance, she had used an acupuncturist.

I have had an acupuncturist go in before one of my consults... and they offer you a room to go in.

So, if people wanted to have a karakia before and after, she said they should do it. The hui discussed how hospitals are becoming more aware of tikanga needs as “more Māori are getting into those roles.” (C)

Another sort of whakamā was talked about in the men’s hui. They wondered if Māori would be “shy... If they’re infertile they don’t want to be identified as the one that can’t breed. The one that can’t carry?” (M)

One woman who was experiencing infertility described how an inner voice would question her saying “what’s wrong with you? ... You’ve done it once why can’t you do it again?” This self-blaming is another contributor to the experience of whakamā that could be a barrier to seeking help.

3.6.6 Men's Reluctance

Most informants thought men are less likely to think about fertility or access AHR. One practitioner, however, didn't believe there was a gender difference in terms of reluctance to access AHR. He said:

Men are as keen as women in this situation to have children. (8)

Whakamā is quite probably a barrier to AHR for Māori men as well. Similar to Māori women's dislike of having to have any gynaecological examination, a few informants said men are less likely to go to the doctor or access health services for anything, let alone for rectal examinations or to be tested for prostate cancer. Thus, as one informant said, "it wouldn't be extraordinary to suppose that they were less hesitant about going off and finding out whether they were infertile." (4)

Men are loathe, we understand, to go the doctor for rectal examination so they're probably loathe to go along and have their sperm tested. (6)

One informant thought that men's behaviour towards infertility and AHR would be similar to behaviour towards vasectomies. Men "leave it to women" to take responsibility for contraception, and she thought they'd be the same about fertility. (1) They'd see it as a woman's issue. Certainly, if there was an inability to conceive, a few informants thought men would think it was because of the woman.

This way of thinking was attributed to having "a very strong male gender identity." Māori men with a strong gendered identity would be less likely to "even go through the motions" of thinking that maybe it was them. This informant said they wouldn't want to know. (4) Another said "men feel threatened."

This kōrero is relevant to the whole question as to why there is a shortage of Māori male sperm donors. One of the informants thought "there would be cultural reasons behind why Māori people would be reluctant to go and donate sperm." Such as, "the importance of whakapapa. Because of the cultural importance of your heritage and of your future as represented by your children." (2) Another informant had talked to some Māori men about it and they'd said they didn't want to be donors. She thought one reason was that "it's like an invasion of privacy." (11) One informant challenged the idea that Māori men are reluctant to donate sperm because they appeared willing to donate sperm up and down the country anonymously. She conceded that they might be "unwilling to put it in a plastic receptacle." (14)

One informant said it was difficult to draw definite conclusions around the reason why there is a shortage of Māori donors. She suggested that perhaps the information about the need for Māori donors was not getting to the right places in the right way and that more work needed to be done to highlight the need in a way that is more receptive to Māori. (12)

Participants told stories indicating that some men are not reluctant to be donors. For instance, one woman's brother had reportedly helped a lesbian couple have children by having "sex with both of them and they both had a child." (H)

Another participant thought there were probably lots of reasons why Māori men don't donate. But they also thought that infertility is not a topic that could be readily raised with men. Participants thought "the stigma" associated with not fathering children "is real strong" and that if you questioned men about their fertility it's the same as questioning the "man's virility... you're asking for trouble." (H) As one of the men said:

When you don't have children you keep thinking you're firing blanks. (M)

One reason proposed was that whakapapa is "tapu" and people wouldn't want to be having "offspring out there to anybody." (H) Another participant thought that men would be "a bit reluctant, especially now when it's open and you have to declare" that you are the biological father. The chance that children might turn up "later on when you've got a family of your own and everything" was thought to be a barrier. This participant imagined that it could be tricky to tell a new wife "I was a sperm donor and I don't know how many... children... my sperm become fathers to... partners would not be particularly happy about that." The hui participants discussed this with another participant saying that it's "no different to them going around the town making babies... Those ones can come back to you too." They were relieved to hear that donors to the clinic have to already have their own family established and that the wives consented as well. "That's a different thing... That's fine" they said. (C)

In addition to the lack of knowledge about what's involved in donating sperm, some participants thought that there would be some shame associated with the actual process. (C) One woman, who had had all the tests she could have, told the hui how her partner had told her "there's no way in heck you're going to get me into a Family Planning clinic and give me a jar so that my little men can be tested." She had suggested that they could "do it at home or rush the container through peak hour traffic to get it to where it's supposed to be, or something, so he doesn't have to go through" with producing a sample in at a clinic, to no avail. (H)

Well men don't like to do that eh. (K)

Perceived Intrusiveness of Procedures

The perceived intrusiveness of AHR was identified as another barrier to Māori accessing AHR. Informants thought that "people tend to shy away from intervention". (6) Another said that "technology is a barrier."

The whole technology stuff is mind boggling. (7)

One informant thought it likely that there were Māori people who wouldn't go as far as seeking tests to determine infertility because of "the intrusiveness" of the processes and procedures, because "it's tied up with issues of sexuality and feelings about yourself, your body... things like giving sperm samples" or having a laparoscopy, she said contributed to what she called "silent infertility." (10)

In another hui a participant who had supported a partner to get pregnant said "it can get hectic." She said it was "hard enough to want a child" but then to have to go "through this testing every month about where you are in your menstrual cycle... and you go through that again, again, and again every jolly month. Blood tests every month... taking their temperatures 3 times daily for 5 years. So, it was frankly

tedious... It was fun for the first 2 years but then it was tedious.” She thought, it might appeal to a limited number of people. (T)

One woman who was yet to approach fertility services wanted to know if IVF was a painful process, uncomfortable or a hard process to go through. After listening to the other women talk about their experiences, she said “it doesn’t sound easy.” She got the impression that “they’re just trying to slap you down every time you think you’ve got a little bit of hope.” To which one of the other women responded “that’s what keeps you going as well, is that little bit of hope.” She explained how you just have to get to the point where you want it, regardless of what you have to go through. On top of which, she added “you have to juggle your partner and everyday things... you’ve got to be determined and face it. And most of us either we’re going to do it, we’re going to lose our partner trying to do it, because he’s getting hōhā, you’re getting hōhā...” (C)

It’s quite invasive. (C)

The other woman felt “you have to be pretty thick skinned to go through it.” The hui participants wondered how the process would be for Māori who were not so “urban” and educated. They could imagine many Māori would find it was “just too much” and they would “drop out” just like they dropped out of treatment pathways throughout the health system. (C)

As one of the men’s hui participants said, “a lot of Māori people of certain generations, they don’t like things getting cut and prodding.” The consumers’ hui participants also talked about Māori not liking operations or having to go in to hospitals. One participant said it was because there’s “a fear of, there’s the possibility that it’s going to be stuffed up, something’s going to be stuffed up, because they might have had a bad experience, or my nana had a bad experience.” (C) Hence, some people would prefer going to a tohunga who would “just touch it and feel it.” (M)

3.6.7 Differential Diagnosis

Some barriers to accessing AHR may occur once people raise the issue with their GP. One key informant thought the GP would unhelpfully “probably start off by making jokes.” (14)

Several informants believed it would be harder for Māori to get a referral to a fertility service. (8) Firstly, like genetic services, for instance, a referral is dependent upon the GP knowing about the fertility services available. (1) AHR is “a sophisticated procedure. It demands somebody recognising that somebody needs it and it demands the doctor interface recognising it.” (7) A few informants drew parallels with the barriers Māori experience trying to access other services, such as, cancer services. Research on Māori access to cancer services, one informant said, suggested that Māori experience “unequal treatment. That at every step of the way, despite their best intentions, it will be harder for Māori to get referred.” (14)

Why should it be any different from complicated cardiac procedures? We don’t get offered them, so why should we be offered fertility treatments. (7)

We're less likely to be referred for heart attacks; we're less likely to be referred for infertility. We're less likely to be referred when you've got an abnormal smear; we're less likely to be referred if we say we've got infertility. (14)

One informant thought that Māori were less likely to be referred to private clinics, because GPs think private clinics “are for European private paying patients.” (12) The GP reaction to the issue of infertility is, as another informant said, dependent upon the relationship with the GP.

As with other health issues, informants expected that Māori “might not present 'til later” and they wondered at what stage Māori would be offered access to AHR services and if they would be offered the same range of treatments as other groups of women might get. (2) For instance, one informant said that having presented, “they may not be considered as high urgent a case as someone else.” (10) This was because, as two informants believed, the doctor that sees them will make judgments about who is deserving. (4,14)

Just because they are Māori... no judgement or assessment should be made about what they may or may not want. They should be offered the choice. (10)

One informant said that as with barriers to access for Māori to other health services, racism would contribute to the barriers to access for Māori to AHR. Both systematic racism (which she defined as “not necessarily intentional”) and “racism of specialists involved.” Even where racism was not a factor, she believed that specialists and doctors often lacked knowledge of and misunderstood tikanga Māori. (2)

Some participants were curious as to how people get started on this journey. For instance, one of the women who had used AHR had asked her doctor to refer her to a fertility clinic. One possible barrier therefore was the need to get someone to refer you. (H)

Then there was the added need to get referred earlier rather than later. The participants at the consumers' hui talked about the unnecessary delays they feel they experienced. Participants perceived that the typical scenario would be that couples go to their GP, and maybe they've only been trying to get pregnant for a couple of months.

If they're in their twenties they're told 'oh, you've got lots of time.'

This had happened to her, as she said:

I'd been off contraception for about a year and I said you know do we go to, do we seek fertility advice? And they said no you're still in your twenties, mid to late twenties you've still got lots of time... Five years later, still nothing's happening.

You get the old clichés: relax, don't stress out, take time out, it's all in your head. (C)

One of the rangatahi said that they had heard of a couple who had been trying to have kids for ages. Their doctor they saw, told them that the best time to have intercourse was on the 20th of every month.

So the 20th of every month, that's what they were doing to try and get pregnant... it worked, but it took them a while. They had to go off on holidays. (R)

Another participant said she asked “lots and lots of questions.” Sometimes she said some doctors and nurses “would start raving on about [doing] it the right way. Well what is the right way?” She said. (H)

The woman who asked her GP to refer her was 40 at the time. Whilst her GP referred her straight away, when she got to the clinic, instead of being put straight onto IVF, she said she “mucked around with AI for a year.” The younger participant said it was “disconcerting” to hear this kind of delay occurring for someone aged 40 years old. (C)

The hui wondered why there was “a reluctance in specialists or GPs” to facilitate access to AHR, in particular IVF. Was it because they wanted people to try right up until there is no possibility of conceiving with AI before moving on to IVF? And did you have to try for 12 months before you could move up to the next level of intervention, despite however many years had already passed before turning up to the clinic? Perhaps it was because of the “higher dollar” figures attached to the more intensive procedures? (C)

The men's hui participants talked about how the general manner of the health professional was so important. For instance, one participant said “within my family the one thing that'll turn them off straightaway is that the doctor doesn't talk to them properly.” For example, they said it was a turn off if health professionals are abrasive or if they won't look eye to eye. They said it was important for the medical professional to be “aware that this person probably needs to be coached through it, rather than saying, you should do this.” Another participant lamented the loss of continuity of care that they used to get when doctors stayed in one place and formed relationships with families. “Now... they move on. That's just the way the contracts are going now. Three years, alright, next one. They don't actually make a place their permanent base anymore.” (M)

3.6.8 Lack of Whānau Support

One informant thought that the biggest impediment to Māori accessing AHR was their whānau.

A few other informants provided insights in to how whānau withheld support. One informant said people she had helped had not been keen on going through AHR because “it was not whānau.” (11) For instance, they perceive AHR to be unnatural. Some whānau might be against AHR if they are against the use of drugs.

One informant who had experienced infertility found the whole way in which society judges people oppressive – especially women, in terms of their fertility and the negative connotations associated with not having had children. These opinions were expressed, for example, through the use of negative terms and through jokes. For example, she recalled snide comments that she should “have it with a real man” and jokes about not “doing it right” and not “sticking it in the right hole.” (14)

One takatāpui participant said she had talked about having a child with her aunty who responded that she wanted to “vet who the man is ‘cause I want to make sure his whakapapa’s good enough.” (T)

Another participant relayed how a whānau member suggested that perhaps she should “look for another partner” if she wanted to get pregnant. (K)

One of the women using AHR said her immediate family knew what she was going through. She thought that the extended whānau had just come to accept that “there is something wrong, and so they don’t ask anymore. It goes as far as my nieces and nephews now who are teenagers and younger... at whānau things and all the kids are playing, and they will say, Aunty, where’s your kids? Even they don’t ask now. So, I think it’s just whether their parents have told them or they just talk amongst themselves?” (C) The other woman said that her sister knew when she was “trying and had been trying for some time.” The sister already had two children aged 10 and 12 and then she fell pregnant.

She actually wouldn’t tell me until 4 months. She waited until she knew it was going to go ahead. ...she thought that I was going to be upset. Because I had been trying and then click out of the blue, suddenly she’s pregnant... I was more disappointed that she didn’t feel she could be honest with me. That I’d been missing out on knowing all this time, 3 to 4 months of her pregnancy and I didn’t know. (C)

When this woman’s sister told her she was pregnant, she also said that she had considered “giving me or offering me the child, but if she could she would have 6 children, and when it came down to it” she couldn’t do it. (C) The other woman could relate to this and said that she “was just straight out with friends and family and said, don’t hide it from me, don’t keep your kids away from me.”

People say don’t bring up the pregnancy in front of her because she can’t have kids and stuff. And that makes you feel more inadequate than what you already feel because you can’t have your own kids.

She said her family are really good. For instance, she found it really helped when she got to look after the babies. (C)

3.6.9 Lack of Māori Fertility Services

One informant believed a significant barrier to access to AHR for Māori was that there were no Māori fertility services. He asked. “Why are they not providing money for Māori, for a fertility service based on tradition?” In addition to a service offering traditional Māori healing for infertility, he thought there should be funding for a Māori version of the existing fertility services. (5)

3.6.10 Cost

More than half of the informants believed that costs associated with AHR would contribute to reduced access to AHR for Māori. Where a person’s ability to access a health service is “largely driven” by their income there is going to be a disproportionately negative impact on Māori given “where the population’s located.” For example, that Māori are over-represented among the low deciles or higher deprivation deciles than the non-Māori population. (4; 14; 6; 7; 8)

Whilst any level of costs could be a barrier (2), some AHR procedures would be particularly hard to access when for example, one IVF cycle could run up to and beyond \$9000. As one informant said, there would be very few Māori who would be able to afford that kind of expense.

I think the average income for Māori women is \$15,000, that's a solo-mum, maybe it's up a little bit but it would be under 20. There's no room in there for people to be paying for IVF. (2)

Again informants drew parallels with inequities known to be associated with other topics. For instance, one informant said “the introduction of new technologies always increases the inequalities” because those who have the least means don’t tend to find out about them or have easy access to them. (4) One consequence of this was that an inequity was created and thus would lead to the argument for a shift in funding to address it. (5)

There is some public funding for some AHR, but contrary to one informant’s desire that “access should be free and equitable across the board” (6) public funding for AHR is limited. In New Zealand some people experiencing infertility can qualify for up to two publicly funded IVF cycles.

One informant talked about Australia’s support, whereby they had lifted the cap on how many IVF cycles will be publicly funded. She said that “the average amount of cycles that gets used is only 2.3 because it’s self-limiting.” For instance, “if you have one cycle, you might have a baby from that cycle and then you might have some frozen embryos so you might actually complete your family from one cycle if you’re lucky.” (13)

Participants thought that AHR was probably expensive and that the cost could be a barrier for some people.

I just always thought that anything to do with fertility and infertility is really expensive. (R)

One rangatahi participant thought that people might feel they were having to pay for their child. As he said:

Maybe another reason why people won't even, Māori people won't even consider it because they'll think, oh no it'll be too expensive... Māori people might look at it as, man, I'm having to pay for my kid? ...I'd think like that. I just said it. I ain't going to pay for a kid, my kid. (R)

How far along the process and which procedures people would use could be partly determined for some people by the cost as well.

For instance, having done 2 publicly funded IVF cycles, and then deciding to look at surrogacy, as one participant pointed out, you’ve still got to “then pay for the cost of an IVF cycle for that other woman to get eggs from her... So I think it does come down to cost.” (C)

When participants found out the actual costs involved, they were shocked and saddened. For instance, participants were told that at the time of the hui a cycle of AI was about \$900, an IVF cycle was about \$9000 with the actual costs varying depending on dosage and amount of drugs used and the number of scans; ICSI would be extra and PGD would be about \$12,000.

Is it really that dear? (C)

That cuts out so many Māori people, doesn't it... how many can find \$900? (C)

You can sort of understand why whānau don't go this way, because they don't have \$9,000 plus a couple of extra hundred just tucked away for a rainy day. It's quite... deflating... If it doesn't work the first time, shit! (H)

How on earth would Māori be able to afford that? That's sad then. (H)

Oh boy! Well, where would you get that in one day? ...I'm sure that there are a lot of people out there that would like to have that but because of the cost... (K)

One participant said she could “imagine saving up for one and then thinking well this is it. I can't afford another.” (C)

One participant wanted to know if there were any discounts for Māori (K) and another participant wondered if any Māori organisations had any money to help with costs.

You know how we do scholarships. (C)

The takatāpui hui concluded that only people who could afford it would access AHR which would considerably reduce access for Māori. This would, therefore just reinforce the status quo in terms of the inequities between Pākehā and Māori. (T) One participant said that Māori without the financial wherewithal to afford AHR would have to turn to their family – for whāngai.

How do I do it and do it quickly? ...if you're resourced, if you're financially resourced then you go to IVF and follow the process like everybody else, and then if you're not you go to your family. (T)

3.6.11 The Exclusion Criteria

Another barrier to accessing AHR is what infertility services are available under the publicly-funded system (8) and the criteria for determining who is eligible. The criteria are based upon the female, and women who had their first cycle of fertility treatment after 1 July 2003 are excluded. (13) The woman's age, BMI and smoking status are taken into account when determining eligibility for public funding.

The criteria acknowledge that there is “very limited money so we've got to spend it where we can get most success.” (13)

Some people may find their access to AHR limited by exclusion criteria implemented by providers. For instance, some informants were concerned about access to AHR for

takatāpui. (6) This is an issue because individual AHR specialists can conscientiously object to providing AHR to lesbians. Informants were not sure what the current exclusion criteria might be. One informant thought that there were rules excluding people who had ever been to prison. (14) This would be a concern to Māori, given the over-representation of Māori in the prison population.

Age

Informants believed that AHR would be restricted to people of a certain age range. Age of the woman is one of the criteria used to determine eligibility to public funding for AHR.

One informant mentioned that the provision of AHR to menopausal women was troubling. He believed that few clinicians felt “very comfortable about that ever, under any circumstances.” His opinion was that older women were physiologically “worn out.” He also didn’t think it was “very fair on the child to start off with that kind of physiology.” Whilst he acknowledged that he was being judgmental, he still said “it’s a sort of twisted mentality that has you not accepting where you are in life, what nature has dealt you.” (8)

The kaumātua hui were interested in women’s ability to carry after menopause. They had thought that it was not possible to do so after menopause, but they had heard of the woman in Italy who with AHR had become pregnant and carried at age 62 years.

As we’ve got older and we’ve found out perhaps one of our children can’t have children. And we say to ourselves, I wish I hadn’t gone through menopause because I would carry a child for you. (K)

BMI

BMI, in particular, excess weight reduces the chances of success with an IVF cycle. Being too thin also affects fertility. Subsequently BMI impacts on eligibility for public funding for AHR. (13) One informant believed this was another barrier restricting Māori access to AHR because Māori have higher prevalence of excess BMI. (12) One informant believed that Māori women “don’t seem to be as up front about that sort of kōrero” about their periods having stopped due to low BMI. (11)

A health workers’ hui participant thought that women with a BMI outside the acceptable range had probably encountered information about the effect of BMI on fertility before getting to the stage of applying and being turned down for AHR. (H)

The kaumātua hui said this would be another barrier to Māori accessing AHR as Māori would be less likely to have the right BMI. (K)

Smoking Status

Tobacco smoking, but also marijuana smoking, by the man or woman reduces the chances of getting pregnant, significantly so when experiencing infertility. (13) It is however, the smoking status of the woman that affects eligibility for public funding. Women wanting to undergo IVF are supposed to have been smokefree for at least three months before treatment.

If you're a smoker your chances of getting pregnant on an IVF cycle are halved. (13)

Geographic Distance

Whether or not AHR services are available locally or not is another potential barrier to access for people not living in centres with a fertility service. (2,7) One informant thought access could be improved by the provision of some AHR services from within health centres familiar to people.

3.6.12 Other Responsibilities

One informant said that juggling other responsibilities, such as, child caring or paid work would be another barrier for people wanting to access AHR. (2)

3.7 AHR – Procedures and Practices

This section presents informants' comments and opinions on the actual AHR processes, procedures and technologies.

Most of the informants were of the opinion that if a Māori person had decided to investigate their fertility, and found they were infertile, that they would be prepared to be part of any process that doctors recommend, (6) that they would do whatever they had to to have a child. The AHR processes and procedures would be seen as just “part of the necessary process to go through.” (2) That is, an informant thought that for those particular Māori that would choose to use AHR “those things are probably pretty straight forward.” (10)

Informants based their opinions on how they thought they would respond personally if they were in the same situation. For example, one of them said she wouldn't “have any particular issues with those things” (2) and another said:

If I were infertile I would go to the max to have a child. (1)

Informants with experience in the field reported that “those Māori who are committed to their fertility and who are seeking fertility go through this kind of arduous process the same as everybody else.” (8)

One informant thought that people “entering that sort of high-scientific sort of thing” are desperate and will therefore do what they're told. “They're vulnerable”, she said. (7) Another informant also said that “when people have infertility it's like they so desperately want to have a child, you name it, they'll try it.” For example, she said that people turned to, for instance, spiritual healers – regardless of their ethnicity, and including those who might have previously been closed to spiritual beliefs. (13)

Because the informants did not think that the Māori who had used AHR, or considered using AHR, would have any issues with the process or practice, they were prompted further. For instance, they were asked if they thought that Māori would experience any issues if they wanted to observe tikanga during the process. Informants maintained that those Māori who chose to use AHR would be that desperate they would put up with whatever they had to. (7)

If people have decided to go down this track then they've decided to go. They're going to do all of these whether or not there's an issue, a special issue for Māori or not. (5)

Another informant thought that issues for users of AHR “would be shared by people generally” regardless of their ethnicity and “people that have an affinity with Māori culture” just have to come to grips with it. Māori who “don’t have much to do with” Māori culture, he thought, wouldn’t be affected at all. (5, 4) For instance, “things like modesty” another informant said they just had to “get over it, because this whole process is a means to an end... you have to do it.” (2)

If you want to go there you’ve got to take your pants off. (14)

As another informant said “anybody who gets this far is committed” to, for instance, get up on the table. (7) Particularly, the woman has to be committed, because as one informant said, she didn’t think any woman enjoys gynaecological examinations, but such was the technology that “this is a business where men are probably involved but the woman’s committed.” (14) With regard to cultural concerns, she said. “What’s culture?” (14)

If you want to go with the new technology of it, you have to go with the new technology rules, the best practice for that technology. That’s the new technology kawa. You don’t take your culture. You assume part of the new tikanga. (14)

One informant did say that at this stage it does become about “preserving your dignity and your partner’s as individuals.” (4) Another informant referred to the historical “long fight” Māori have fought with the medical system “over appropriate respect and treatment of all body parts... and our whole approach.” (10)

Informants did raise some concerns about AHR and had plenty to say about what the issues for Māori might be with the procedures presented for their consideration. For instance, one informant said “we still have to make sure that the technology, the new technology is really safe.” (14) Another informant was concerned that client records were treated as confidential. (3) As mentioned in a previous section, one informant said the important thing for her, even when it came to the AHR process was that “whatever happens, to focus on what’s in the best interests of the child.” (2)

The tests and procedures are presented in what could be a chronological order of use or from least intrusive to more intensive. As one informant suggested, people’s comfort with the procedures changes “as you go down or up the scale of interventions.”

Māori would probably cut off early in the process... the more intrusive it gets. (10)

Participants at hui generally believed that if people wanted a baby and they were unable to get pregnant any other way, then they would go to AHR and they would do whatever they had to.

It depends on each situation. I think if someone really wanted a baby and could not have a baby they would go to this extent. (K)

I think if you’re willing to go that far then you’d do it. Yeah. If you were desperate for kids. (R)

If you really want to have kids then you'll basically put yourself through whatever you need to do. (M)

3.7.1 Assessing Infertility

With regards to the tests involved in assessing infertility, one informant thought there would be a lot of issues raised for both Māori men and Māori women. (10) The perceived resistance to testing was thought to be so great that one informant thought that “for some young people it might be easier to end the relationship and find somebody else with whom you can have a child rather than go along to get a test and see what’s wrong.” (6)

One informant believed that “a lot of women don’t know why they can’t have children.” She thought it was important to know, so she supported the idea of testing. (3) Another informant thought it more likely that women get tested first or are less reluctant to be tested. Partly, this was “because women are more likely to have at some time in their lives had to engage with a health practitioner about their sexuality... about their sexual functioning... women get periods so it’s much more sort of there and it’s much more, somewhat more out in the open than males.” (4)

One informant knew that some women and their partners were reluctant to have a laparoscopy or an x-ray for several reasons. In addition to having to be admitted to hospital, she believed people didn’t like that they are awake through the procedure and that “the person who is doing it is there in the room; because of the dye going through the tubes and things and all the dignity issues. But apart from that it is also painful.” A further cause for resistance, she added, was “because of the invasiveness of a very important part of the body that has you know lots of meaning attached to it.” (12)

One cause for male reluctance to testing was that there are some suspicions and paranoia “that the sperm might end up in the wrong place or be used for something else.” This informant said that with sperm testing “the only thing that might happen is you might get the wrong label so the sperm count might come back with somebody else’s sperm count.” Samples given for testing, he assured, “are never used for any other purpose.” (8)

Again, if there was a cost involved then that could be a barrier to getting assessed. (T)

One participant suggested that if a woman had a poorer chance of success due to age, for instance, then the process for determining infertility should be sped up. For example, they shouldn’t have to “go through a trial of 12 months or a year” of trying to get pregnant. For Māori women choosing “to breed at a later onset in life” and at higher risk for infertility due to some of the ill-determinants such as smoking and BMI then the tests could be made available earlier. (T)

Some participants had been through the process of getting assessed for infertility. One woman said that she and her husband went to see a gynaecologist when she was 22 after two years of marriage with no pregnancy.

For a time I had to take my temperature every morning... he didn't have to do anything until he had to give a sperm thing when we went to the hospital and ...they inserted dye up through my tubes to see if they were blocked.

The tests showed that she had “a medical condition and once I learnt what was going on in my body it was easier to accept... I am fertile I just cannot carry pregnancy full term.” She said that they considered all the options including adoption and surrogacy, but “I chose not to because I was married to a man” with eight children. (H)

Other participants knew of whānau members who had been tested to find out “which one of them couldn't have children” (T) “just to say if he was shooting blanks or it was her. And that's what she needed to know.” (K)

We have karakias for my sister and my brother... unfortunately she doesn't want to take this other part. (K)

One participant said that the information about all the options needed to be made available and discussed before people undergo any tests. Because the options available to them might not be acceptable anyway. That is, people needed to consider what “choices they want to make in the end rather than necessarily doing all the testing getting all the information then making those choices.” For example, many people do not have amniocentesis because they “wouldn't abort a baby anyway.” So, “why would you do the test and put yourself under stress?” (H)

One barrier to being assessed was the fear of finding out that maybe you are infertile. Then, as one participant said, you “have to give up your denial. Until the test is done, you can say oh, it's going to happen one day. But at some point you get the test done and it says you can't have children or you can't have children this particular way. You have to face it.” (C)

Men's Reluctance to Get Tested

Some participants thought that “it would take a lot to get the male to the doctor to prove that it was him.” (K)

One man thought that it was because the men he knew who hadn't been able to father children, were “both pretty staunch.” He said. “That's dangerous territory... to ask them about that.” A health worker said her organization was “coming across that a lot and that is that males they get this image like... it's not me, it's her. It's like oooh no, I'm not going to get tested.” (H)

The men's hui also said it “is that men's psyche - I ain't the problem, it's her.” They thought “it would probably take a fair bit to realise that you are the problem.” They said it's “that macho thing.” Also, men were more likely to think it was the woman that was having the problem “because that's what's reported on more often, rather than the man being infertile.” They concluded, however, that “at the end of the day, if the most important thing was to have children, then you'd do whatever you needed to do.” (M)

One of the men talked about why he wouldn't provide sperm for tests.

When I tested for cancer, and they wanted to test my sperm and all that, I wouldn't do it. I said, ooh yuck, no, I ain't doing that. Give me an injection. It's a macho thing. A lot of men, they still hide inside themselves about that. I was one of them.

The barrier to testing for men is, therefore more than having to go into a room and masturbate in to a cup. Although this man said that that was off-putting as well.

Yeah and put it in the cup. What you've got to do in the meantime to get it into that cup. It's a bit degrading to our men to do that. It's not macho... What you're doing behind the door. That's enough for me. Yeah, shame.

The rangatahi thought men might be reluctant to be tested because they felt “whakamā. Just shy, shame.” They thought men wouldn't like to have to masturbate in to a cup. Also, that testing “questions the manhood” and that men could be “scared of the outcome. And some people might just not want to know more ... Just go natural and if it comes, it comes.” (R)

One of the men who had been tested confirmed that he had thought it was his partner that had the problem.

Men in general usually assume any problems with fertility is related to their partner and so did I until I got to the point where 'okay well we've examined your partner we know there's something wrong there but that doesn't wholly explain what's going on.' Then we went through the exercise of checking my sperm and all that sort of carry-on and finding out there's issues there - they won't stick together... back then sperm washing wasn't really an option... so that's pretty much where we finished it. (C)

One of the women at the consumer's hui said her partner was not happy to be tested at first. She thought it was “the male pride, bravado and that, no it's not me, my boys swim kind of thing and there's nothing wrong with me.” She also thought he was reluctant because he'd “have to go into a room and spit into this jar.”

When he first went there, when he got home I said to him, oh how did it go? Oh, I was embarrassed, and I said, why? And he said because you go there and you get given a brown paper bag and you get pointed down the floor to a room and he said there's a waiting room for the people and everyone knows what you're doing. And I said, but have you thought that everyone else there is probably been in that same position as you and they've had to walk down that hallway and they know what you're doing but they've probably been through it as well. And he went and did the test, but he didn't want to talk about it after that. And then, he had to do another one a year later. By that time he was over it. It wasn't an issue anymore because he knew that if we wanted to get anywhere he was going to have to get over it and move on from that. Also, he came to a lot of the scans and things that I had done. Him being there, what he had to do was nothing compared to what I had to go through, the tests and that. You get your legs put up in stirrups and things. You can have a doctor and a nurse, and you can have medical students there all having a look up. And I said to him well how do you think I feel? You go into a little room and do your testing by yourself. You get some privacy... And basically you're in a room on display with 3 or 4 other people looking up your private bits as well. With nothing that's hiding your face. That's what you really want to do. Once he had come into those examinations room with me and

seen what I had to go through. He got over it. It's really just become nothing. I have done 5 cycles of IVF. So every time we have got to the transfer stage, or the collection stage and go give his samples, it's nothing now. It doesn't bother him. Because at the end of the day if it works and we get what we want. It's nothing.” (C)

Men's Reluctance to Donate

Hui participants discussed the supposed shortage of Māori men willing to donate sperm.

As mentioned in a previous section, it could be because men feel whakamā. One man said:

You wouldn't go there unless you were actually put in a situation or it just came up that someone has actually come to ask you to do that, to have a child together. (C)

Some men would have concerns “around who is the other whakapapa that we're joining up...? Who is the partner? What is their hapū? What is their iwi affiliations and are they even Māori, the other person?” (C)

There could be concerns around child access also. (C)

A men's hui participant said you “don't want to spread your whakapapa all over the place. You've got to keep control of that ... For me it would be hard to not know who your kids are out there.”

They said it was important for Māori to stick to their tikanga around whakapapa because “if you broke that down as a mindset, then you've broken down the whole culture. Then you start compromising your culture.” (M)

One man thought that “Māori men are not shy to donate the sperm if they know the people.” But, they're not just going to go off to the clinic and offer some sperm that anybody could access and use.” (M)

3.7.2 Gamete Donation

One informant reiterated that she couldn't know what concerns would come up, as she said, “well you don't know until you do it.” (1) Another informant said she could “see how those would need to be options that people needed to explore and consider if other options didn't work.” (2)

One informant likened sperm donation to an old practice whereby Māori women slept with visitors to the tribe thus increasing the tribal stock. He therefore saw no mismatch between the current practice of sperm donation and Māori practices of old.

The idea of going to get sperm is not much different to... the other old practice when visitors come you might... women might be able to sleep with them. 'Cause Busby and all those got offered lots of women and there were children from these things... And so when the sperm donor, he went away, then the tribal stock was increased. There's lots of evidence on that. So I don't see any sort of cultural mismatch there. (9)

Informants acknowledged that we don't know how Māori feel about gamete donation, though we could extrapolate from what's been expressed about related issues, such as, organ and tissue donation. But, gamete donation was seen to be totally different because it raises concerns about the integrity of whakapapa and it effects "the next generation down." (4) Thus, as one informant thought, there could be a lot more issues that we don't know about. (11)

Some participants thought donation was a good thing and they believed that there would be plenty of Māori who would be happy to donate, if they knew about gamete donation.

Māori people, we are so giving... I know that there is a lot of people out there, in my whānau or my friends... they would go along and do that sort of thing. Only if they had the knowledge to. (C)

The men's hui thought that sperm donation would be something that the next generation would be more open to, especially "if this is the way to keep us going." (M)

Conversely a rangatahi said he didn't think he'd be able to do that. "Because in the back of my head I'd be going I've got a kid out there somewhere and I don't know where they are." (R)

Some participants were surprised to learn that a whole embryo could be donated. (R)
A kaumātua hui participant asked if these are "sometimes leftovers." (K)

Participants thought that donation was "a pretty serious decision" to make and that there was a lot for the individuals and their whānau to consider and talk through. (T)

As those who had been through the process said, "it's not as easy as just popping along" and donating. Donors "have to go through counselling sessions." The donor has to give consent for children born as a result of their donation being able to access their details once they turn 18. Donors have to make multiple trips to the clinic to bank enough. (C)

Do-It-Yourself Donation

The rangatahi hui thought it was "weird. That someone else would go out, just to get a baby, from someone that they know." One woman said "I would rather get my own donor." (R)

The other thing you don't know if they're doing it at home is how many donations he's doing. He might be put it to all your guys' mates and ... at least through the clinic you know you're only allowed to give four, four lots away but he might be travelling the length and breadth of the motu, just... donating you know. Yeah some do. There's that gay guy, who has helped three lesbian couples have children but presumably they all know him. (H)

3.7.3 The Obligations and Responsibilities of Whakapapa

Whilst there are people who go around without the other half of their whakapapa, and they live a good life without it, one informant thought this was not ideal. (1) Another informant believed that people conceived through AHR, who may not have access to some of their whakapapa, will have to face the consequences of that in the future. She thought that more questions are going to be asked about whakapapa, especially “as Māori take hold of more embryo donation.” (7)

Because Māori are perceived to be concerned about the integrity of whakapapa, some informants believed that Māori would prefer and would be more likely to make arrangements with potential donors from within their own environments “in order to take care of things like whakapapa issues and that connectedness.”

If they could find someone that they knew and trusted that could provide them with sperm, that that would be optimal as opposed to necessarily having donor sperm from someone you didn't know. (2)

Several informants knew of lesbian couples who had had a baby. They believed that they had tended to use donor sperm from a whānau member of the partner who wasn't going to carry the baby.

Whakapapa carries with it obligations and responsibilities that could cause Māori to be wary of donating or using donated gametes. As one informant explained, there would be an expectation to maintain the relationship, once it was acknowledged. She referred not only to the potential relationships between donor parent and child, but also between children who can whakapapa to the same donor. They would therefore be siblings, thus linking their respective families as whānau. She said, “I think you'd be quite hard pressed to find a Māori who didn't think that was then a link.” (2)

Another informant said it was problematic that the sperm donor “might have children out there and they wouldn't even know where they were.” She said that “part of it's about responsibilities and part of it's about whānau really.” She believed that if they “knew that they were out there that they would want to have something to do with their lives.” (11) This feeling could therefore be a barrier to sperm donation. She didn't know what the situation was with egg donations and embryo donation which was an even newer procedure available. Although she felt better about the arrangements made to enable embryo donation, in that the couples meet each other and negotiate about how they're going to interact after the baby is born. (11)

One concern raised by an informant was that with our small population size there is a greater chance that children born of donor sperm could meet, “especially if you've got people who identify as Māori and who move in Māori circles.” (2) Whereas in America, she thought, chances are, children born into different families but from the same donor sperm “could go their entire life and never bump into anyone who knew the donor father.” (2) This was both a reason to support that children are told if they were conceived using donor sperm and “to make sure that there are precautions taken around that.” (2)

Rangatahi were shocked to hear that the mother could not find out the identity of a sperm donor and that the child could not find out until they are 18 years old. (R)

A kaumātua hui participant thought that the child must have “rights” for instance, to know how they were “brought into the world.” They thought that “when the child finds out the way they were conceived. Well they might have a problem with that because they were conceived different to ‘my friends or my cousins.’ Thus, the participant thought it was important for the child to know. (K)

Another reason “why it’s important to be absolutely honest all the way through” is to prevent unintended incest from occurring, for instance if a child born from a donated gamete met “up with the one that the parents have kept. Well they could start having a relationship with their brother or sister. That would be a really dreadful thing.” (K)

3.7.4 The Tapu Nature of the Body

A few key informants said that some Māori beliefs about the body and body organs being tapu contributed to a reluctance to donate organs and therefore taking the eggs out of the body can be seen as not being okay for Māori. (13, 7) But, as another informant said, some Māori are donating organs. That may be because for some Māori, concerns about tapu may not be there. It depends “where you sit on the cultural spectrum.” (14) Or, as another informant explained it:

You don’t give away your body parts without really considering all the implications of doing so and for me tapu in itself does not necessarily mean that you can’t do something, but it means that due respect and due thought must be given to what you’re doing at every step of the way. (2)

3.7.5 Embryo Donation: Early Whāngai?

One informant suggested that embryo donation was actually “just an early adoption.” It’s “a sort of adoption in-utero rather than outside” and he said “we’ve got fairly sound views about that” (8). He thus believed Māori views about whāngai could be applied to embryo donation. Another informant wondered if sperm and egg donation could also be seen as whāngai. (13)

Whilst whāngai could be considered a cultural precedent for embryo donation, actually referring to it as early whāngai was an uncomfortable idea for some participants. They thought that “that’s stretching the word.” Both a takatāpui hui participant and a rangatahi hui participant thought it was changing the concept of whāngai. “Unless they’re related.” (T)

Whāngai would only be within the whānau. (R)

If embryo donation was occurring between strangers, then it would still be like Pākehā adoption.

I would only say whāngai if they gave birth to the child and then handed the child over. (R)

A kaumātua hui participant said that the concept of early whāngai “needs to be added on to our tikanga.” (K)

3.7.6 The Ideal Donor

The concept of the ideal donor was raised by a few informants. One informant, said she “would need to know the background” of the person, especially with regards to their health and mental stability. She wondered if the clinics checked the validity of donor information. (3)

The clinics do have criteria to determine who can donate sperm. Ideally he is someone who has had children, although that is apparently not set in concrete. He should have talked to his partner about donating and made it a whānau decision. (12)

Talk of an ideal donor caused one informant to think of eugenics – that is, controlled breeding. (14)

One informant said it was important that donors or surrogates were not paid. (3)

Participants wondered what criteria were applied to sperm donors and which men, if any would be excluded. For example, some participants thought that gay men are not allowed to donate. One participant thought that a New Zealand fertility clinic was reconsidering this. Another participant said they probably already do have gay men’s sperm, “but they don’t know it.” (T)

A kaumātua wondered if men on medication, like himself for instance, would be excluded. (K)

A rangatahi had heard that people can stipulate that they want a child with blue eyes. Another rangatahi said she would be concerned about “what kind of sperm am I getting? ...Is this dude a psycho or whatever?” (R)

3.7.7 Māori Sperm Like Gold

Whilst it is apparently difficult to get gamete donors “across the board” (5) some informants believed that men were particularly reluctant to donate sperm.

We have more women prepared to donate eggs given they have to go through a whole IVF cycle, than we have men prepared to donate sperm. (12)

One of the topics talked about was the small number of Māori sperm donors that fertility clinics have to draw upon and the issues that creates.

The clinics, for instance, reserve Māori sperm for Māori women/couples needing donor sperm and limit the number of families that could use sperm from the same donor even more so than they do for sperm from Pākehā/European donors. Still, the small number of donors increases the chances that recipients of donor sperm might know each other. One story that was shared shows how this could be problematic. Two Māori women who knew each other were using the same fertility clinic and potentially could have been recipients of sperm from the same donor. This was unacceptable to one of the woman who did not want to be linked to the other via their children being siblings. Thus, access to donor sperm is reduced for Māori.

As outlined previously, informants could only guess at why Māori men might be reluctant to donate sperm. One informant said it was not consistent with the fact that there are Māori men having unprotected casual sex with women despite that a baby could eventuate. She believed they behaved like that mostly without thinking; whereas, the decision to donate sperm required an “active thought process.” She thought that “the men who would be more likely to have unprotected sexual intercourse with people on a casual basis are not going to be the same men who actively think I am going to donate sperm to help someone have a baby.” (2)

She thought that there “would be cultural barriers either from within a person or from their family” that would prevent Māori men from donating sperm. Also, she thought that some people might be against sperm donation because they would see it as “wasting human potential.” But, she thought that idea was unrealistic since the same rationale would not be used to stop Māori men masturbating. (2)

In addition, to “the attitudes, beliefs, philosophies, and cultural values” that might prevent someone from donating sperm, there are the practical issues around having to make multiple trips to the clinic to donate. (12)

As mentioned previously, a further factor contributing to low numbers of sperm donors is possibly the way that fertility services are trying to “sell the need.” (12)

Participants wanted to know why Māori donors were wanted? (H)

Some participants said that if they needed to use donated sperm that they would want a Māori donor.

I'm a Māori female and I want to have a donor that is Māori and from this iwi. (H)

I don't want a Ngāpuhi. I want a Whātua. (R)

Which caused others to ask “can they do that? Can they pick?” (R)

One participant had recently been advised to find her own egg donor because there are so few sperm or egg donors, “and that applies to European or Māori.” She had seen more advertisements for egg donors rather than sperm donors, although she knew that the clinic she was attending “only had one Māori sperm donor and it's like gold, and that's because it's so rare.” (C)

One takatāpui participant knew of a cousin who had a European lover who wanted to have children. The participants' cousin reportedly got one of her brothers to act as a donor. “The upshot of it was, the Pākehā, the Dutch girlfriend got pregnant. Soon as, she was on a plane back to Holland!” (T)

One participant said “we're stalked for our genes.” Other participants too had heard of Pākehā deliberately trying to have a Māori child. They said. “That's been around for awhile.” (T)

Health workers' hui participants were repulsed by this idea. They asked, were Pākehā wanting Māori babies because they were “the lowest price?” “Is it politics?” Someone else asked. “You get tangata whenua status if you've got Māori children?” “You get free maternity care” someone else suggested. (H)

This raised worries about how easy it was for non-Māori women to access sperm from Māori donors through the clinics. They said. “How would she provide for the child's origins and culture?” They thought it was good that Māori sperm was saved for Māori clients. (T)

One participant wondered how far things would go. For instance, maybe one day “because you haven't got any leaders in your hapū and your paepae... you can then decide who is going to be your leaders in the future and who therefore you have the sperm donors from that line and that particular whakapapa to the exclusion of anyone else... where does it stop and where is the element of destiny or spirit?” (T)

Another participant could foresee a time when Māori genes would be taken. She believed this had happened in some Pacific Island country, where genes were taken to “produce big, strapping rugby players.” She was concerned that Māori “don't get a say sufficiently to stop that.” (T)

3.7.8 Cross-Cultural Donation

A few informants wondered if non-Māori could request to use gametes from Māori donors and if there were any policies preventing Māori from donating to non-Māori. One informant wondered if people could request, for instance, “a Pakistani father, or a Fijian father.” Similarly, one informant wondered if Māori donors could specify that they only wanted to donate to Māori. (7)

3.7.9 Within Whānau Donation

Where informants expressed an opinion on within whānau donation, they agreed that it is not appropriate for brothers and sisters to co-create children. One informant said that in pre-colonial Māori society “incest was a death sentence. It was seen as wrong.” (9) But, one informant thought it was “actually common and does happen where people have children with their cousins. Once you're further away than that, my understanding of it is that it tends to be okay.” (2) One informant suggested that we need to look for the “cultural precedence” to see it informs us about these things. He was concerned that “people are marrying, hell, too close, far too close” and it's seen as acceptable. He had heard of first cousins marrying and second cousins. The minimum he had been taught was three. This was supported by genealogy research. (9) As for a sister using sperm donated by her brother, one informant was unsure saying if it was someone else she “wouldn't have a problem” but if it was herself, she'd feel it was a bit close. If the person was a second cousin that would probably be acceptable, she said. (3)

Participants discussed different scenarios that could be made possible using AHR; for instance, gamete donation within the whānau and across generations.

There were concerns about preventing incest, but no consensus on what constituted an incestuous connection.

The kaumātua hui knew that sometimes in the past, relationships with cousins were arranged “to keep the right whakapapa and keep it in the family.” If a brother or a cousin or other relation of some female that wanted a child, was proposed as donor, an application would have to be made to ECART (The Ethics Committee on Assisted Reproductive Technology). (K)

Even though sexual intercourse is not involved, participants were still wary for the child. They said “you’ve got to look at what’s going to happen when that child is 15 and they come back and find” out how they were conceived and who they whakapapa to.” (K)

Within whānau donation raised concerns about increasing the risk of passing on an inheritable genetic disorder.

You would have to check on what was inside the genetic make up of those. If they were both who had some genetic disease. (K)

There was general resistance to the idea of a sister receiving donated sperm from a brother, father, grandfather or a sister carrying an embryo for a brother or father. Donation and surrogacy between sisters was less offensive.

One of the more complex debates was the topic of gamete donation across generations. Informants differed in their opinions on this. A few informants thought that for Māori, it was not appropriate for men to have children with their daughters (2) therefore it would be inappropriate for a father to donate sperm for his daughter to use. One informant said, “I would see that as incest.” (3)

Conversely, informants believed this same restriction would not apply to a father donating sperm to his son and son’s partner, although they still felt uncomfortable about that. This arrangement would transgress “collective rights” for example if sperm was donated from a father to a son, the child would biologically be the child of their grandparent (10) putting them on the same generational level as their father, uncles and aunts. Similarly, this could occur where an uncle donated to a nephew. (7) One informant said this would confuse relationships for example, the responsibilities and obligations of tuakāna/teina relationships. It could complicate the line of descent and inheritance or transmission of knowledge and status. This informant said it just confused “the way we operate with each other.” (10) Across generation donation was the most contentious area, one informant thought, because of the impact on whānau structure and the implications for tikanga. Thinking about the future she asked, “And when they have children what’ll happen there?” (7)

The example of a father donating to a son became more complicated for informants, if the mother-to-be was not Māori. One informant thought that the consequences for the child “could be really grave” in that they might one day have to defend themselves against challenges from, for example, uncles. How would a non-Māori mother be able to protect the child in those circumstances? This is akin to the challenges that some people who are whāngai have to face sometimes on the marae.

To avoid these kinds of consequences, informants believed it was imperative that whānau were consulted beforehand and that the child would also need to be raised with accurate knowledge as to their whakapapa. Because, as one informant said, “Somebody would find out sooner or later.”

You can't keep that information confidential either, within Māoridom. (11)

Thus, thought needed to be given to how the child would cope and their need to be able to carefully identify who they are and where they come from. (11)

It could be, then, that some Māori will be supportive and open to AHR if gamete donation is occurring within the same generation or kept within whānau, but less open to AHR when gamete donation “is outside clear whakapapa lines.” (10)

That donation could occur across generations was offensive to some hui participants. Rangatahi said that getting sperm from the man's father was “like sleeping with your dad, father-in-law.” They squirmed at the thought, even though they knew the woman and father-in-law were “not going to have sex.” But, another rangatahi participant said it would allow them to keep “the same line.” “But it's still icky,” the others said. (R)

The men's hui discussed this scenario as well. The potential outcome could be that the man's child was his brother. But this was not a problem in terms of traditional whānau structures, such as tuakāna/teina, because as the men said. This occurred through whāngai arrangements anyway.

It was suggested that the tikanga, that is the right way of perceiving and understanding the relationship, is set by the whānau.

We all know what the tikanga is, for those who know the family... And you keep pushing it out man, and that child takes the role of being the brother, like the mother actually treats him like a brother and everything else, then the rest of the family take on that role as well. (M)

The takatāpui hui discussed within whānau donation also. One man said he could not be a donor for his sister. “It's got to be several generations removed.” He said. But another participant said that in the past it wasn't. She had had lots of cousins offer to be a donor for her and her partner.

I think that's great... it wasn't a weird thing, it wasn't a ...horrible thing to experience. There is that level of respect and understanding of difference within your own family community, and finding a way for that to still be a loving and caring situation. And how more loving and caring than if your brother or close cousin, or even cousins offering to be surrogates? You know, I think those are beautiful ideas, they're not new ideas they're old ideas of ours, that we've practiced. (T)

Another scenario the rangatahi thought was “gross” and which they called “inbreeding” was where a couple, who had frozen embryos stored, found out that a child of theirs couldn't have children, and the question was asked, could they donate an embryo to their child? This would result in the child carrying and giving birth to a sibling.

The takatāpui hui thought that even donation across generations was not a problem for Māori. They referred to whāngai arrangements where the grandchild is raised by their grandparents.

One of the takatāpui participants' brothers had been a donor for her and a partner. This enabled the child "to be from both of us." The participant did not have a problem with her partner having sex with her brother, given that that was her partner's preferred way of conceiving. "That's okay. That's whakapapa." Other participants at the hui said they would not have wanted a girlfriend to sleep with their brother. Actually, the woman's partner decided against having sex so the brother put it in a cup.

He did that because he loves me not because he wanted to have sex... it was to have a child.

She explained how important it was to her that the child would be related to her. Otherwise her partner could have walked off and "I will never see her again. You see there's no claim, whereas regardless of the relationship, the claim will always be the genetic one. ... That to me was the most important."

With regards to her partner having sex with her brother she went on to explain:

After 5 years, that's the least of my problems. I just want to get it over and done with so we had a connection. Both of us. And therefore great. There you go. I would much rather it be with my brother because I know his history... Whakapapa. That was the most important thing to me. (T)

Individual vs. Collective Decision Making

Two informants questioned the authority given to the individual to decide on gamete donation in isolation from their whānau and the wider 'collective.' One informant said they would be interested to learn if there was a generally held opinion on this. (7)

There are sometimes sad implications for the wider whānau that are overlooked by the individuals directly involved in decision making. One kuia told this story:

My son has donated his sperm. I have a mokopuna that's 20 years old and I just found out at Christmas. I thought I only had the twins that's 4. Only 4 mokopunas. But 20 years old. The sad thing about it is, I never got to know that mokopuna. That's my cry. Though my son says to me, the parents, ah the mother is going to tell her who her father is, and he says to me, Mum she will come looking one day. So for me, but it's 20 years that I haven't seen... this mokopuna. And my heart cries out for that. (K)

3.7.10 Gamete Storage

Some informants spoke of the benefits of gamete storage and some raised concerns about storage. But, one informant suggested that even the concerns should not be seen as barriers. (7)

For instance, gamete storage "is quite a good idea for infertile couples" in that it possibly saves them from having to go through repeated IVF cycles to achieve only

one pregnancy. (8) Another informant thought it was great that people, for instance who get cancer, could store their gametes for later use. She referred to a case that had been in the media where a woman had a child after her husband died from cancer. (1)

She also talked about the potential for gamete storage to be used by women who choose to delay child-bearing. Gamete storage could allow for them to store their young eggs for later use when with their older age their fertility has dropped off. Projecting in to the future she actually thought that this is what young women are going to have to do. “Why should women have to suffer because we want a career?” She asked. Gamete storage could increase the control and thus the choices available to women. (1)

Some hui participants could see positive uses for gamete storage. One participant said this technology could be used by young woman who go through early menopause; that their eggs could be kept “so that they can use them later.” (K) Similarly, women having to undergo chemotherapy could do the same.

Put that kind of spin on it aye, it becomes a positive. I can't see how you'd see it as a negative thing. (M)

The men's hui and the Māori health workers' hui did not think that gamete storage would be a barrier to Māori accessing the services. (M)

If you've already made the decision to go down that track you've kind of bought into the whole process. (H)

Other informants suggested that there were a range of concerns that would come up for Māori around gamete storage.

Anything being stored is an issue. (7)

That all sounds a bit bizarre to me I have to say... in the realms of science fiction... it just seems a bit unnatural to me to freeze something to save it for later on. (6)

One informant was concerned that consent is gained, for example, she hoped consent had been gained from the man who died as in the case above. (3) Particularly though, informants thought concerns would be greater when considering freezing embryos. (12) As one informant said she felt that it would be “culturally strange” to have eggs sitting around in storage. (3) About this, another informant said he'd heard that “there are thousands of these little entities around the world and people don't know what to do with them.”

One informant asked “how long do they last? Do we know yet?” Another informant said he'd heard people asking ‘does the embryo get old?’ This was a valid question, he thought, because one of the problems, he said, was that Dolly and other cloned animals aged early. (8)

The rangatahi grimaced when they learned that embryos could be frozen and stored.

There's a baby waiting. (R)

The takatāpui hui joked, “do you still call it whāngai when it’s frozen? Makariri whāngai. It just sounds wrong.” (T)
People wanted to know if you could freeze sperm yourself and they asked “is there a shelf life?” The thought of leaving gametes frozen for use by future generations was shocking. “Jesus. Crikey.” Someone exclaimed. (T)

A men’s hui participant said that Māori look at rocks as having a mauri, so frozen embryos must also have a mauri, he thought. (M) A takatāpui hui participant was similarly “very uncomfortable” with the thought of embryos being frozen. It depended upon when “the wairua enters the baby.” If the wairua enters the baby at about 5 or 6 weeks when the eyes are formed, then the frozen embryo does not have a wairua yet. But, if the wairua of the child enters at conception, they would ask “when you freeze the embryo what happens to the wairua? Is it just suspended?” (T)

Disposal

More than two-thirds of informants added to the thread on disposal of stored gametes. They wondered what happened to the stored gametes when they were no longer needed. Do people forget about them? (6)

All these sort of anti-abortion people out there in the world they’re all saying well horror, horror you can’t destroy them they’re human beings you can’t destroy them, there’s life there, how can we dare destroy it. (14)

As one informant said Māori have not had the opportunity to explore this topic yet. (11)

Do you bury them or do you just chuck them out down the sink? (11)

Another informant said he knew that some women had a full tangi process when they lost a child through miscarriage and then there were others, he didn’t know what they did.

As a Māori, what is the tikanga? (6)

Another informant thought that we need tikanga developed to cover storage and disposal of gametes. (9) And another informant stressed the importance of having respect for the gamete, particularly embryos, and treating them “as something that’s tapu and needs to be thought about and respected at all times.” (2) She was sure there were or could be nice ways to dispose of gametes. For example, she thought there needed to be places, such as, within a conservation area where people could bury gametes and there needed to be an appropriate process for them to follow. Especially this should be in place if the recipient died. She said there would need to be an appropriate process for “retrieving their goods” in a respectful way. Certainly she said they shouldn’t “get flushed down the toilet kind of thing.” (2)

One informant confirmed that there were indeed options in place and various ways people’s gametes could be given back to them. (12) That these options existed, was an example of how an “essentially Māori practice” had been adopted as best practice. It was good, this informant said, that people were at least given the option. (5)

The takatāpui hui talked about disposal.

I suppose disposing of them is an unkind way of saying, talking about it. Because it is still life beginning isn't it? Is it? I don't know. I suspect so... not at a medical level... But I think at an ethical level there's an issue.

They then discussed the difference between sperm and eggs and embryos.

Embryos I think would be a potential problem for Māori to consider because those potential products have life. Are life. They are life. They already have whakapapa aye?

Thus, if embryos are a life, “do we just say okay just flush it down the sluice” or do you “have an appropriate ceremony as in passing away?” (T)

I don't have any problems with storing... as long as it's not stored next to a takeaway bar or something. Or a urupā. (T)

Ownership

A few informants said that ownership of stored embryos was “fraught.” (4) Not only in terms of them being used after the death of the father, as in the case mentioned previously, but as another informant pointed out, couples separate.

It's hard enough sorting out the matrimonial property let alone the embryos... is this property? Are there property rights for this? (14)

Does the couple have to decide ahead of time that their embryos will be destroyed or donated? “Who's going to need counselling about that?” she asked. Will legal cases ensue? She thought it was “hugely complex” and advised that we “have to allow ourselves to recognise that we're probably going to make some mistakes even with our best intentions and our best hopes not to.” And, even if Māori had hui to discuss all the issues and come up with appropriate processes, she didn't think we could “sort all this stuff out... and I think we're going to make mistakes and we need to be ready for that.” (14)

The Māori health workers' hui were concerned about gametes being used after the donor dies. (H) The kaumātua hui also talked about consent. They implied that consent could change over time, for example, that someone was a donor could cause a dilemma for them “when you have a second relationship.” (K)

One participant told how her brother died in an accident. He and his wife had had one child together, but she wanted to have another baby to him. She reportedly, “asked if she could have some sperm to have a baby, but she was turned down because it had to be consented by him.” The participant thought this was “a shame.” She thought that his whānau should have been able to decide. The hui then discussed the need for husbands to “leave sperm in the bank” for their wives to use after their death. Like “a form of insurance.” (K)

3.7.11 Artificial Insemination

Informants considered both AI done outside of and within fertility clinics. AI as a procedure was supported, as one informant said, because for “people of reasonably normal fertility it’s a successful way of getting pregnant.” That is, the odds of getting pregnant using AI rather than “any of the artificial technologies” he thought were much higher. (8) AI was also seen to be closer to what would happen naturally. For example, an informant said “if there’s a way to get the husband’s sperm in to the woman’s womb that practice would be permissible because you still have blood lines.” (3)

Conversely, if AI was being used to insert donor sperm, rather than a partner’s sperm, then informants expected Māori to be more resistant to it. This would be because of the same “issues around genealogy and lines.” (12)

Although he personally didn’t have an issue with AI, one informant thought “a whole lot of cultural issues” come up when thinking about AI. Particularly, he asked “what’s the tikanga?” He wondered if AI, as a technology was appropriate to the culture and suggested we be looking to see if the culture informs us about the practice. (9)

DIY AI

A few informants preferred the do-it-yourself approach to AI. They knew of takatāpui who had pursued conception through private arrangements using AI. These cases, they characterized as open, saying there were good relationships with the fathers and all parties were involved.

They have a kind of open awareness and knowledge of each others’ whakapapa and they’re creating new whānau... and so my experience of that is actually really positive because the, I think, important factors are in place there. One is the openness of information and knowledge about whakapapa. Children are being born into a caring loving environment and will be fully aware of their heritage. All the whānau are aware. (10)

We were all involved in a sense, in different capacities... that was hugely important in terms of how we’ve continued to interact with what we’ve created, the person that we’ve created, and the way we were involved in the, in the creation of this child has continued throughout his life and I expect it to continue. (6)

However, with privately arranged AI the legalities, obligations and liabilities re parenthood and guardianship might not be as clear. (5) There also has not necessarily been the same level of testing, for example, for hepatitis and HIV. One informant was particularly concerned about HIV in the Pacific. (14) She therefore recommended that “anyone who wants to do anything related to artificial insemination, any person of any mixes or couples or whatever should have the right to access quarantining, testing for HIV, STIs and should be able to access best practice. Because they’re going to do it anyway.” She thought that the failure of the law to provide for privately arranged AI, was naïve. To protect everybody involved, including the child, donors and recipients “should be able to access good legal assistance.” (14)

A health workers’ hui participant believed that people were “well advanced in doing it at home” (H) but the takatāpui hui participants were particularly aware of do-it-

yourself assisted reproduction methods. They knew that takatāpui men were still getting asked for their sperm. One participant said that “there’s always been stories within our whānau that get us in stitches about how someone gets pregnant by so-and-so.” (T)

Within my own whānau, or second cousins even, there’s always ways and means of ensuring that they have a child, or they have offspring... without going through the bureaucracy of non-Māori services. (T)

The rangatahi were freaked out to hear that people did AI themselves.

Can you do it yourself? ...Oh my Lord. That’s freaky... I thought you needed professionals to do it... Wouldn’t it be like really unsafe to do it at home? (R)

They thought DIY AI carried a higher risk of transmitting diseases. (R)

A kaumātua participant thought, “That wouldn’t be done very often aye? Done at home.” And if it was done privately, one participant wondered if the people involved could do a private agreement through a lawyer. (K)

One woman who had done DIY AI said she kept thinking “I’m undermining it or I’m sabotaging the whole thing. All this stress. People do say that about you’ve got to relax.” (C)

The Indignity Of It All

AI within the clinics was seen by several informants as “a fairly invasive procedure” (4,11) and “clinical” (11) even though medically it is not seen as invasive. But as one informant said, “emotionally and in every other sense it is incredibly invasive.” (12) And then “there is the whole indignity of it all.” (12) Because AI is a procedure requiring women to, as mentioned previously, get up on the table and be exposed, some informants said it was important to acknowledge that some women might be uncomfortable. Talking about what’s going to happen beforehand was suggested as a way to help women manage their individual reaction. (4) Providing continuity of care, rather than having a different person administering the procedure each time was suggested as another strategy for maintaining the dignity of women. This informant called for consideration to also be given to “peoples past experiences as well” for instance, if they have survived sexual abuse they may have particular difficulties with invasive procedures. As another informant said, in some cases it goes beyond women requesting that they are cared for by a female provider, but that “it becomes necessary” that this is so. (12) Allowing partners to be present and to participate in the procedure was supported if that’s what the couple wanted. (6)

One informant wondered what the impetus would be and what the requirements are for “mainstream services to ensure that they preserve the dignity of their Māori patients.” She thought there needed to be “a whole lot of processes” in place to ensure that clients get to this stage of intervention “fairly intact.” (4) Another informant said that “there are ways that people can be more culturally sensitive” for example, she thought that “some people would rather be treated by a Māori nurse.” (2)

A few informants talked about the need to respect “the preciousness of life” and “the sacredness of our creating new life.” (6)

There should be a lot of sensitivity with assisted insemination because this is the start of a life. (3)

The rangatahi grimaced when they heard what was involved in an AI procedure. Even so, one rangatahi said:

I don't see anything wrong with it, if that's what you want to do. (R)

The health workers' hui thought is was “so invasive.” (H) One of the hardest things to cope with according to one of the consumers' hui participants was that even though, it was only one nurse doing the AI, it was a different nurse every time. The other thing she felt was that she was being milked, because AI is about \$900 a cycle every month and she eventually had to have IVF which was about a further \$9000. (T)

3.7.12 Ovulation Induction

The worst kind of attitude people might have about the process used to induce ovulation is thinking that the drugs used “generate monsters.” One informant said the same kind of baseless comments were common to the genetic engineering debate also. (8) Another informant wondered what drugs are used. She said, “You need to ensure that the drugs being used don't produce disabled children.” (3) Another concern she had was that the drugs could cause women to have more than one baby at once.

If you get five babies it has a huge impact on the relationships e.g. the male partner cannot cope. Anything more than one baby could create problems. (3)

Another informant was of the opinion that even though there were policies in place to prevent multiple births occurring, he said. “You're still likely to have twins.” (8) Some people, regardless of their ethnicity, are against use of any kind of artificial medicine (13) and among Māori there are people who speak against pharmacotherapy or anything that's put out by pharmaceutical companies. A few informants thought that these people would probably be against the drug regime associated with various AHR procedures. One informant suggested that resistance would vary depending upon the degree of intervention. For example, taking a pill, such as, Clomazene used to double egg production to increase the chance of conception occurring as a result of sexual intercourse or AI is probably is more acceptable, certainly to Europeans she said. (13) Whereas the more intensive course of drugs used during an IVF cycle could be a barrier for some people. Another informant thought that women generally, not just Māori women, would be reluctant to “resort to medication to do what your body ought to be doing naturally, and what you expect it to do, and what your Mum's body did, and your sister's and Aunt's, and why do you have to do this kind of artificial thing?” (12)

One informant said about Māori who are against the use of drugs, well “don't take them then.” She also said about the drugs used to induce ovulation that “there's all levels of risk.” (14)

One informant had heard from a woman that “it’s a horrible process,” that with all the hormone treatments “she felt like she was off her face all the time.” Thus she was of the belief that “it can be really, really horrible for people.” (11)

Some participants were amazed at what could be done with drugs and technology now.

That is really sophisticated. (T)

Some participants were okay about ovulation induction being used, as one participant said if the drugs help them to have a child he didn’t have a problem with that. (M) Other participants did not like the idea of ovulation induction, as one rangatahi said:

It’s unnatural and people might not want to use drugs. (R)

Some of the kaumātua hui participants were worried about the effect of the drugs on the eggs and that the resulting person could be “sick.”

What guarantee does it have for producing a normal child? (K)

Obviously if it doesn’t work then the tapu is violated. (K)

Someone else wondered “where does that hormone come from?” (K)

It was astounding to one kaumātua hui participant that we both “sanction the bill to stop our children having babies” and have them “go on the pill so you won’t have babies” and now want to use drugs “to help them have babies.” (K)

Whilst an informant said she had heard “traditional stories about rongoa being used for abortions and prevention” she did not know if rongoa had ever been used to “heighten one’s ability to conceive.” (4) One informant said that women experiencing infertility often used “herbal medicines, rather than European style medicines.” She had occasionally talked with Māori women who said they had used “traditional medicines.” (12)

3.7.13 In Vitro Fertilisation (IVF)

The drug regime and method of delivery involved in an IVF cycle were seen to be particularly invasive. Informants said “doing injections everyday is very invasive.” (7)

It’s a very gruelling process to go through so a lot of people will only go through one cycle and can’t face a second cycle, it’s just too hard. (13)

It’s a “huge commitment. It’s physical, emotional, financial, political” and “draining.” And ethically, “there’s all those big issues and each person and couple has to go through them.” (14)

One informant said that for some people it is “a huge thing” whereas others could “just do it.” (7)

One informant thought IVF was a moral issue. In addition to asking if IVF was culturally appropriate, he would ask “is it tika?” Is it tika to even consider using in-vitro fertilisation? (9)

Two informants were uncomfortable with the medicalisation of conception. That is, one informant said “it’s a bit of a machine this producing children from this in-vitro fertilisation.” (11) The other informant was reminded of a sociological argument that described doctors “as the high priests of modernity.” IVF was an example of what he thought was meant by that viewpoint. (6)

I guess this happens right throughout the health sector, is that doctors are framed or positioned as the creators of life. (6)

Whilst he accepted that medical invention is necessary in some cases, he believed it was “not the only way that it can be done” and he was concerned that medical interventions, like AHR, provided an opportunity for people to “abrogate their responsibilities and pass it over to the medical interventionists.” (6)

The concerns associated with removal of eggs from the body and storage and disposal of excess embryos outlined above were sometimes raised when discussing IVF. A few concerns are recapped here. One informant was suspect about the procedure and asked. “What guarantee is it that those are your eggs?” She thought IVF was “quite a horrific exercise” and it made her think people must be desperate to go through it. (3) As mentioned previously, some informants queried what would happen to unused embryos collected during an IVF cycle, (3, 4, 11) and “how do we view them” and how can we deal with them in an appropriate way and dispose of them respectfully? (11)

One informant was concerned that there would be a greater risk of a child from IVF, being a Down-syndrome child or having some other kind of condition. (5)

The interviewer implied that the best-looking embryo is chosen to be put back in, which one informant thought was strange a concept. He said, “You and I mightn’t have been the best one.” (8)

The rangatahi and the men’s hui thought IVF was good. (R)

That’s neat aye? Yeah. It’s awesome. Very clever. Tutū buggers. (M)

A takatāpui hui participant thought that if you got to IVF then “all other avenues” for having a child have presumably been exhausted.

By the time you get to the point, my assumption would be that you would have a consciousness or an awareness that you simply want to have a child. So you go like the clappers to do whatever it takes to have a born, healthy young thing, a child. (T)

There was some discussion that being conceived using IVF could have long term repercussions for the child. Thus, it was important for whānau to know and understand and for the parents to take on the responsibility of ensuring “that child’s cousins or other siblings and everything like that are actually knowledgeable enough

not to put that person down. Not to use that knowledge negatively towards them.” The participant thought that children could taunt: “Well you weren’t conceived naturally. Who are your parents? Who are your real parents? Who are you?” Being conceived through IVF or carried by a surrogate, could be another thing that people could use against someone. Transparency was important to “the safety of that child, and those children, through all their development as a growing person.” (T)

Continuity of care made one woman’s experience of IVF easier. She was able to have the one specialist do her scans, egg collection and transfers and the specialist also rang her with the results. She said they were able to develop a good rapport which meant she didn’t feel as hesitant or dumb asking questions.

In the beginning I felt scared to ask questions because you don’t want to be like an idiot. Or you ask questions and you think maybe I should know that before I came. (C)

One participant wanted to know if you could decide “that you would like to have two” eggs transferred back in. (H) A takatāpui participant also wondered who had the power to decide that and who chooses which eggs are going to be put back in and how did they decide that? (T)

There’s a policy to only transfer one egg in women under 35 to prevent multiples being born. But, both women who had been through IVF had “been lucky” to put back more than one each time. (C) A health workers’ hui participant suggested that this policy should be reviewed for Māori given some of the barriers to AHR.

Because of the expense of \$9,000 per cycle, or whatever it is, wouldn’t it be a better option for Māori to actually have more than just that one egg and implant it back into them? (H)

Another participant said though that if they couldn’t afford \$9,000 per cycle, could “they afford to bring up triplets?” (H)

3.7.14 Intra Cytoplasmic Sperm Injection (ICSI)

Few concerns were raised about ICSI. Informants who commented on it acknowledged that it is a specialised procedure and further along the continuum of intrusiveness, but for one informant it was “a means to an end” and “sometimes it has to be done.” (2) She didn’t see any moral difference between each of these AHR procedures.

Because ICSI might be chosen as an added procedure due to the health of the sperm one informant thought that ICSI particularly could raise issues for men, in terms of how they view “their standing and their sexuality.” She sensed that Māori men might be slightly more affected by this than Pākehā men. (12)

Two informants were concerned about clinical issues, such as, hygiene and preventing complications. One informant said she would be concerned about “getting germs.” (3) A further informant said there was a need to ensure “at this stage with this high intervention that you know people are informed and make informed choices.” (4)

An informant did not think ICSI had been debated in Māoridom. (7)

Participants wanted to know how much ICSI costs. (H) Given the high cost of the procedures at this level, and given that Māori “morbidity rates are high or suscept to them in a low category for reproduction... ICSI, could be a very useful way of shortcutting all those other processes. Together, I think with the surrogacy technique... that’s got to be a benefit for us.” (T)

When there are factors threatening success, like advanced age, another participant said “don’t muck around with AI, go straight to ICSI. So you are one step further along in the process knowing that part of it so you only have to hope is that when they put it back, it imbeds and you’ll be able to carry.” But, others asked, can you skip the other steps in the process? (T)

The rangatahi were amazed that ICSI was available, but one also said, it was playing God.

The men’s hui thought ICSI was “very interesting.” But, one participant had concerns about which sperm got selected.

The slower sperm, they must be no good... maybe the reason was he wasn’t meant to survive... It’s kind of like cloning. Is there a choice of who’s going to be developed now? (M)

It’s just another way of saying we’re of no use anymore aye? We’re just sperm donors. (M)

3.7.15 Surrogacy

Some informants recognised the benefits that surrogacy can provide, for instance for “people who’ve gone through cancer treatment and have lost their womb” surrogacy could be their only way of having their own child. (13) About surrogacy, two informants said:

I think that that would be the most generous and special gift that a person could ever give to somebody else. (2)

I think it’s a great way of having a child. (6)

There are different types of surrogacy which one informant said “raise quite different issues.” There is “a full genetic surrogate” who has genetic links to the baby or gestational surrogacy, “which means they’re just incubating the baby” and they haven’t got any genetic link to the baby. (13) The configurations possible were confusing for some informants and they struggled to find the right terms for people involved, for example, between “non-biological” and “biological mother?” (9)

Whāngai as the Cultural Precedent

There was one informant who thought there was no cultural precedent for surrogacy.

I don’t know of any precedents in our culture in which someone else had someone else’s baby.

He thought Māori “opposition to utilitarianism” would come into discussions about surrogacy. He concluded that, this science was unknown and therefore he said “there was no precedent. Therefore it needs a new tikanga.” (9)

Other informants, however, seemed to have fewer problems or concerns with gestational surrogacy. This is because the child would genetically be the child of the recipient couple, thus the bloodlines would be intact. The surrogate would just be “like the basket for the time” (11), “lending their body to carry the child” (3), housing the baby (2).

A few of them said that gestational surrogacy was akin to whāngai.

Whāngai means to nurture and before it used to mean to nurture after the child is born and now we have the technology to fly in helicopters and jet planes and we also have the technology to nurture before birth. The kaupapa is still the same, the technology’s changed. (14)

One informant asked. “Why should it be any different from whāngai?” And since whāngai is acceptable, “why shouldn’t surrogacy be acceptable?” (7)

Thus, one informant thought that surrogacy was “much more acceptable than other technologies.” She thought this was because “it is closer to the familiar, and closer to things that have happened in the past” like whāngai. (12)

The principle is nurturing family lineage and nurturing literally in a different technical capability. (14)

Surrogacy and the Integrity of Whakapapa

One informant thought it was preferable to have a surrogate who “is a blood relation.” (6)

One informant thought surrogacy was “cool. ‘Cos you’d only do it for someone that you were really really close to.” (2) She believed that she could whāngai or do surrogacy for her sister.

Current policy requires that people needing a surrogate have to find their own, but they may not necessarily know anyone who could or would do this for them. One informant thought this could be a barrier for people who don’t feel comfortable having to find their own surrogate. (12) So it’s not the most common AHR option, said another informant, who also pointed out that a further potential barrier was the need to apply for ethics committee approval once a surrogate was found. (13)

Surrogacy thus raises concerns about the integrity of whakapapa. At least, with the current policy the surrogate and recipient parent/s are required to meet each other. This was good, according to one informant because “that means that the line is transparent,” that “there is a whakapapa. That child will have a whakapapa.” (9) Another informant said it depends on whose gametes are used and the whakapapa of the gamete. She said questions would come up around iwi membership. For instance, would the child be able to claim membership of their genetic parents’ iwi, if Māori, and or the iwi of the recipient parent/s? (7)

Surrogacy: Under the Radar

One informant thought that IVF surrogacy provided through fertility services is actually “rare in New Zealand.” He thought that “spontaneous surrogacy is much more common.” That is, where people make private arrangements between themselves. He called this a kind of “social surrogacy” for instance, when a sister might have a baby for her sister but using her sister’s partner’s sperm. (8) Another informant had heard of a case where a twin sister did this for her twin.

The one twin carried for the other and they inseminated with not her husband’s sperm, so she was the surrogate. It was her eggs plus her sister’s husband’s sperm. They did self- insemination and she carried that baby for her. So surrogacy does happen, under the radar. (13)

To one informant, this arrangement was seen as preferable to going through a fertility clinic. (13)

The Legalities

Under New Zealand law, if you give birth to a child you are classed as the mother. This was raised as a problem because, the child could genetically belong to another couple and they have to adopt the child after birth. (11)

Because of the risk that the birthing mother could change her mind and decide to keep the child, one informant said surrogates should “be a mother already” and they should be sure that they “could be pregnant and stay sufficiently detached from the child” so that they “could give it away when it was born.” This informant thought she could only be a surrogate if she knew that the child “was from another persons egg and sperm but not if it was my own. If it was my own then a shared custody arrangement could be made but I couldn’t give up the baby if I knew it was mine.” She still thought that she would feel she had “a closer connection to that child than... to any other children apart from your own on the face of the earth, I think, because the child had lived inside you.” (2)

One informant said that “so much around these decisions has to do with the quality of the relationship of the people concerned and the quality of the relationship between the surrogate mother and the others involved.” (10)

Intergenerational Surrogacy

A few informants considered what the implications and reactions would be to a sister carrying a child for her brother. As one informant said, “they’ve made this thing with Māori that you can’t carry your brother’s child because it’s incestuous.” (1,7) However, she believed people thought it was acceptable for a sister to carry her sister’s child. She didn’t understand the distinction and thought it was acceptable to be a surrogate for a sister or brother. (1) Another informant said that whilst she “could see the tikanga behind that being something that Māori would be less likely to do” and she could understand why some people would say “it’s almost like an incest thing in that the seed of your brother should not be inside a sister” but if she did have a brother who needed her to be a surrogate for him and his partner, she said she would still do it. (2)

One informant explained that the problem was really “the perception.” Whilst, it wouldn’t be incest, it could still “have an impact on the child in the future,” especially if “no-one explained that your Dad and Mum’s egg was put into Aunty.” (3) The child would potentially have to cope with the public perception that there had been incest between their mother and uncle. She believed the same problem would result from a daughter carrying for her father.

That child’s going to have to live with it... People would never understand. (3)

The informant who said she would whāngai or be a surrogate for her sister if required, thought she could also be a surrogate for her father if, for instance, he had a new wife who couldn’t have children.

It would depend. If he was a great dad and you really wanted to have another sibling. I’d much rather do that myself than have someone more removed do it. (2)

One informant thought it was important for people “to go back to the whānau” and “have a whānau hui” to make sure that what they are proposing “is ok for their whānau.” She believed that it would come out sooner or later and the child would be the one that would “be marked.” She believed that if people were not prepared to involve the whānau in the decision “then we don’t think that that should go ahead.” (11)

Another informant also wanted the whānau to be involved.

Within whānau, often we can as I say, if they’re functioning well, we can often talk about the implications and then deal with the implications if everybody is in agreement. (10)

As some informants said “it’s the relational things that get messy” (9) and some cases can get “very complex.” One informant said it was easier to follow using diagrams. “Without diagrams, I get very confused in this area.” (7)

The concept of surrogacy and the technique involved in assisted surrogacy was new to some participants. One rangatahi participant thought it was “cool” that someone’s embryo could be inserted into a surrogate? (R)

I think it’s great that somebody else can have, can carry your child for you. (R)

One of the men’s hui participants said his sister had been a surrogate for her best mate (M) and another rangatahi participant knew of somebody who had offered to be a surrogate for a cousin who couldn’t have a baby. (R) One kuia at the health workers’ hui was relieved to hear that an egg could be recovered from her daughter, put with the partner’s sperm and then implanted in to the daughter. As she said:

My son in law ... knows about how you can find a surrogate person to have an egg and have a child, but that would mean my daughter would have no play in. But now that you’ve told me that you can get an egg, an egg of hers and sperm of his and then they could be put together and put into my other daughter, that’s good. Ka pai. (H)

One kaumātua hui participant thought that support for surrogacy was widespread. She said that if a person went on TV and said “that they want somebody to be a surrogate for them... they’d be overwhelmed with the amount of people that would turn up.” (K)

Another participant told of a woman who “went out and got herself pregnant” so her brother and his partner could have a child. Since her intention was always to give the child to her brother, and the brother and his partner “more or less was with her carrying that child all the way through... went in and she cut the cord and she had her baby” the participant likened it to surrogacy – “like a private one... This was the same thing ... it was like they’d given birth to that child. It was quite lovely.” (K)

The only issue, one of the men’s hui participants could think of, was the actual burden of “carrying the child.” (M) But as the following kōrero shows, there are a number of practical barriers to surrogacy to be overcome and negative opinions and attitudes about surrogacy to be faced.

One of the women experiencing infertility said that a sister had offered to be an egg donor and surrogate if needed. But, as this woman said:

It’s not just something that you pick up the phone and say I need to borrow your womb for 9 months ...It not only affects her and I, it affects the extended whānau as well because not everyone is going to be happy with that arrangement. (C)

Current policy requires people to find their own surrogate or at least it is probably easier and faster for people to find their own surrogate. They then have to apply to ECART for approval and that could take up to 6 months, providing sufficient information has been supplied. ECART apparently prefer surrogates to be under 35, but this woman’s sister is 36. Both parties need to attend counselling sessions and get legal advice.

As the above quotes show there is a tendency for whānau to look within their own whānau for surrogates. Which one health workers’ hui participant thought was “okay.” (H) But, some participants expressed reservations about who within the whānau could carry for whom. For instance, there was support for sisters carrying for sisters, but questions about sisters carrying a child for their brother. Carrying for a whānau member of another generation, for example, a grandmother being a surrogate for one of her children was also worrying for some participants. (R)

One health workers’ hui participant wondered if it was even medically possible to carry for a brother or a male first cousin. She thought that maybe the baby would biologically reject the surrogate. As she said:

Well it’s frowned upon first cousins having babies. (H)

No. I don’t know if I could carry my brother’s child. ... Yeah, definitely with my sisters. I don’t know if I could do it for my brother though. (H)

Other participants thought it was “alright” (R) for a sister to carry for her brother and his partner. As one of the men’s hui participants said “it’s just a perception” that “it’s a sexual thing” and he said “if you have it spelt out to you properly, a lot of those people with notions around it, you can actually convince them to look at it in the right manner.” (M)

Another participant thought that the surrogate would need to be quite clear about how she was thinking about her role. She said:

You haven’t got anything to do with it. You’re just a womb.

She also thought there needed to be “really good education around it so that people fully understand that” the surrogate is “just the house... otherwise they’d think it was incestuous.” (H)

But one participant worried that thinking that you were “a vessel” could be detrimental to the mental health of the baby you were carrying. As she explained:

When you’re pregnant they say that you should take time out and meditate... even the hormone reaction that you’re sending through to your children... and then if you’re just thinking I’m a vessel, are you depriving that of the unborn child? ... That’s 9 or 10 months that a child hasn’t had maybe possibly that nurturing ... You’re the only one that can feel it moving and ... then given to a voice they might not have heard so much. What does that for attachment issues? ... with mental health they always refer back to ... inside the mother’s puku and all the things that happen and the outside environment and how they affect pregnancy. (H)

On the perception aspect, a rangatahi participant knew of someone who had been a surrogate and even though people knew she had been a surrogate, they “still go up to her and go, ‘Oh how’s your baby?’ And you know she doesn’t have it.” (R)

One men’s hui participant said he knew “a lot of the old people these days don’t like that aye? Someone else carrying. ... And they’re not all that old, late fifties.” He thought it was because they didn’t want babies being taken away to another iwi.

In our iwi, you know, we expect our ones to stay in our iwi. Not to go out to another iwi. (M)

He added that he wouldn’t want his own daughter carrying for someone else.

I wouldn’t want my daughter to be a rent-a-womb for someone else... you carry our blood. You carry your baby. (M)

In a similar vein one participant wondered “if you are a surrogate mother do you say, ‘oh, I will just do Māori’.” (K)

This kind of thinking again points to the importance that Māori place on the whānau and that surrogacy, impacts on us as whānau and therefore whānau need to be involved in talking about surrogacy. (T)

Some participants wondered how surrogacy would impact on whakapapa. For instance, one participant asked “if you are ... recording whakapapa where does that child’s name go? Does it go under the birth mother who birthed that child or under the parents?” (H) The rangatahi hui thought that the surrogate mother would not be recognised in the whakapapa, it would just be the biological parents.” Then one of the rangatahi asked “Are they still known as the biological parents? Like if it’s their embryo, are they still biological?” (R)

The surrogate mother, I mean, she’s just the kete. She’d be probably acknowledged but not in the whakapapa sense. (R)

The kaumātua and rangatahi hui thought it was “weird” (R) that the biological parents had to adopt the baby under current NZ law.

It’s a bit rugged. It’s their eggs and sperm. A bit rough. (K)

The rangatahi said the law needed to be changed. They thought that the person giving birth should sign something that says that they won’t keep the kid. The rangatahi were aware of cases overseas where surrogates had changed their mind and decided to keep the child.

It’s hard because with adoption you’ve got seven days or something, haven’t you? To change your mind and say, no I’m going to keep the baby. But if you’re a surrogate, do you have the same right to change your mind? It’s not your embryo, it’s somebody else’s. (R)

3.7.16 Pre-Implantation Genetic Diagnosis (PGD)

Several informants supported PGD (3, 8, 14). PGD is available for people who, because of a family history or increased risk of a genetic disorder, such as Down Syndrome, Huntington’s Chorea and Haemophilia, can apply to have tests done on their embryos prior to implantation. They therefore have to undergo IVF to get it, even though they might be naturally fertile. Whilst testing could be done after an amniocentesis, PGD takes the diagnosis back before implantation so women don’t have to abort if the genetic disorder exists. (7) One informant thought it sounded like “quite a traumatic experience to go through, just so that you could check for genetic disorders” but accepted that it would be less traumatic than finding out after an amnio and having to make a choice at that stage to terminate. She concluded that if there were four embryos, for example, resulting from the IVF cycle, then it would be “far easier to make a decision about what you do at this early stage.” (2)

One informant supported PGD, saying that he thought it’s a decision that needs to be made by the couple. If they are faced with a greater risk of having a child with a genetic disorder, they should know there is an alternative to that risk or that PGD could reduce that risk. “I think that’s fairly acceptable” he said. He said there was another argument “about rights,” the right to know, but he asked also “is it good for you to know?” (8)

It wasn’t the horrific diseases, so much that he was concerned about preventing, as he believed they were very rare. It was more important to reduce the occurrence of disorders, such as, Down Syndrome, he said.

And the ones that are totally fatal don't seem to me to be so important because you're not burdening the family with a child that is a major burden for the rest of their lives. It's the ones where there are things like the Downs that are a bit more difficult. (8)

Whilst one informant said she was “supportive of people with disabilities” she also said that “in today’s world we have a responsibility to prevent” the disabilities from occurring in the first place. (3)

It's our responsibility to prevent those disabilities happening. (3)

One informant was against PGD. For her, she said “that’s where things start crossing the line... I don’t think that’s right.” Personally, she and her partner would not abort regardless of the existence of a disorder. So they don’t even have the tests. Where a pregnancy wasn’t going to “come to fruition then it’s probably no point in proceeding. I think that’s probably a case where people need to make their own decision.” (2)

As for testing for Down’s or Huntington’s she acknowledged that these were disorders “people would rather not have... but for me, Down Syndrome isn’t something which should prevent someone from living.” (2)

I'm not saying that it's an easy thing to have happen, to have a child who is born with it, but I think to deny people life when because they've got something that you don't see as normal... (2)

Another informant thought this was a controversial procedure because “there’s some Huntington’s Chorea people who’ve had really worthwhile lives and some Down’s people that have worthwhile lives.” She didn’t like the idea of “making designer children” and was unprepared to support using PGD to prevent Down’s, but she did “like the idea of getting rid of terrible disease or having a choice to have a child be born without haemophilia... I can see that quite clearly.” (7)

I think variability of society is very good. (7)

One informant said that when she was a child, “handicapped” children “were just considered like part of our community and that was all there was to it... you just had to learn that those people had to be respected and looked after as well and it was just taken for granted” She believed that Māori were an “inclusive race of people” who accept people regardless of their abilities. (11)

PGD is a particularly big issue for people whom it affects. For instance, disability groups. Disability groups do not define disability in the same way. (10) As one informant said, “potentially it’s society devaluing their right to life. It’s society judging the quality of life that they have and I think it’s to do with issues of tolerance.” (2)

Potential Uses of PGD

One informant was concerned that whilst PGD could only be used currently to test for known increased risk of a genetic disorder, “in five years or so, probably five to ten years, it’ll be used routinely in IVF.” (13)

One informant was worried that PGD could eventually be used “to screen for other genetic factors.” (10)

That’s scary, if we at some point decide that it’s okay to go into other areas of screening. (10)

For instance, a few informants said it was frightening that PGD could be used to test for and aid gender selection. Gender selection is illegal in New Zealand, which one informant said was “fair enough” (3) But, another informant was sceptical. He thought it would be easy enough to choose to implant the male or female given the clients preference. (8)

A further concern raised by two informants was that, “if they identify the gene for gay, lesbian, for homosexuality then” PGD could be used to avoid having a homosexual child. (6, 10)

One informant was “not convinced that taking a single cell from a developing embryo long term is going to prove to be safe.” She preferred the use of prenatal amniocentesis rather than PGD. (7)

I worry about the cell they take you see. What’s gonna happen in the future with that? (7)

Again, some Māori would ask: he aha te kaupapa?

What’s the kaupapa? What are the outcomes? Who’s the beneficiaries? (9)

One informant said we should “look at the long-term outcome.” On parallel topics such as xenotransplantation, he said some kuia looked at the intended outcome and concluded “on the basis of the good that was going to come out of this research then they said you keep an open mind on the matter.” (9)

Since PGD was so new to New Zealand there were lots of questions about how it could be accessed and how much it would cost. A participant asked if there was any public funding for PGD if it was needed.

Some participants thought PGD was a good thing if it could help people to avoid having to, for example, nurse a grandchild through a horrible and fatal illness. (K)

If I had a history of that in my family, I’d be looking at that ... I think it’s a good thing. (R)

Whilst, another rangatahi thought it was weird to be able to do PGD they also thought that “some of us will have to come to accept it one day if that situation comes around.” (R)

Participants at the takatāpui hui were also for “getting rid of disorders and diseases.” As one participant said “if you’ve got a crap life, because of the quality of your life, reduce it.” Thus PGD was seen as useful for people who do suffer from genetic disorders. But, one participant wondered how successful the procedure would be at

eliminating the possibility of the targeted gene “appearing further down the whakapapa line.” (T)

Whānau who have had babies with some of the disorders that PGD can be used to detect, may feel differently though. As illustrated by one health workers’ hui participant’s story. A whānau member gave birth 4 months prematurely to twins. Both were born deaf, one had cerebral palsy and the other had problems also. She came from a very strong Catholic and Anglican family who viewed children as a gift.

They’re our miracle babies because they were never supposed to have survived at all ... she would never, ever, have aborted because she believed that babies were a gift, that she was meant to be pregnant with them and she was meant to have them early. (H)

But, as one kaumātua hui participant said, “where do we draw the line? Should we screen for diabetics, those that are going to have pain from diabetes or heart disease or... What about diseases that have major impacts on the rest of us... Type 2 Diabetes.” (K)

It’s the hereditary things that we get in our whakapapa, that comes down to. Where we got them from? We don’t know. (K)

One woman who was experiencing infertility acknowledged “the moral issue” in “choosing what genetics you want.” She acknowledged that there were different opinions on the subject, but said that she felt there was a view that people who were having trouble getting and staying pregnant should be grateful to accept what they can get.

You’re getting too fussy. You take whatever baby you can get if you can’t have children... If you really want a baby you will have a Down Syndrome baby, it’s just a baby. (C)

Te tapu me ērā atu mea, kua e tutū me ngā ira tangāta.

PGD did raise questions and concerns for participants. They wondered if we were mucking around with human natural reproduction too much and talked in terms of PGD being a “cleansing process” (T) and they associated PGD with eugenics. They wondered how far this technology could go and worried about how it could be misused. For instance, access to PGD is restricted at the moment, but one participant believed it could eventually become a commonplace procedure for women using IVF replacing the need for an amnio. (C)

You sort of look at it and you think, shucks... are we mucking around too much with trying to get pregnant. And what implications do they have for us ... are we actually mucking around with human nature too much? ... It’s kind of scary when you can already tell whether or not the baby that you’re carrying is going to have something wrong with it and you’ve got an option to terminate... I guess... if you’re desperate for a baby, you’re desperate for a healthy baby. (H)

Despite being reassured that PGD could not be used for sex selection, a few participants were sceptical. One said sceptically, “really?” (M) And another said, “Yet.” (T)

The takatāpui hui worried that it might be discovered that there is a gene that predisposes you to be takatāpui, “and then people might say that you don’t want that gene do you? It might go too far.” (T)

Partly, participants could see why PGD was a controversial technology “because you can even tell if your baby has blue eyes or green eyes... It’s like Hitler wanted aye, a pure white race.” (M)

They could do away with fat Māori noses too aye? (M)

That’s not what life’s about aye? You’re meant to take the beauty is in the eye of the beholder. That little defect you see in that person is something you may be attracted to. (M)

One kaumātua, said, “I might end up having a frog for a mokopuna” then explained “that’s how my whakaaro is thinking because” of all the choices people have now. She said “it’s like yeah just dial a baby.” She imagined people would be able to specify that they want “a blue eyes baby with blond hair, that’s going to be Arnold Schwarzenegger.” But, she said, “it’s all false.” She reiterated that what was important for Māori was “tika and pono and all those things.” (K)

The takatāpui hui concluded that “this type of technology could be manipulated and it’s something that we shouldn’t just accept.” One participant thought the moratorium on genetic modification was a useful parallel that should be applied to PGD. But, another participant asked, “is this genetic modification?” At the very least a participant thought that PGD should be subject to ethics committee approval processes. (T)

Can I go back to this metaphor of a kūmara? Is it a bad kūmara or is it a good kūmara? I’m starting to think the bloody thing is rotten... it’s starting to make my guts churn. It’s starting to make me feel weak in the legs. (T)

One participant said all these issues needed to come under iwi authority. But then another participant questioned that “even if it went to our hapū, or our iwi... I would still question the control associated... as humans we are trying to control something. Something we have no control over ultimately.” (T)

It is, who is doing the controlling? To what end? And I just always ask that question. (T)

A different perspective was that PGD was not that strange a concept to Māori as they have always manipulated genetics.

I think that all our tīpuna, sort of had a, they did it in a different way. Through whakapapa. They chose to some degree, our ancestors did choose to some degree. (T)

4. FERTILE GROUND FOR MĀORI INVOLVEMENT

In this section, informants' suggestions for improving the involvement of Māori at all levels, from a policy level to provision of fertility services, to improving access as a consumer are presented. Ways to improve fertility outcomes for Māori are proposed, along with ideas on how to prevent infertility at a primary level. Whether or not there is a place for Māori in the provision of fertility services is also discussed.

4.1 Primary Prevention

Several informants said there was a need to raise awareness of fertility, infertility and AHR among Māori and that this would most effectively be done by Māori. This research would play a role in doing that. (1) "Appropriate levels of information" needed to be shared and made accessible to ensure Māori are better informed. (6) Appropriateness of the communications needed to take in to account that "it's a tender subject and is culturally sensitive to women regardless of race." (3)

Audiences for the information were identified as the general public, school children, and women and men.

Someone has to educate the public. (3)

Two informants thought that school "is the place to begin talking about fertility and protecting your fertility" (12) but the other informant wasn't sure what type of education or at what age it should be delivered to children. (3) She didn't believe that the current level of sexual and reproductive education was happening and any way she would rather it was delivered by Māori for Māori.

We need our own people to educate our own. (3)

One informant thought a special effort needed to be made to get information to men. She said that "men don't like the fertility issue being the thing that they go and find out things about." (1) She suggested that the topic be incorporated into hauora tāne information so men could hear about it opportunistically.

A few informants said that addressing "the lifestyle choices" which impact on infertility prevalence is going to help reduce infertility prevalence. (5) For example, reducing the prevalence of and treating STIs and reducing smoking. (8)

Firstly, the takatāpui and rangatahi hui suggested a need to look at prevention of infertility (T) especially if our fertility rate has dropped off (R).

There should be groups out there to help instill better lifestyles. Like just help people get jobs and education and make it easier for them to do that. And just promoting non-smoking and stuff like that, bring the fertility rates up. And then also incorporating the tikanga Māori side of it. (R)

Secondly, as one participant said "basically nobody knows anything about it." (M) Thus, many participants talked about the need to get information about fertility, infertility and AHR out to people.

We must get some money and take this out all around for other people. (H)

Many participants said people need to know about and have access to information about all of the support systems (T) earlier when they are still in their youth. A health workers' hui participant believed not enough was done to promote "planning your fertility." She suggested that "maybe at 17" years old, rangatahi should be encouraged to think about and start planning their future. (H)

For takatāpui as well, all the information should be available at the Rainbow Youth (a support group for takatāpui) end of things "rather than at forty year olds trying to find out about how to do it... because we only figure this stuff out when you get to your forties and think shit, better hurry up." (T)

The rangatahi participants confirmed that they got no information on infertility and AHR at school.

It's more about contraception and being safe, and don't get pregnant. (R)

They said that they were taught about human reproduction "in science." But, the rangatahi also felt that there needed to be more education about infertility and AHR.

It needs to be put out there. They need to understand, you know, how important it can be for us. (R)

The kaumātua also wanted to know what was available. Because as one kuia said, "we have to support them... So it's good for us to know what's happening." She said, "we're there to help them as their whānau... Especially in our Māori tikanga ways."

When our kids come to us now and we hope they don't have this problem but if they do have this problem, we've got the knowledge now. Or hope we can keep it and support them if they come to us and say this but without being horrified and up in the air. We can understand it a lot more from what you just told us. (K)

The men's hui said health professionals needed to be trained as well.

You need to get those health professionals up to the plate so they know. (M)

Education Strategies

Because of the perceived widespread lack of knowledge among Māori of infertility and AHR, one man said "start anywhere." But, he stressed the need "to get the right information out there you know? Not that scare reporting." He warned that reporting about cloning and even just the word genetic "scares a lot of people" and this could be a barrier to effectively reaching people as "it would stop them firstly from investigating it." Thus the quality of the communication was important "because if you don't get it right in the beginning, then it can shut everything down." (M)

Marae Based

Participants said the strategy for taking this information to Māori should be controlled by Māori. (T)

It's getting to talk to people face-to-face... It's getting Māori to face, to grasp it. (C)

Using word of mouth, the information should be taken via hui “into the community” and should involve people “from the community... so that it's actually the people” who have experienced infertility or people who haven't been able to have more children despite their desire to, that tell their stories. (H) The hui would need to be prepared to provide support to those communities that come.

I think it should be marae based. Well whatever it is then the control is with the Māori. (T)

A takatāpui participant added that “if you actually are able to do this marae based you will probably actually in some way help us out as well to get our whānau talking about those issues. To actually have other perspectives given which aren't heterosexual.” (T)

The health workers' hui suggested that the researchers “get your group together” and go throughout Aotearoa. They gave an example of a similar strategy used by “the late Doctor Eru Pōmare, Vera Ormsby, Irihapeti Ramsden and their kaumātua from Christchurch.” (H)

It should go out to the people. (H)

Because the information isn't necessarily easy to communicate simply and quickly, the men thought there should be at least two health professionals to run workshops on it. The information would then spread to others. (M) Māori media, such as Māori magazines and Māori Television should be used to raise awareness of the issue also. The men's hui said it would be good to have information available at “Māori events that they have all up and down the country.” The health providers who have stalls at these could add information on infertility and AHR “to whatever it is they're promoting.” (M)

Only the men asked if there was a pamphlet they could take away from the hui.

This kind of strategy however, would need funding. (H)

One participant suggested getting information “out through our health providers.” (T) It was not clear, however, which specialty of health professional would be best to take on this issue. The health workers' hui thought that midwives should know about infertility and AHR but they said there was a gap in service to Māori women after postnatal care. Services providing to Māori women, such as cervical screening, could take the information out to women also except they were usually limited to talking just about cervical screening. The hui wasn't sure if infertility naturally fitted within sexual health as the existing sexual health organizations didn't seem to touch the issue. As one participant said, “I don't like to tie it to chlamydia and STDs.” But it needed to be mentioned, “because most people don't even realise” that untreated chlamydia can lead to sterility. (H)

4.2 Increase Public Provision of Sexual Health Services

It was suggested that existing sexual health and Māori health services incorporate infertility in to their information on sexuality, because infertility should be dealt with within “the context of sexuality and life.” (4)

At a primary care level, health professionals could ensure clients understood their reproductive cycle. For instance, one informant suggested simple things like showing clients how to use a menstrual calendar, possibly a temperature chart and undertaking some preliminary testing such as a sperm count. (8) Another informant was “not so sure that’s actually what happens.” (5)

The health workers’ hui thought that Family Planning should provide information on infertility and AHR, but they didn’t think Family Planning currently did anything on this issue.

It’s all about young people and stopping the STIs, and stopping unplanned birth. But to me the whole family planning is me as a person, myself... and how to conceive naturally. (H)

4.3 Māori Friendly AHR

One informant did not believe that existing fertility services were meeting Māori needs. (11)

Another informant said it’s important to have accessible information to read before going to the fertility service.

It’s important people understand it before they go there... I’d need half a day with the doctor before I got on the bed. When you’re conceiving a child you want to be in a good mood, not cringing. (3)

Another informant stressed the need for the intervention process to incorporate and allow for “that to be special and thought of sacredly at all times.” (2) For example, another informant said “there must be some way of ensuring that if that couple wants their family to be involved that there’s some way that that occurs” and that if they want to “they should be able to have some sort of arrangement where they feel that it’s a family event.” (4)

I suspect that once you’re going down this whole track of using infertility services to have a child, that family becomes extremely important and the support of your family becomes, your need for them is heightened. And so there must be some sort of mechanisms for ensuring that if the couple want their family involved that there’s a capacity for that to occur. (4)

Involvement of the whānau is important for a number of reasons. If mātauranga Māori me nga tikanga Māori is recognised, then the whānau should be consulted because they have integral rights and responsibilities. As one informant explained, whānau rights or the rights of the collective have been supplanted by Christian beliefs and practices that give precedence to individual rights. For instance, she spoke about the

process of seeking ethical approval for AHR procedures. The ethical approval process focuses largely on the individual and does not require that individual to “consult the rest of the whānau.” (11)

Whānau involvement is important also because of the effects of going through the process of AHR.

Some of these processes, they're hugely invasive and knock people around dramatically. (11)

Whānau Support

The kaumātua hui particularly talked about the role of whānau support. One woman said she would “like my whole whānau to be involved as well. Because without them I would be nothing.” She said she “would want to go out and show all my whānau that I am standing up to use this new technology... and, I would go out and use this technology to help others.” (K)

It's important to have whānau to support you because they will also be part of the make up of that child. (K)

The participants talked about the desire of kaumātua and other whānau to be able to support people right up to and including going in to theatre with people. For instance, they said that “the man is allowed into the operating theatre when the wife is having a child. Why can't the support person? ...it might be the nanny or the kaumātua.” If that's what the woman wants, then she should be allowed to have that level of support. (K)

The woman who had been through fertility treatment said that services needed to explicitly let people know that it's okay for them to take whānau support in with them, because in her experience they didn't do that. (C)

Whānau have responsibilities and may be called upon to awhi whānau members going through AHR. One of the things we need to know, through further research, is: are whānau mediating? As one informant said, she did feel that her whānau “did mediate some of the harsher effects of being infertile.” But she wondered, “Is there more trauma because you're Māori and you're infertile.” (10)

Fertility services need to recognise and provide for, whilst remaining flexible about cultural beliefs and needs. As one informant explained, some cultural concepts “are extremely important” and they need to be translated “comfortably into the contemporary world.” But, they shouldn't “be used to limit Māori's ability to express themselves.” For instance, she said “we have to be careful about setting cultural mores and beliefs and values because practitioners accept them as conceived wisdom and they then apply them and don't allow Māori the right to say ‘Yes I want this’ or ‘No I don't’.” (4) Not every Māori couple is necessarily going to want to observe any of the range of cultural beliefs and practices that would be appropriate.

Participants had a number of suggestions for how fertility services could make their services more Māori friendly, and thus more accessible to Māori.

Having a Māori name for the service is, one participant thought, “a start.” Services could be asked to describe “what else have you got other than your Māori name that helps make the service more accessible for Māori.” (C)

Allowing for cultural diversity was one theme. As one woman said, if she was infertile, it would be very important to her that her tikanga was respected. As she explained it:

It would be mostly that it wasn't compromising other people's view of me. (K)

She said she would “need all the support around me that I could get” and she would want to follow tikanga, and act in accordance with her cultural values. (K)

But other participants said that not everyone would want to do karakia, because “we're different people” and we will utilise what we need to. (T)

The takatāpui hui said “you can only encourage people to practice cultural values.” (T)

One participant who had experience of fertility services thought services could do more to make it alright for people to uphold their tikanga. She said it shouldn't be left up to the client to be staunch when they're in that situation.

You have to be pretty staunch Māori to say, hang on a minute, we haven't done our karakia. Because it's all officious... (C)

At a pragmatic level, a takatāpui participant said the language needs to be accessible. She gave an example of getting test results she couldn't understand.

It's all gobbledygook... looking at numbers, foreign words and gobbledygook doctor speak. It was a barrier to me. I freaked out. So with this stuff I think it's making it, providing first rate information but not in a complicated way, but in an overly explained way would be really helpful for Māori. (T)

She also said “you have to be pretty tenacious” to ask for clarification and explanation.

Some of the barriers to accessing AHR services would be the same as for any other health service and providers needed to do everything they could to reduce the financial barriers. For instance, the Māori health providers talked about how they follow up, how they go to people's houses, even though they're not paid to do it.

*We don't get paid and we probably should... It's about getting the car and going to their house... the issues for Māori for this specific **take**, they're across the board in just about everything, the services that are to do with Māori and it's accessibility, it's cost, whether or not the woman actually understands what is happening... It's exactly the same issues with cervical screening as what it is for here. (H)*

A further barrier identified was fear. Anything fertility services could do to help people overcome that fear would be useful, particularly fear that inhibited people from taking the first step towards treatment.

They're frightened. They don't want to make the first step. (K)

Involving Māori services to provide information and to then support whānau wanting to investigate if AHR is for them was one suggestion that was made. Another option was to have more Māori actually working within fertility services.

One consumer of fertility services said it was important that everybody be professional, but she also thought there could be more “aroha.” (C)

One suggestion was for fertility services to appoint a Kaiarataki, a person on a part-time basis, perhaps a kuia who was retired and had the time and inclination to do this sort of work. This would give Māori the “option of having somebody with them who has not a doctor's knowledge of it but almost a bit better than the lay person.” A Kaiarataki would also be able to support staff who might have questions about how to work better with Māori. (C)

Just having a brown face with you sometimes, somewhere gives you a feeling of solidarity or something. (C)

Just to see a Māori face. Having a darker face, gives you a bit of a smile. (C)

The men's hui talked about the importance of the health professionals' manner and how they speak to Māori clients. The consumer hui talked about this too in a more detailed way. Two women had not liked the way in which the nurses relayed negative results.

They don't even ask can you talk. Or are you able to take the call. You could be at work for all they know. And they're going to tell you no, well you're not going to sit there and carry on doing your work for the rest of the day. It's the same as if you ring for test results, some people numbers matter to them and they want to know what their numbers are and what their levels are, or anything like that. And if you ask you get a sigh, 'hang on, I'll get your file' and all that. (C)

This woman said she felt like she was just “a number or a name that is getting ticked off on the list and they are saying to you yes, no, yes, no or whatever”.

You have chosen to go there, you should be treated with respect when you go down that road as well. (C)

She said she shouldn't have been treated like she was being a bit of a hōhā.

I've rung the clinic sometimes and I thought oh god I don't want to talk to her and just hung up.

The other woman said it was similar for her when she asked questions, for example, after having a scan.

You have just had the scan, or something, and the doctor is still there and I would ask questions and it was like flicking through and it was like, sigh... it was like now I have to explain this. No. We haven't got time we've got too many people to see. So, time, time, time.

“Time is money,” the other woman said.

It is like that and it was really hard to actually even ask questions at that point because of that feeling that they've got so many people to rush through. And yet you could be sitting there for ages waiting for bloods to be taken.

One of the woman said that she decided to have the result put in writing and left at reception for her to pick it up.

It was kind of a god-like thing, that they can ring up and say I'm sorry and you know straight away.

“Yeah, but they know that it's devastating news, for Christ's sake.” The other woman added. The hui wondered if the nurses become blasé about it after a while, and forget how hard it can be for people. Another participant said it's a hard job to give bad news. Still the hui thought “it wouldn't hurt for them to ask how they would like to be told. Or you know lets take a second and go through it.” Another participant said it sounded like it was “quite cold and detached and professional” and that there wasn't “enough whānau, aroha ki te tangata stuff.” (C)

The hui then talked about how the services should ask how they could improve what they are doing. One woman said she was sent a letter asking for her comments on the service she had received. But she had not responded because she had so many things she could have said.

Some of it was too embarrassing to tell them about how horrible it was, how invasive.

She had also worried that her feedback could not have stayed anonymous because she thought that so few clients were Māori and she would have been identifiable. Other participants stressed the importance of giving the feedback because as one participant said. “Unless we say those things offend us then nothing is going to change.” (C)

4.4 Addressing the Effects of Colonisation

As one informant said, “we've had layers and layers and layers of colonisation.” (14) One of the most insidious forms of colonisation has been the replacement of spiritual beliefs and the altering of the Māori psyche. Particularly, informants attributed much loss of mātauranga Māori to “the impact that Christianity has had on people's thinking and their value base.” (11) One example of a psychological change Māori have been impelled to make is to shift from thinking as a member of a community and living by “community values” to thinking of oneself as a wholly autonomous being and “living a more nuclear, a more individual sort of focus” with less reliance on community. (5)

One of the outcomes of colonisation has been the creation of, if not the institutionalisation of, inequalities between Māori and Pākehā. These inequalities are maintained by the way in which services are “planned and structured” for example, when health service planning is based on the needs of “the total population which is driven by 85% being Pākehā.” This creates the barriers to access for Māori, but it’s done at a structural level. (14)

Another informant said the “differential things occurring with access” are largely driven by the way in which “the services are structured, and funded, and available” and distributed. (4)

You’ve got services which are structured to not accommodate. There’s all those issues about whether the, the way in which we provide infertility services increases inequalities for Māori or not, and I suspect it does. (4)

When talking about reducing the inequalities, the focus is not on what’s occurring at the structural level. The talk is about “well these things occur to population groups which make them more likely to have ‘x’.” This leads to a focus on “health status” and people’s need for health services. (4) As another informant said, then all of the barriers to access come into play. On top of that, Māori “will be judged by a system that holds us as the people who are deserving” as they measure us against Pākehā norms. (14)

Fertility services may want to provide equal access and be concerned about Māori not having equitable outcome, but if they seriously want to improve things they need to review the policies by which they are operating. For instance, the criteria used to determine eligibility for publicly funded AHR. That is a single set of population criteria. It doesn’t suit the different sub-populations. “That’s how Pākehā get privileged in the health system.” (14) There should be two sets of population data, rather than just using a whole national population data, so that criteria can be established based on the needs of the Māori population. (14)

For example, smoking status is used in the criteria to assess eligibility for funded AHR. Māori women of child-bearing age have a smoking prevalence rate of 60%. This same informant said the criteria “is unrealistic” to assess Māori women’s eligibility for support based upon Pākehā women’s smoking prevalence rates and how smoking has impacted on their fertility. Thus, it becomes a political issue as Māori rights as an indigenous people are shrouded by “their number majority-minority bullshit.” She concluded:

We must never let them minoritise us like that. (14)

Some of the hui participants believed there was a need to address the potential inequities that could result from criteria used to determine access to AHR. For instance the criteria determining who will get public funding for their IVF. If it’s based on providing funding to those people most likely to succeed, then Māori are likely to be disproportionately excluded from support because of having, for example, higher prevalence of smoking and obesity. (H)

One participant wondered about the politicians, government and the medical field. She asked what was their agenda with regards to the procreation of tangata Māori? She was concerned that expectations might be falsely raised for some Māori who think that they can one day use AHR, but when they do try to they'll get knocked back by the barriers that currently exclude Māori.

There's a lot of choices for us out there. But, they're false choices... it looks good so Māori will say 'oh yeah I can go get a egg.' Well half of them don't know the cost, or your medical history. So it's giving a lot of false hope to our mothers... my teenage kids, they'd say it's alright Mum, can go and get a egg you don't have to worry about it. But looking at the medical history, the whānau history, they won't get into that. (K)

A kaumātua participant became more concerned as the hui progressed about “the political side” of the issue particularly with regards to the survival of Māori. (K) For similar reasons, a takatāpui hui participant concluded that AHR has “got to be a benefit for us. If, Māori know about it and they can access it equitably.” (T) Which caused another takatāpui participant to suggest there would be iwi political implications, given that she foresaw AHR not being equitably delivered to all iwi.

I can see this whole process going out to different... iwi, more than others and before others. (T)

4.5 Where Are the Māori Providers?

There are different levels at which Māori should be involved in the provision of fertility services. One informant highlighted the lack of involvement of Māori at a Governance level. She explained that Te Tiriti o Waitangi, Article II, assured Māori of their continued ability to determine their own resources and their own taonga; for example, that could be language, but in this case it might be around children. So an informant raised the question, “Should Māori, as a collective group, have a role in some of the decision making that could occur around” issues which affect whakapapa? She wasn't sure, however, how Māori working with the Government at a decision making level, rather than at the operational service level, could be actioned. (2)

The takatāpui hui also asked, “Where does the power reside in the decision making?” They wondered what other political factors influenced the decision making and directed this kaupapa. Decisions were being made about our destiny as Māori. It was fine if these decisions were being made by your own for your own people, “but it's when other people choose...”

To imagine that we have control over the future, in my view, is a ludicrous idea. It's a fabulous one to have, nurture along in your own mind. But I think in reality that's certainly not going to be in our living history...

An informant thought there could be more co-ordination around AHR. Another informant wanted to see the development of Māori providers of fertility services. His ideal would be a Māori “natural fertility clinic” that would include traditional healing

options and people that assist with improving fertility. Though, he also thought there could be Māori providing the fuller range of AHR. (5)

Other informants thought existing Māori health providers could assist with education and advocacy services.

We need to have GPs, we need to have Māori people who are around to provide information. (1)

For example, the traditional within whānau response to infertility could be facilitated by Māori health providers. As one informant said:

If people want children and they haven't got them then we need to work as whānau and make sure that they get them. (11)

One informant described ways in which she had facilitated processes that led to whāngai arrangements. The process involved facilitating kōrero within the whānau. For example, one couple she had helped were “too whakamā to say anything” about their infertility and their desires to have children.

If somebody else goes and stimulates the kōrero amongst whānau then somebody sure as eggs rings up and says yeah so-and-so is having a baby and we don't know what to do and is there anybody that you know could take them like just supporting that stuff to happen. (11)

One informant believed that there's a lot of support at ECART level for Māori families to help each other and to help their families to have babies through the transfer of gametes, or of sperm or eggs or even for surrogacy. (7) With supportive advocates more whānau could be assisted to do this.

Another potential service that could be facilitated by Māori health providers is the establishment and provision of support groups. The current lack of any support network for Māori experiencing infertility contributes to infertility being a secret. As one informant said:

There's no support groups... we do tend to rely on the broader whānau to deal with that. But, I know just talking to other infertile women basically they've just kind of shut it off, not talked about it. (10)

Hui participants thought that “ordinary Joe Bloggs” people were not involved in the decisions that were being made around these topics. Especially given that it's not an issue that has been tackled by Māori before. (H) The takatāpui hui thought that the lack of Māori participation was obvious. They wondered if the Māori people on the ethics committees were there simply to do “powhiris or karanga?” They said that respected Māori people that have a good broad understanding of the issue need to be at the decision making table and that Māori needed to set up some way of “checking and monitoring” what was happening. (T)

As the kaumātua hui pointed out, “there are real issues for tikanga Māori when Pākehā start playing around with scientific stuff. It invariably impacts seriously on our tikanga and the things that our tupuna taught us.” They wanted some sort of support mechanism that provided for people, like Māori members of the ethics committees, to be able to discuss and talk more widely with other Māori. (K)

There was recognition that not every Māori is going to be worried about tikanga, but still the kaumātua believed there needed to be a place for the discussion, “amongst ourselves” of the “papa Māori or that Māori dimension.”

As we move further and further into the 21st century, possibly fewer and fewer will worry about tikanga. (K)

We have to build bridges so that our people, if they wish to, may take advantage armed with both sets of knowledge. (K)

It would help to have both to work together, but I think it’s very important that Māori should have access to their whakaaro too. (M)

One of the problems raised by the takatāpui hui participants was that Māori are now in a position of having to be “reactive because it is going to happen anyway.” If Māori can not stop the process and do not get involved, “then it is decided by others about your destiny... So you remain still the recipients.” (T)

Fertile Ground for Māori Involvement

Most of the participants could see the potential for Māori providers to get involved at various levels.

Some of the Māori health workers’ hui participants thought they should have knowledge of AHR because, whilst they were contracted “just for like we say cervical screening... because we work for a Māori provider we actually holistically take care of what we can.” Thus, they could add AHR knowledge on to what they were already doing and deliver the information and refer people to AHR services as required. (H)

One participant said that AHR “should be a part of women’s health.” But other participants thought it should also be part of men’s health and then they agreed that it was a whānau hauora issue. (H)

Some participants could see a role for Māori advocates to work within mainstream fertility services. For example, one participant thought there would be many Māori kaumātua who could and would be willing to do this work.

We need a Māori place where you can go in or people know that they could go to the place on the marae somewhere, where you can find out about it, and that person says to you, look you go to such and such, or I’ve got the thing here, go home and read that and then come back and I will send you on to the next place. We could provide those services. (C)

A rangatahi said that “Pākehā have different whakaaro to Māori people” so mainstream AHR services could benefit from having “someone Māori in there” just to help them understand.

Maybe they want to do some little karakia process or something... And the Pākehā might be, ‘what for’? (R)

One participant thought that people who might need AHR are going to be more likely to become aware of it if information and services were available at community based and marae based Māori health services. (C)

The takatāpui hui said “you’ve got to be in there, in order to change it.” They wanted Māori to be more involved than just being part of the workforce associated with AHR. (T)

The men’s hui thought that Māori men would be more likely to donate sperm if they knew who they were helping. One man thought that Māori health providers could operate a service whereby they helped connect people who needed gametes up with donors, even within the same whānau.

Instead of having this, like, go and bank it, for anyone to use, if you had Māori health providers and you had some kind of service to awhi people, so they can facilitate... like if you find out that someone’s infertile and you can put it through the whānau or you can find someone within your own network... I’m sure that it would work too. (M)

Māori health providers could also facilitate and help set up support groups for Māori who were experiencing infertility. (M)

A consumers’ hui participant thought that some of the initial testing could be done by GP’s working for Māori health providers. (C)

Participants thought that if there was a Māori fertility service, it would most likely “be more holistic in terms of offering or having mirimiri and sessions on all the other things” such as, the menstrual cycle. (C) It would look after te taha wairua and provide access to a tohunga. (C) The Māori men’s hui also thought it important for Māori to have access to tohunga. (M)

A whole lot of stuff could be done by Māori health providers. Then only needed to go to the specialist fertility clinics when you get up to freezing sperm, freezing, storage, AI using frozen sperm... AI using sperm... fresh stuff, can be done by the Māori health provider... when you get up to IVF, when you’re using frozen sperm, frozen eggs then you need to be in those kinds of facilities. (C)

Even then, this participant thought there was no reason why the Māori health worker couldn’t go along and awhi people through that process.

A Māori fertility health service would still need to be “professional” as well as operating in accordance with tikanga Māori.

I would want the best. Brown faces don't always make it better to have Māori services but you have got to have good Māori services and you want the best Māori services. (C)

One participant thought that developments in AHR were not going fast enough. Particularly, she was thinking about Māori getting involved in the delivery of information and AHR services. As she explained, “we get caught up in the mainstream scenario” helping them to be culturally appropriate, and “our own endeavours become either short circuited.” Her vision was of an AHR service that was controlled by our own iwi and iwi, hapū or whānau based. (T)

Another participant doubted that we had the structures presently to deliver such a service, to which the other woman replied that “we make our structures up because they change from generation to generation.” What mattered to her was that ground roots people at the marae and community level have access to AHR in “a way that they can evolve.” (T)

The hui predicted that the growth in the power, authority and mana of iwi organisations over the next 10 to 15 years is going to have a significant impact on the lives of the individuals members of those hapū or iwi.

It might have a big impact even on things like this. Particularly with policy. (T)

For instance, one participant said Māori had contributed to a lot of changes in terms of the development of ethical considerations and the way techniques are applied in health. (T)

I have no doubt that in the future there will be Māori based services and technologies because we can be adaptable to these things and it will be hapū based or maybe tribally based. (T)

4.6 Workforce Development

A common issue across health and social services is the need to increase Māori involvement in the workforce. One informant spoke about the need to increase “the numbers of Māori and Pacific and people of other ethnic backgrounds into policy positions,” to ensure that policy will innately reflect the backgrounds and the cultures of people who live in New Zealand. (2)

There are only one or two known Māori working for fertility services throughout New Zealand. With regards to the lack of Māori working in AHR as specialists, doctors, nurses and laboratory technicians, another informant said that there’s “something fundamental in the clinical pathway that we’re missing, and I don’t know what it is.” (7)

As one informant said, we have the capacity to think through the issues raised by AHR, “but we don’t have the capability” to address the topic. (9)

These are not our scientists. These are outsiders doing all this. Just like we need Māori geneticists there should be Māori scientists. Other peoples work can inform us but that's all it can do. (9)

Even having Māori working, for instance, on reception in clinics would help. (12)

Sometimes even the hospitality, like even the reception or whatever when you go in there, that you get from Pākehā as compared to Māori. Like my grandparents, they can't go to a hospital anymore, they just get angry. Because they're rude aye? Yeah... Only some Pākehā that have experienced being with Māori and stuff would understand. (R)

One informant was concerned about the lack of any Māori counsellors knowledgeable about AHR. This was a problem because the ECART could require “cultural counselling” to be undertaken. She believed it was inadequate to just have Māori counselled by the existing non-Māori infertility counsellors and where fertility services assisted clients to access a Māori counsellor from the general community, this informant believed this was little better than “asking somebody on the street to, to counsel somebody about something.” (11)

She wanted Māori to have access to Māori counsellors with a background in the topic and who “have got the tikanga knowledge as well.” (11) But, as another informant explained “infertility counselling, never mind Māori infertility counselling” is a very specialised area. She thought there were only about eight infertility counsellors in the whole country. (12)

Given that AHR is a specialised field, one informant said it would be useful for the Māori community to have information on how to get into this field.

The kaumātua hui first wanted more Māori people involved in delivering information about AHR “out to the people, so it's not the Pākehā telling the Māori what to do again.” (K)

If it came from our own, telling you and helping you, it wouldn't be such a horrendous thing to have to do. (K)

They thought the best messengers would be Māori who had experienced infertility and AHR.

There must be somebody out there that's had this done to them, and we need a story to tell about them. It would open up everybody's eyes. (K)

As an Islander and a Māori person, that has experienced that kind of way of giving birth, that particular couple can actually teach other Islanders and Māori people that hey, its fine, its okay, go ahead and do it because we've done it and we've experienced it and we've had our family behind us. It's okay. That's what us Polynesian and Māori people need, is people who have actually experienced that kind of way of birth. (K)

The kaumātua hui supported the need to “bring together te ao Māori in to Pākehā or te ao Samoa and te ao Pākehā.” They said this wasn’t an issue specific to infertility, but across health “Pākehā have all the information that deals with us,” and they thought that “slowly we’re getting people into” their services. (K)

The takatāpui hui also saw the need for Māori scientists and professionals to be working in this field. They were shocked that “we’re not even answering their phones.” (T)

4.7 Māori Involvement in AHR Policy

There was a theme that Māori have had minimal involvement and inadequate discussions as Māori of infertility and AHR as a topic.

Of course, some Māori have been consulted or involved in policy development processes. However, one informant who remembered attending a meeting about AHR felt out of his depth. He said, “I didn’t even really know what was going on, ’cause it was so complex and they made it so complicated... I think we were there to ensure that issues with regard to Māori and whakapapa and all that were considered.” He did not, however, remember what the outcome of that consultation was. (6) Another informant said “it’s such a difficult area in consultation, because you need the knowledge link.” He believed that on most matters Māori had “been contributing to it numerically but whether it’s been adequate, who knows?” (8)

Whilst the takatāpui hui participants had faith in the ability of the Māori members on AHR ECART or ACART committees “to be able to understand the environment that they’re in and to apply the guidelines that are available” they expressed a need to develop guidelines “that are uniquely ours.” They wondered if there was specific knowledge that the Māori members on those committees needed to help them. (T)

When Māori have been involved in driving the consultation with Māori then they have made sure that Māori women who had sought treatment for infertility were consulted.

Another two informants believed that New Zealand was at the forefront in using identifiable donors, “because of our mingling of the cultures.” (13) That is, they believed that the importance Māori place on ensuring that people have access to their whakapapa information had “essentially been adopted by the mainstream as a value of, of how they should operate.” (5)

The AHR ethics and advisory committees have had Māori members but one informant said “it’s just not good enough. It’s like dial a kaumātua. It’s just half pie.” She believed that the Māori AHR-related ethics committee members needed to have access to a wider network of Māori with different views and that the Māori members should be able to consult them, but they had never been resourced to do so. Of course, the requirement to maintain confidentiality meant that discussion of cases before the ECART committee could not be discussed with others. Still, this informant believed committee members would be better placed and more accountable if they could engage a wider group of Māori in setting general principles and kaupapa. The lack of

“hui to set kaupapa” and develop a resource outlining the “ethical guidelines for reproduction” was a reflection of the lack of commitment to Māori, she believed. (11)

Several informants wanted to see more opportunities provided for Māori to kōrero and explore in depth the range of issues AHR raises and to talk about how we can best support people to get through the AHR process. (10, 11) One informant said the first port of call for consultation should be “Māori in that profession and Māori who have used the services and technologies, because they’ve been through it.” (3) One informant knew there were key people who could be invited to hui on the topic. (11) Others with a particular interest, such as sexual health workers should also be consulted, but one informant argued “it’s really important to have input from a wide range of Māori people.” (2)

They often have, you know, like a token Māori in there. (11)

But, like any health issue, the people most likely to contribute during consultation are, one informant thought, the people most likely to be directly affected by the topic. As he said, if they are only a small proportion of the population, then it becomes challenging to identify them and provide them with access to the consultation. Or it becomes necessary to identify key people in communities through whom information can be channeled. (6)

At the Māori health workers’ hui, a participant said that in other countries they’ve developed policies that support people to have children, for example, in Singapore the middle-class are being supported to have children. Whereas here, “we’ve developed the opposite policies to stop us actually having children.” (H)

4.8 He Aha Te Kaupapa?

Several informants wondered what the tikanga associated with various procedures and technology would be.

What is the tikanga associated with all this complicated technology? Is there any? Have we got any? I don’t know. What could we liken it to? (7)

But one informant said that applying cultural norms to a technical thing was problematic. He said we actually needed to be asking, “Is it tika?” That is, “is it right to do this?” He said we needed to talk about kawa and tika. But, then he said, “You can’t get to ‘tika’ unless you ask the kaupapa question.” Which is, “what’s the purpose of it all? And therefore what are the appropriate steps to make that possible?” To work out the kaupapa we need to look at the outcomes, that is, “what kinds of humans are we talking about here?”

What kind of culture are we expecting out of this?... What kind of persons are we talking about? (9)

He suggested that we needed to “be careful about” what we’re creating. (9)

A kaumātua hui participant also expressed this sentiment when they said that “the decisions we make today will have consequences later on in life, so I just pray that all these things that we make today, whatever decisions we decide now, will have no impact on our future later on, our people later on.” (K)

This raises the question of who should set tikanga, who should decide if AHR is right or not? The same informant believed that “in the old days the tikanga would’ve been developed by your appropriate authorities and whānau, hapū and iwi” involving ariki, tohunga and kaumātua. So, he recommended that there should be “some very serious seminars by recognised authorities in this area” involving “your biologists and your medical doctors” who he considered to be “the new tohunga.” The old traditionalists should also be there, he said. (9) One woman was concerned that any such process should involve “people who really understand what tikanga are about” and not people who mix up tikanga Māori with “things which were actually introduced at the time of Christianity or introduced through European views.” For instance on the position of women in society. So particularly, she wouldn’t want to see any tikanga setting process captured by people using it to push religious or sexist views. (2)

It’s really important not to have the group captured by people who are going to limit Māori potential through their narrow minded views of tikanga. (2)

She also thought it was important to get a truly Māori perspective, “as in people who identify as Māori who currently live in New Zealand as opposed to people who have an antiquated view of tikanga.”

One informant did not think it was necessary to set tikanga because tikanga would differ for different whānau, but certainly the range of Māori views on AHR needed to be facilitated. (11) Another informant said it was up to individuals to set their own tikanga.

You make the rules for your body. You’re the rangatira. (14)

Who are we to determine assisted human reproduction? (T)

Kaumātua hui participants said these questions, he aha te kaupapa and is it tika, need to be taken to and discussed by Māori “people who have tikanga.” (K) They also said “take it to the people, the Māori people first” and that Māori communities should be consulted, being sure to include Māori men and women “and others outside of the European focus.” (K)

You’ve got to get the men involved in it too. The old men. (K)

The takatāpui hui thought it was an important topic that needs to be discussed and that there needed to be “a whole lot of talking or wānanga about knowledge and new ways of thinking about present things and the past” to determine the tikanga, whilst keeping it real. (T)

The kaumātua hui talked about how things had changed so much.

Look at our own maraes... well take our eating habit... nice kai. We are having to change... we want to keep tradition but we're still having to go with time and change what we've done.

They thought that for some people the “tangihana is the only thing we have stayed true to and everything else we have adapted and adopted in order to accommodate what we are doing.” (K)

So all those things are happening and we need to hold firm enough, tikanga Māori. We must have both and go forward. (K)

5. RESEARCH AND INFORMATION NEEDS

Informants identified a range of information they thought was needed to assist policy development, discussion and decision making around AHR for Māori. Gaps in knowledge and the need for further research are presented in this section.

Before informed discussions can be held, one informant said, we need to be looking at how whānau are being reconstructed. That is, “the ways in which whānau has evolved?” A related focus for research is to “think through” the relationship between whakapapa and collective rights. (10)

This same informant thought it would “be quite interesting” to study traditional Māori views on infertility as expressed especially in te reo Māori manuscripts. Further, she believed “that Māori women should do some of this work as previous investigators may have suffered a gender bias in their interpretation of information.” (10) Another informant thought it would be interesting to find out what traditional approaches to infertility existed. (5) Further research could ask, also, how Māori could go about developing a tikanga appropriate for AHR? (9)

We need good prevalence data. We need to know how many Māori are affected by infertility and what are the causes. For instance, one informant wondered how much of the infertility is related to leaving having children to later in life.

Does education come into it? You know the more professionally qualified you are the more you're likely to have a professional career. (9)

In recognition of the deep hurt associated with infertility for some people, one informant wanted more discussion about infertility to occur and research into the ways in which we as Māori are dealing with it. She was particularly concerned about compounding that hurt by the ways in which people talk about infertility.

Looking at how Māori are dealing with infertility would look also at the role of whānau? She wanted to know if whānau mediated the effects of infertility?

Another informant said there needed to be research with men specifically, (4) in addition to finding out what Māori generally think about the technologies or other ways of giving birth.

In addition to establishing the prevalence of infertility for Māori, we need good data on how many Māori would want help and what sort of help they would prefer. Only good data on what's happening for Māori can tell us if infertility is “an issue that is going to come up in the future.” (4)

It was proposed that research needs to determine whether or not Māori are getting equitable access to the full range of AHR treatments and technologies; that they receive the necessary treatments; the manner in which they are offered them and that they are offered them in a timely manner. And also if they had a choice of a traditional Māori provider, a Māori mainstream provider or just the mainstream, what the preference would be. (5)

Current service providers want to know how they could be more accessible to and appropriate for Māori. So, research is needed on the effectiveness of existing services for Māori. For instance, one informant wanted to know if “Māori see an organisation like *fertility NZ* as useful? And if not, what would be useful?” (13)

Information is needed on how best to promote good fertility and how best to communicate messages about protecting fertility to Māori. (12)

The takatāpui hui participants wanted narratives, kōrero purakau, research that recorded and interpreted Māori stories about the diverse ways to whānau. This research, they said, would suggest how those stories could be interpreted “and what they mean for us as contemporary people.” (T)

The consumers’ hui thought there needed to be more research done with Māori who have been through the process (C) and the men’s hui suggested that future research should try to include “an older generation’s view; for example, like the ’60s babies.” (M)

The takatāpui hui said we also need research on why Māori aren’t participating. One participant wondered if AHR was what happens when everything else has failed. (T)

The consumers’ hui was concerned that the lack of information on how Māori are accessing or not accessing fertility services was undermining the opportunity for those services to enhance their delivery to Māori. Further, any assessment of delivery to Māori needed to be informed by information on the prevalence of infertility among Māori and how many Māori might or are seeking assistance from fertility clinics. (C)

In order to get funding for a Māori fertility strategy or any of the other recommendations put forward by participants, statistics on the prevalence of infertility among Māori and barriers to accessing AHR needs to be determined. (C)

A further research focus could be to look at what happens once the woman who has used AHR gets pregnant. The hui suspected that the woman might be more invested in her pregnancy. There’s also likely to be a lot more anxiety and stress around it.

6. DISCUSSION

This section presents a summary of the main results and recommendations arising from the study. First, what is meant by “a Māori view” is discussed. The rest of the results fall into five sections. The first main theme groups kōrero about the motivations for having children. The second section considers what Māori attitudes towards infertility might be, and the subsequent section outlines Māori attitudes towards AHR. Māori thoughts on the actual AHR technologies and treatment processes are presented in the fourth section. There is a final section that considers the potential for Māori to be more involved at all levels of policy development, primary prevention of infertility and AHR.

6.1 A Māori View

Participants were asked to comment on the Māori view, but as many of them said, seeking a Māori view is problematic as Māori are diverse and Māori will hold the full range of attitudes from positive to negative about AHR. The key informants and hui participants preferred to speak from their personal perspective and acknowledged that their view was very much influenced by their own level of knowledge and experience of infertility and AHR. They suspected that the prevalence of negative attitudes towards AHR among Māori would be high, but that that would shift to more positive attitudes if Māori knowledge of and use of AHR increased.

6.2 Ensuring the Survival of Māori

Surviving as a unique people and culture is the overriding kaupapa which is served by tikanga that enshrine the importance of whakapapa, the purpose of relationships and alliances and the valuing of children. Good fertility has been necessary to ensure Māori have survived and are sustained. But as the informants and participants pointed out, it is not enough to just ensure Māori are genetically continued but that identifying as Māori is what is needed to ensure Māori language and culture are also continued.

The importance of ensuring the survival of Māori was a conscious lived objective. Some informants and participants believed it was part of their identity as a Māori and as a Māori woman. Thus, having children was seen to be a cultural norm. It was also the norm to have children earlier rather than later. Some informants believed that the importance of having children overrode the requirement for the mother to be in a healthy and stable relationship with the father.

There was a feeling that the right age to begin having children was in the woman’s early 20s. Participants of different ages had experienced pressure to have children at different times. Other generations were used to children coming during their late teens, whereas the rangatahi participants were now being encouraged to continue their education, travel and establish their careers before thinking about having children.

Informants and participants believed most people assumed they would be able to have children whenever they wanted to. It was also assumed everyone naturally desired to become a parent. These assumptions contributed to negative attitudes towards and experiences for people experiencing infertility. For example, when people without

children are considered ignorant of the realm of experience associated with birthing and raising children, or when people without children or with only one child are questioned about their supposed choice not to have any, or not to have any more.

Gender stereotyping, the assumption of heterosexuality and the inevitable division of power between men and women could all be seen as beliefs and values constructed to serve the kaupapa of survival.

6.3 Historically-held Māori Views on Fertility and Responses to Infertility

Informants and participants believed that Māori had a range of responses to infertility in the past, although they did not believe that infertility was a Māori concept, nor that it was a pathologised experience. Instead it was accepted that some people have children and some don't. Because of a communal extended whānau way of life, all adults were involved in the care of the children of the whānau. In the Māori language, for example, the same words were used for mother as for aunty and father as for uncle. Cousins were referred to the same as brothers and sisters.

Some informants, however, recalled that lack of children was sometimes blamed on mākutu, and some participants believed that tohunga had helped relieve infertility, and could still do so, using various rongoā Māori.

If a relationship between a man and a woman did not result in children, informants and participants believed that in the past, a third party might be brought in to have the children, the relationship might be ended, or the man might take on more than one wife.

There were various ways in which whānau would ensure whakapapa was continued and strengthened, for example through tomo (arranged marriages). Whāngai was the most well-known practice used to ensure whānau and hapū sustainability. Whāngai served a myriad of purposes, an offshoot of which was that the people who had not birthed children could still be parents.

There was a perception, however, that whāngai was not available as an option any more because people were having fewer children. Also, fewer people lived as close to whānau these days, so whānau were less likely to know of a person's need for a child. The range of welfare services available today also helped people to keep their children.

A perhaps contemporary arrangement is to allow others to co-parent a child.

One way of thinking about children that shapes people's attitudes towards infertility is the belief that children are a gift, for instance, from God. The implication for infertility is that some people believe that some people are blessed with children and others are not, and that those who are not should just accept their fate. Or worse, that that couple were not supposed to be together.

6.4 Infertility

Informants and participants thought having good fertility was important. Infertility, however, was thought to be a phenomenon of the times, that is, a contemporary problem.

Changes to Māori society meant that Māori now lived longer, infant mortality rates had reduced, and quality of life had improved. Modern Māori no longer needed to have six children to get two who would survive past childhood. Medical intervention – contraception, abortion, vasectomies and tubal ligation – enabled people to have more reproductive choice. Attitudes towards sexuality, sex stereotyping, family structures and family size had changed also.

Economic changes and adoption of the colonisers' culture and lifestyle meant more Māori were delaying having children, preferring instead to complete their education, travel, secure employment, buy a house and find a suitable partner first.

With the loss of Māori lifestyles - such as extended whānau living in close proximity - and the rising cost of living, having fewer children was seen to be an economic necessity.

Government social policies were implicated in some of the shifts of attitude and economic pressures. Participants talked about social expectations that women should be in the workforce rather than stay-at-home mums. Raising children was not valued by society and beneficiaries were stigmatised, adding to the pressure on Māori women not to have children.

Not only were today's Māori seen to be having children later, they were also having fewer children. In just the last three generations, significant drops had occurred from grandparents being born into large families with more than 10 children, to parents being one of 6, their having 3-4 and their children thinking of only having 1-2.

Believing that you've got to own your own home and your own baby was a foreign belief, contrary to mātauranga Māori, but one that was seen to be supplanting Māori beliefs, so increasingly Māori would move away from whāngai and adoption. The attractiveness of and demand for AHR would subsequently increase.

6.4.1 Infertility – How It's Defined

The way that infertility is defined has been changing also. This research suggests that Māori have very different ideas about what infertility is. Some informants and participants were more familiar with the term sterility, which they thought was a permanent state of being. That people could move in and out of infertility was news to many participants, with some coming to the realisation that they could apply the term infertile to themselves. There were divergent opinions on whether infertility was a social problem or a health problem. There was some resistance to it being medicalised. Historically, Māori would have applied an holistic analysis as to why some people didn't have children despite their trying. How Māori would define infertility was not arrived at in this research and remains to be developed as Māori knowledge of infertility and AHR grows.

6.4.2 Infertility – The Causes

Similarly, a person's understanding of the causes of infertility is going to be influenced by their adherence to a biomedical analysis, a social systems analysis or application of mātauranga Māori.

Participants thought many environmental, social, psychological and biological factors contributed to infertility. People needed to be physically healthy and fit, economically secure, with access to good food. True intimacy was required. One participant had used Te Whare Tapa Whā (the four-sided house model of health) to analyse her own inability to conceive again and concluded that her mental health problems, loss of fitness and self-esteem and her partner's drug and alcohol abuse had contributed to their loss of fertility.

There was concern about Māori experiencing disproportionate rates of STIs, diabetes, heart disease and other morbidity that could undermine fertility.

6.4.3 Infertility – Te Mamae

Informants and participants who had no personal experience of infertility imagined it to be a very painful and sad state to be in. Because of their recognition that they couldn't know what it would be like to be unable to have children, they similarly believed it was problematic for others to make judgements about AHR. Informants and participants expressed a great deal of empathy for people who might have experienced infertility.

Contributions from informants and participants who had experienced infertility suggest that a negative emotional reaction to infertility can be compounded by society's lack of understanding and lack of knowledge about infertility and what can be done about it. The assumption that every woman can easily get pregnant and carry can create environments ignorant and insensitive of the feelings of people having trouble conceiving and carrying.

6.4.4 Infertility – An Emerging Issue For Māori?

Without prevalence statistics, the informants and participants could not say whether infertility would become more important an issue than it appears to be today. They were shocked to learn that Māori fertility rates were so low and were predicted to drop further. They believed that if Māori fertility rates ever dropped below replacement level, Māori would become pro-active about increasing fertility rates. They suspected that a decreasing fertility rate, combined with increasing rates of infertility due to disproportionate prevalence rates of illnesses that undermine fertility, and a drop-off in Māori tikanga that supported whānau to have children, such as whāngai, would result in increasing prevalence of infertility among Māori in the future and subsequent increased demand from Māori for AHR assistance.

The lack of good information on prevalence of infertility among Māori and Māori access to fertility services needs to be addressed.

Recommendation:

Further research is needed to determine the prevalence of infertility among Māori.
Further research is needed to determine Māori access to and use of fertility services.

6.5 Māori Attitudes to AHR

Historically Māori have been presented with and have adopted many new beliefs, behaviours, processes and technologies. If AHR, like the kūmara, car or use of telecommunication devices, is deemed useful to the survival and sustainability of Māori as a unique people and culture, then it is likely that AHR will similarly be embraced by Māori. The details of the technological processes involved were seen to be secondary to this ultimate purpose behind undertaking any AHR procedure.

6.5.1 It's a Right, Right?

Three sets of 'rights' were referred to by informants: the human right to found a family; Treaty of Waitangi rights; and, the right to medical treatment. The right to found a family was contested, as some informants believed the argument was incorrectly extended to the right to conceive, carry and birth your own genetic offspring, and this conflicted with the belief that children are a gift. Further, believing this is a right led people to expect the State to fund AHR, which some informants were non-committal about.

6.5.2 Treaty of Waitangi

It was proposed that a Treaty framework could be applied to the issue. Analysis using the Treaty as a framework would provide for consideration of Māori involvement at a Governance level (Article One) in Government policy and purchasing decisions; recognition of the failure to protect Māori health, fertility, knowledge and tikanga (Article Two); and recognition of Māori individuals' rights to choose AHR and to receive equitable outcomes from fertility services.

6.5.3 The Right to Medical Treatment

Informants talked about how infertility is being framed as a medical condition, which supposedly strengthened arguments for increased funding for treatments. None of the Māori informants presented it as such.

6.5.4 Nature's Way or No Way

Informants and participants talked about people being against AHR, and a few expressed resistance to interfering with the 'natural' course of human reproduction or God's work. Some participants felt AHR was like 'playing God.' Others were uncomfortable with the notion of gametes being 'cleaned' and that choices could be made about which gametes to keep and use. This raised the spectre of control and the possibility of discrimination occurring, for example against non-heterosexuals, Māori and people with Down Syndrome. A few participants believed AHR breached certain tikanga, for example, the tapu nature of te whare tangata (the house of the people i.e. woman's reproductive system). Some participants warned that AHR could also breach tikanga around whakapapa.

The destructive effect of colonisation was one of the reasons why Māori were now supposedly struggling with new technologies such as AHR. Māori social structures and processes for considering and managing change had been dismantled. Thus, Māori had not had the opportunity to consider AHR in a Māori way and establish new tikanga regarding AHR. Rapid advances in AHR technology were outstripping even the general public's awareness. That Māori seem to be the last to hear about a new technology only compounds the insults of colonial destruction.

Recommendation:

Māori seeking AHR should have access to information about the range of Māori views they may encounter, and they should have access to knowledgeable counsel about tikanga Māori and AHR.

6.5.5 Concern for the Integrity of Whakapapa

Historically, a break in whakapapa or a loss of whakapapa is not positive for health and identity. Being able to recount your whakapapa is a significant tikanga.

Most informants and participants supported absolute transparency and openness about genetic origins, that is, whakapapa. They also believed children born using AHR should be raised with the knowledge of how they were conceived, especially because it is the child and its whānau who will have to carry the practice and they thus forge new tikanga around it.

Informants and participants expressed concern for the children born using AHR. Research is going to be needed to ascertain if there will be any untoward negative impacts on them and their whānau.

Recommendation:

Future research is needed with whānau who have used AHR or with people born as a result of AHR to look for unintended negative impacts on them and their identity.

Some informants and participants thought that some of the problems that arise for whāngai children could arise for AHR children. For example, some iwi supposedly don't consider whāngai to be members unless they can genetically whakapapa to that iwi.

Recommendation:

It is recommended that Government facilitate a process whereby iwi can be educated about AHR, fertility services and Māori fertility rates, and encouraged to consider the implications for them and their people who may experience infertility or want to use AHR and the resulting people born via AHR.

6.5.6 When Does Life Begin?

The question of when does life begin was raised for some informants and participants throughout the research. This is another question that was probably not being discussed anywhere in Māoridom. One informant warned that it should be clear why the question is even being posed, e.g. the question is asked to justify beliefs and philosophies aimed at controlling groups such as women.

6.6 Access to AHR

Informants and participants believed Māori should have equitable access to AHR but they suspected Māori were not accessing AHR. They cited a range of possible barriers to Māori access of AHR services, many of which mirror barriers to Māori access typical of many healthcare services.

Recommendation:

Future research is needed to analyse the differences in incidence of infertility, stage of diagnosis, fertility treatment accessed and outcome between Māori and non-Māori in New Zealand.

6.6.1 Fertility a Low Priority for Māori

Informants and participants did not think that fertility or infertility was on the Māori agenda. Mainly, there are too many urgent concerns and not enough funding or capacity to attend to those. Whilst the informants and participants thought fertility was an important issue, they could not raise it in importance over other concerns. Neither was it clearly defined as a health issue. They doubted that Government would support any focus on the topic, as it would contradict a perceived push to stop Māori having babies. Further, Government policy was only to fund Māori-specific initiatives where a ‘disparity’ existed. As Māori have a higher fertility rate and nothing is known about the prevalence of infertility among Māori, Government support for any intervention specifically targeting Māori to improve their knowledge of or access to AHR is unlikely.

Recommendation:

Further research is needed to determine the prevalence of infertility among Māori.
Further research is needed to determine Māori access to and use of fertility services.

6.6.2 Māori Don’t Have a Problem with Fertility

Informants and participants believed that the predominant stereotype of Māori was that Māori had too many children. This was encouraged by a policy and media focus on, and problematising of, Māori teenage pregnancies and Māori women having children whilst recipients of the domestic purposes benefit. This focus tended to deflect attention from falling Māori fertility rates and the possibility that some Māori experience infertility.

6.6.3 Lack of Awareness of Infertility

Informants and participants said that infertility was not a topic likely to come up in daily conversation, nor was it something people shared widely outside of their immediate whānau. Thus, even most of the research participants had not thought much about the topic. Further, they thought there was minimal information about infertility accessible to Māori, e.g. from health services. Participants were not sure that knowledge of reproduction was ever very good, and gave examples of misinformation they had been given on how to improve conception, such as ensuring the woman does or does not orgasm during sexual intercourse. Lack of knowledge about the reproductive process, and that a woman’s fertility declines with age etc., meant that it was likely there were people who did not know they were infertile and could be helped, and others might think they were sterile and beyond help. Neither would people know at what point they should seek help.

Recommendation:

Information about infertility needs to be accessible to Māori. It would need to address the myths about Māori fertility rates.

6.6.4 Lack of Knowledge about Fertility Services

Even if people suspected they were infertile, participants did not believe there was sufficient information about what could be done to help or where to go. For instance, participants thought it sounded like Family Planning would be an organisation that could help with infertility, but others said Family Planning's focus was on STI prevention and contraception.

Hui participants commented that the terms, language, highly technological processes and bureaucratic steps involved in accessing AHR would be a barrier. For instance, information on the public funding criteria for some AHR needed to be clearly articulated and accessible.

One participant thought that her referral to fertility services had been unnecessarily delayed. Another participant thought the conception of her child had been unnecessarily delayed because she had not been advised to go straight to IVF. Both women felt uncomfortably dependent on the professionals for advice.

Recommendation:

Fertility services need to ensure that Māori are equally aware of their existence and what they do.

Information on fertility services and AHR procedures and technologies needs to be comprehensible by the full range of potential Māori clients, including those from lower socio-economic groups.

Health professionals (both at primary and secondary healthcare level) should be encouraged to refer women to fertility services if they are at risk for infertility. This should include briefly asking women who have not had children by their late 20s (including single women and lesbian women) if they had aspirations to have children, and if so, whether they were aware that their fertility was going to decline more rapidly from that point on.

6.6.5 Inability to Articulate Need Directly

Informants thought that some Māori might not know how to raise the issue with their GP, because of whakamā. Participants talked about a range of thoughts and feelings that could be part of being whakamā. Feeling that Māori tikanga is not allowed or feeling ashamed or guilty about being infertile could be expressed through whakamā. Many of the barriers that prevent Māori women from presenting for cervical smears would similarly prevent women from attending appointments that might involve gynaecological examinations. Such as, the lack of respect shown by health professionals towards te whare tangata, ignoring modesty or a person's fears of the process or outcome of tests. Conversely, many of the strategies used to diminish the strength of or remove those barriers could be used to improve Māori access to AHR.

Recommendation:

Fertility service providers need to understand about whakamā, and be committed to addressing practice that could contribute to whakamā. Fertility services working to be more accessible for Māori need to communicate clearly to potential Māori clients how some people feel afraid, shameful or embarrassed, for example, and they need to state clearly how they operate in order to reduce whakamā.

6.6.6 Men's Reluctance

Informants and participants differed in their opinions on how Māori men might respond to infertility and sperm donation. They thought men would be less likely to present for infertility tests, that men would be more likely to think it was the woman's fault if they couldn't get pregnant, and that men could feel that their masculinity was under question and experience whakamā just as much as women.

Participants guessed that Māori men would be more reluctant to donate sperm because of the tapu and importance placed on whakapapa. There was not a consensus view, however, with one participant suggesting that men are quite happy to get different women pregnant, but they're not keen on masturbating into a cup to do it. Another informant thought that maybe Māori men just didn't know there was a need for more Māori sperm to be donated.

Recommendations:

Further research is needed to explore Māori men's attitudes towards and experiences of infertility.

Further research is needed to explore Māori men's attitudes towards sperm donation.

Information about infertility, AHR and fertility services needs to be relevant and acceptable to Māori men as well, and needs to be comprehensible by the range of men including lower socioeconomic men.

Perceived Intrusiveness of Procedures

Participants and informants imagined people would drop out of the process of seeking help or AHR as the process got more intrusive. Intrusiveness was described in terms of physical examinations, testing, the emotional commitment and mental stamina required to keep trying despite repeated failure, and the depth of intrusion into such 'private' topics as sex and sexuality. The more complicated the procedure, and the more technology involved, the more likely people would drop out.

Differential Diagnosis

Informants suspected that some of the barriers that reduce Māori access to other healthcare services would similarly occur when Māori should be referred to fertility services. They thought GPs may not take the possibility of infertility seriously if it was a Māori client, and that Māori would be less likely to be referred on, for instance, because of the cost of AHR. As with other health problems, informants thought Māori probably would present later for help with their fertility.

Judgements made by health professionals about whether to refer a client for help and what for were also expected to disadvantage Māori clients, for instance due to personal and institutional racism or lack of knowledge of Māori tikanga. The manner of the health professional was also implicated as a potential barrier, for example, if they were abrasive and proscriptive. Participants wondered if health professionals followed a policy of starting with the least intrusive and least costly interventions and moving up the continuum of treatments as infertility persisted.

Recommendation:

Further research is needed to determine whether Māori seeking help with their fertility receive equitable access to services and equitable treatment.

Lack of Whānau Support

Informants and participants talked about the range of ways whānau members react when someone hasn't had a child or is experiencing infertility. Unhelpful attitudes included being against AHR, cracking jokes about knowing how to have sex properly or needing to get a new partner. Whānau members avoiding the topic, or withholding information about their own pregnancies or children, was also not helpful. One participant said that what did help her was getting to look after the babies.

Recommendation:

Information on how to support a whānau member who is experiencing infertility should be available and accessible to Māori whānau.

Lack of Māori Fertility Services

One informant believed that a significant barrier to AHR for Māori was that no Māori health providers are funded to, or are known to provide, any level of service addressing fertility.

Recommendation:

The Government should review why no Māori health providers are involved at any level in the delivery of fertility services to Māori.

Cost

Whilst some participants thought fertility services were probably expensive, many were shocked and saddened to find out how costly some procedures were. Having to pay for AHR was therefore going to be a major barrier to Māori access to AHR, and would reinforce the status quo in terms of inequities between Pākehā and Māori.

One participant thought that some people could be put off accessing AHR because they might feel they were having to pay for their child.

If the cost of intervention increased as procedures got more intrusive, this would contribute to increasing numbers of Māori dropping out along the treatment pathway.

The Exclusion Criteria

Informants and participants thought the criteria used to limit funding of AHR would be a further barrier to Māori accessing AHR, mainly because Māori have greater prevalence of excess BMI and tobacco smoking, both exclusionary criteria. No informants or participants were sure of the actual criteria used.

Recommendation:

Research from a Māori perspective needs to review the potential discriminatory effect of the current criteria for public funding of AHR.

Other Barriers

Geographic distance from a fertility service and whānau responsibilities were other barriers likely to disproportionately limit Māori access to AHR.

Recommendation:

Research looking into equitable access to AHR needs to also consider geographic spread of Māori. For example, do areas with high proportion of Māori such as Te Tai Tokerau and Tairāwhiti have equitable access to fertility services?

6.7 Māori Attitudes to AHR Procedures and Practices

Most informants and participants believed that people experiencing infertility who have decided to seek help, because of their desperation, will do whatever they have to regardless of the cultural appropriateness of a procedure or treatment practice. Having committed to pursue AHR, Māori were supposed to get over their particular personal and cultural desire to be treated in a particular way and accept whatever was done to them, assuming that that would be AHR best practice.

This perspective seems to contradict much of the rest of the results, where informants and participants have outlined in detail the perceived concerns about AHR they think Māori would have and the barriers to Māori accessing AHR. Unless they think that Māori who use AHR are a particularly limited sub-group of Māori, who do not share those concerns and are not constrained by the same barriers as other Māori, or they somehow manage to suppress or overcome them.

Recommendations:

Further research is needed to investigate the experiences of Māori who have sought help with their fertility to assess their satisfaction with the service they received; and factors that contribute to decisions to pursue and end AHR treatment. Also, the research should determine whether the demographic profile of Māori who use AHR vs. those that choose not to use AHR is significantly different.

6.7.1 Assessing Infertility

Informants and participants thought there would be a lot of resistance among Māori to undergoing tests. So much so that they thought it was probably easier for people to end their relationship and find a new partner to have children with. One participant thought if people were aware of all the options for becoming a parent, they may decide not to get tested – if, for instance, they knew they would never proceed with

AHR anyway. Others thought women would be more likely to want tests so they could find out what was wrong. Participants thought men would think it was the woman who had the problem anyway.

The more invasive and costly the test, for example a laparoscopy, the more likely it would be a barrier for Māori.

One informant thought some men might be worried that their sperm would be misplaced or used for something else.

It was suggested that testing should be offered earlier to women at risk of infertility, for instance due to age, smoking and excess BMI.

One barrier to getting tested is the possibility that tests could confirm infertility and then the woman and/or couple have to face the emotional consequences of that outcome.

Recommendation:

Good information about the various pathways to parenthood in addition to AHR, including whāngai, adoption, co-parenting, and counselling and infertility support groups and services, needs to be made available to people prior to testing.

6.7.2 Gamete Donation

One informant drew a parallel between modern-day sperm donation and an historical Māori practice where Māori women had sex with visitors to the tribe to increase the tribal stock. Overall however, Māori attitudes to gamete donation were a mystery to the informants. Some hui participants believed Māori were generous and therefore would be happy to donate if they knew there was a need and if they knew how to do it. One participant thought younger and future generations might be more open to it, but a rangatahi participant said he didn't think he could donate because he'd always wonder if he had children out there that he didn't know. Another rangatahi thought it was weird that someone could have a baby to someone they didn't even know. Some participants didn't even know embryos could now be donated. Some participants thought donation was a serious decision that should be thoroughly discussed within the whānau.

The Obligations and Responsibilities of Whakapapa

Gamete donation raised concerns about how people would fulfil the obligations and responsibilities of whakapapa. Firstly, participants said the ideal is to know both sides of your whakapapa. Children born via AHR and denied essential whakapapa information could potentially experience negative impacts throughout their life.

Recommendation:

Further research is needed to determine Māori need for gamete donation.

Because of these concerns, informants thought Māori would prefer private donor arrangements so they could ensure tikanga is observed.

Informants believed that lesbian women were most likely to arrange sperm donation privately, especially seeking to ensure that both women in a relationship could whakapapa to the child. For example, by having a male sibling or relative of one of the women provide sperm to inseminate her partner.

In addition to some donor parents feeling connected, Māori children born into different families but who have a common donor father could feel they were siblings. Because whakapapa carries with it obligations and responsibilities to maintain relationships, donor gametes between strangers could be difficult for Māori.

A few participants thought there was a risk of accidental incest occurring if people didn't know their whakapapa. One informant thought it much more likely, given the small population of Māori, that children with a common donor father could meet. This was just one reason offered for why children should have full information about their whakapapa.

Not only did participants believe children should be raised knowing their whakapapa, but they believed children should also learn about the method by which they were conceived, for example if they were conceived using IVF.

The tapu nature of the body was put forward as a possibly reason for why some Māori might be reluctant to donate body organs and therefore eggs. But as one informant said, it depends on each person's understanding of tapu and their application of tikanga.

Some kaumātua thought that embryo donation was not unlike whāngai and therefore Māori views about whāngai and tikanga could be applied to embryo donation. Some younger participants were uncomfortable with whāngai being stretched in this way.

Recommendation:

Kaumātua and other experts in Māori tikanga should be asked to develop clear guidelines for Māori on AHR.

The Ideal Donor

Participants wondered if there were checks to ensure that donors were sufficiently healthy mentally and physically, and if there was a criteria determining who could donate. Others were concerned about who gets to set the criteria and who might be excluded as a result – for example, gay men.

Shortage of Māori Sperm

Informants were aware that the shortage of Māori donor sperm presented a barrier to access for Māori. Participants said that if they were in need of a donor, they would want a donor who was Māori and probably from their iwi. Other participants wondered if people were allowed to specify what ethnicity they wanted; particularly there was concern that Pākehā or Europeans could choose Māori gametes. The concern was that non-Māori would not provide adequately for the child's origins and culture, and that Māori genes were deliberately sought for their gifts or for the political status that the parents could appropriate by having a Māori child.

Participants were not convinced that Māori men were particularly reluctant to donate sperm.

Recommendation:

Further research is needed to determine Māori men's attitudes to sperm donation and identify barriers or support.

Within Whānau Donation

Gamete donation between whānau members was seen to be problematic if the people involved were too closely related, though participants differed in their opinion of what was too close. Even though sexual intercourse was not involved, participants were concerned for the child – how they would feel when they were older and how others could decide that the child had resulted from an incestuous relationship and how they could use the information in a hurtful way against that person.

Donation and surrogacy between sisters was not offensive to participants. Donation across generations was thought to transgress collective rights. For example, if a father donated sperm to his son and son's partner, the child would biologically be on the same generational level as the father. This created problems for tikanga around tuakana/teina (sibling order) relationships. It could complicate the line of descent and inheritance of knowledge and status. The child could face challenges later in life which would be harder to respond to if the mother, for instance, was not Māori.

Some participants thought precedents could be found in Māori history for all forms of gamete donation, within and across generations, and for surrogacy. Other participants thought there were Māori precedents in that children were given to grandparents and raised as the next in line. The tikanga – that is, how certain relationships should be understood – was determined by the whānau.

Recommendation:

Further research into Māori stories about whakapapa, whāngai, tomo and other arrangements that occurred to ensure people had children and heirs could help identify precedents, parallels and tikanga that could be used to guide Māori considering AHR.

Individual vs. Collective Decision Making

Some participants questioned the authority given to individuals to make decisions to donate gametes when there were impacts for the wider whānau.

Recommendation:

Further research is needed to explore the attitudes and impacts on whānau of people who have donated.

6.7.3 Gamete Storage

Some informants could see the benefits of being able to store gametes, with one informant thinking that in the future gamete storage would be used to increase women's reproductive choices. For example, young women could store their eggs, allowing them to delay childbearing.

Other informants thought freezing gametes was bizarre and culturally strange. Freezing embryos was particularly challenging. There were lots of questions about shelf life and the viability of frozen embryos. The thought that embryos could potentially be frozen and used by future generations was shocking.

How strange freezing embryos was depended upon the spiritual status of the embryo, that is, whether it had a wairua at conception or at some later point in its development. One participant asked, for instance, if the embryo has a wairua from conception and it is then frozen, what happens to the wairua?

Disposal

Informants and participants thought there should be tikanga to guide the storage and disposal of gametes. They thought that frozen embryos, because they were tapu, required greater respect than that afforded to body waste flushed down the sluice.

Recommendation:

Māori kaumātua and other experts on Māori tikanga should be involved in setting guidelines for Māori on the storage and disposal of gametes.

Ownership

Ownership of stored embryos was identified as problematic. Some participants could foresee that difficult cases would arise, for instance, where a couple with embryos stored separate or, as has happened, when the man dies.

This raised questions about consent procedures. Participants thought consent could change over time. They also wondered if men should leave sperm in the bank like a form of insurance in case they died.

6.7.4 Artificial Insemination

Participants considered AI done both outside of and within fertility clinics. They thought AI was more successful and more natural, and therefore likely to be more acceptable to Māori than more intrusive procedures. Although, when a stranger's sperm is being used, similar concerns about whakapapa as have already been mentioned would surface. Do-it-yourself AI was thought to be the preferred choice for lesbians seeking to have a child. It was also assumed that all parties knew each other and were committed to some ongoing recognition of and relationship with each other and the child. However, with privately arranged AI the legalities, obligations and liabilities re parenthood and guardianship might not be as clear. There was a concern that testing for hepatitis and HIV might not routinely occur either.

Recommendation:

Information on the different pathways to parenthood should include information on DIY AI and the things people need to consider, such as, the legal status of the parents and donor and how to protect against the spread of STIs.

The Indignity Of It All

Informants and participants considered AI performed by clinics to be incredibly invasive, even though it is not considered so in medical terms. Participants were concerned that the dignity of women was cared for adequately. For example, having

the same clinician throughout rather than a different nurse each time would be preferable, allowing clients to honour the moment in respect of the process of potentially beginning a new life and working in a way to minimise fear and whakamā.

Recommendation:

It is recommended that fertility clinic staff involved in AI procedures are educated as to the barriers to Māori women's access to AHR, such as, whakamā, and fear that te whare tangata will not be shown due respect, and that fertility clinics review their procedures with a view to minimising fear, discomfort and whakamā for women clients.

Ovulation Induction

Participants thought there would be Māori who would be against ovulation induction because it is not natural or could lead to a multiple birth. Māori who are anti-pharmaceuticals would most likely be against the use of drugs for this. Others wondered where the drugs came from and if the drugs could mutate the eggs.

A few participants had heard of rongoa Māori being used to prevent conception and birth. Only one had ever heard of it being used for enhancing fertility.

6.7.5 In Vitro Fertilisation (IVF)

The drug regime, method of delivery, testing, and transfer procedures involved in IVF were thought to be particularly invasive. Informants thought that some Māori would find IVF challenging physically, emotionally, financially, politically and ethically, while others would have few qualms about it. A consumer of fertility services suggested that the intrusiveness could be mitigated by having continuity of care from one specialist.

Participants talked variously about being uncomfortable with the medicalisation of conception, worried about gametes getting mixed up and transferred into the wrong people, and children from IVF being at greater risk of being a Down Syndrome child or having some other condition, or that the child could suffer some long-term damage. Being an IVF child was a factor that some participants thought could be used negatively as a taunt or to discriminate against a child. Thus, they argued that it was important for the wider whānau to know about IVF and support that whānau and the IVF child.

Participants raised questions about the storage and status of excess embryos. They wondered what processes were followed for disposing of excess embryos and expressed a desire for processes to be respectful.

That an embryo could be selected for transfer based on how it looked seemed like a strange and potentially flawed concept. One participant questioned the authority given to the person who chooses which embryos would be used.

Some participants who were new to IVF thought it was very clever.

Some participants saw IVF as a last resort. They assumed people who wanted to do IVF had exhausted all other possibilities. Using IVF implied a sense of desperation.

One hui thought that the single embryo transfer (SET) policy should be reviewed given some of the barriers to AHR facing Māori. That sometimes it might be better to try for multiples rather than enforcing the need for repeated IVF cycles.

Recommendation:

Further research is needed to explore the subjective nature of the intrusiveness of AHR procedures with a view to developing a measure that could assist with tailoring of treatment supports to reduce barriers and drop-out for Māori.

6.7.6 Intra Cytoplasmic Sperm Injection (ICSI)

Participants thought ICSI probably had not been debated in Māoridom. They themselves had less to say about ICSI than other AHR procedures. ICSI was thought to be further along the continuum of intrusiveness, but a procedure that was probably necessary in some cases. The participants wondered if ICSI would particularly raise issues for men around their standing and sexuality. There was some concern about hygiene, and the cost of the procedure being a barrier. Rangatahi thought ICSI was like playing God, and one man worried that the sperm selection criteria might interfere with natural selection processes.

Others saw ICSI as a potentially useful procedure for Māori given Māori having disproportionately higher morbidity affecting fertility, and that ICSI could be used to increase success rates, thus reducing time and money spent trying to have a baby with just AI or IVF.

Recommendation:

It is recommended that AHR policies be reviewed with a view to addressing and removing barriers to AHR for Māori. For instance, whether cost could be reduced by recommending that IVF with ICSI be used earlier in the process.

6.7.7 Surrogacy

Surrogacy was thought to be beneficial especially for people who because of disease had lost their ability to carry their own child. One person thought surrogacy was a very generous act.

Some participants found the different surrogacy arrangements confusing, and others said the different sorts of surrogacy raised different issues. For example, where a surrogate carried the intended parents' embryo (gestational surrogacy), the integrity of whakapapa was not undermined. Whereas, when a surrogate is also donating an egg to the process and is therefore the biological mother, then concerns about the integrity of whakapapa would arise.

It was proposed that gestational surrogacy could be likened to whāngai in that the kaupapa of nurturing another person's child was the same, except with surrogacy this was able to be done before birth. Thus for some participants surrogacy was more acceptable than other AHR technologies, because it was closer to familiar tikanga that had been practiced by Māori. One participant thought that a form of 'social surrogacy' where, for instance, a sister has a child for her sister, is still occurring and is probably preferable to going through a clinic. One participant thought new tikanga needed to be

developed to guide surrogacy arrangements. This would be particularly necessary with more complex surrogacy arrangements.

Some barriers to surrogacy are that people have to find their own surrogate and that surrogacy has to be approved by ECART. Māori, however, may prefer to find their own surrogate from within whānau networks. Though, this doesn't mean that there couldn't be some service that assisted with the process.

The current law, whereby the birthing mother is the legally recognised parent even though she may be carrying another couple's child, was problematic. Participants would give precedence to whakapapa. The law, therefore, needs to recognise when a woman has been a non-biologically-involved surrogate and clearly assign parentage to the child's biological and intended parents. Participants were concerned to protect the intended arrangement and to protect the intended parents and their child against a surrogate's claim for custody of the child.

Intergenerational Surrogacy

Whilst surrogacy arrangements between whānau members may be preferable, some configurations are likely to be less acceptable. For instance, when a woman carries her brother and sister-in-law's baby or is asked to carry for her father. The concern is that people may liken the arrangement to incest and that the child could suffer some negative impact because of such misrepresentations. Involving the whānau in the decision-making and ensuring whānau understand was proposed as one way to prevent misperceptions from happening. Intergenerational arrangements were particularly worrying for some participants.

One participant wondered what the long-term psychological impact on the child of a surrogate birth might be, because of her perception that in mental health so much is blamed on what happens in the womb.

One man said he wouldn't want his daughter to be a 'rent-a-womb' for someone else. He would only want to see her carry her own. Similarly, there was a desire for babies to be kept within the iwi, not given away to other iwi or people of other ethnicities. This sentiment stretched to surrogacy as well in that this sort of commitment would best be extended to whānau.

Recommendations:

The relevant family laws (and e.g. Human Assisted Reproductive Technology Act 2004) need to be reviewed with a view to extending better protection to the biological and intended parents of embryos carried by a surrogate and better clarification of the parental rights and responsibilities of surrogates. Like a sperm donor, a surrogate should not be legally recognised as the mother, unless she also donated her egg.

The Ministry of Health and fertility clinics should work together to raise Māori awareness and knowledge of AHR, including surrogacy.

6.7.8 Pre-Implantation Genetic Diagnosis (PGD)

Some participants were supportive of PGD given that it could help prevent the occurrence of a number of disorders, especially disorders that heavily burden a whānau emotionally and financially, like Down Syndrome.

Those who were against it saw PGD as crossing the line into the realm of designer babies. Some people who would not abort regardless of the existence of a disorder were against testing for any disorder. Some people did not think Down Syndrome or Huntington's were disorders that should be prevented.

Some participants were concerned about how PGD would be used in the future; for instance, to identify and eradicate other genetically determined conditions and behaviours such as homosexuality. Even though sex selection using PGD is illegal in New Zealand, participants were still concerned and one medical professional was sceptical about adherence to this law. Participants expected PGD to become part of routine IVF free of the current level of monitoring and they believed that PGD was a technology that could be manipulated by one group to further their own beliefs and values. As with the rest of AHR, PGD should be considered within the context of the underlying purpose/kaupapa for applying the technique.

One participant wondered if it was safe to extract one cell, and she wondered if there would be any long-term harm to the resulting child. Another wondered about the long-term effect on whakapapa, for instance, could a genetic disorder be successfully eliminated from the genetic line? Participants asked about the cost and wondered what criteria determined who could or could not use PGD.

One person said that people who had suffered infertility should be grateful to accept whatever they get, even if the baby had Downs.

Other concerns about PGD had to do with humans meddling in the process of natural reproduction, meddling with genes which are tapu and behaving contrary to Māori values of pono, for instance by trying to avoid having a child with certain characteristics or disorders.

PGD highlights the need for iwi to be discussing AHR and, at least for iwi and taura here/urban Māori groups to be forming policy, tikanga and guidelines for their people. One participant would like to see iwi control what happens with regard to AHR for their people.

A different perspective offered was that a precedent for PGD could be found in Māori culture, as tīpuna used to 'manipulate' genetics to various degrees, for example through arranged marriages.

Recommendation:

Iwi need to be facilitated to discuss AHR, including PGD, with a view to setting policy, tikanga and guidelines for their people.

6.8 Fertile Ground for Māori Involvement

Participants envisioned a comprehensive approach to address infertility and access to AHR for Māori. An essential component should be to review the statistics on Māori fertility and infertility and ensure that infertility is prevented at a primary level.

They believed that Māori would most effectively be able to raise awareness of fertility, infertility and AHR among Māori. Some participants suggested that sex

education in schools may need to be reviewed to ensure basic information about protecting fertility is being covered.

The impact of smoking, obesity and STIs on infertility supported the idea that stronger links could be made between infertility as an outcome and infertility as a motivation for smoking cessation and weight loss.

Information on the range of responses to infertility needed to be disseminated to Māori to improve their access to AHR. Participants thought the information needed to be taken out to all Māori, but particularly rangatahi, and that a special effort would need to be made to reach men. Kaumātua needed to be targeted also because of their role in their communities – advising and supporting whānau who might need AHR.

It was important that the relevant health professionals were up to date with AHR also, although participants were unclear about which type of Māori health professionals should take on this issue. They thought that midwives, cervical screening providers, and sexual health workers should all know the information. They thought that sexual health and Māori health providers should incorporate relevant information into their existing service delivery. Family Planning was one organisation that participants assumed should provide information on infertility but apparently they currently do not cover this topic.

Participants thought information about genetic modification and cloning had scared a lot of people and would present a barrier to effective communication of information about AHR. Thus, communication strategies favoured by Māori should be used. For instance, face to face hui on marae using Māori messengers, such as Māori health professionals and Māori people who had experienced infertility and used AHR, should be run at the community level, as opposed to holding hui at a regional or national level and these should be promoted via word of mouth and Māori media.

Information could also be disseminated at Māori events such as the national Kapa Haka Festival where health providers often have stalls.

Recommendations:

Ministry of Health and Fertility Services should support a programme to raise awareness of Māori fertility, infertility and AHR among Māori communities.

Family Planning should review its role with regards to infertility.

6.8.1 Māori-friendly AHR

Participants had a number of suggestions for how fertility services could make their services more Māori friendly and thus more accessible to Māori.

Barriers for some Māori include the language used, medical terms, test results and the way doctors speak. The officious manner of nurses and doctors can be a barrier. Participants said providers needed to be aware of this and if necessary over-explain, rather than leaving it up to the client to have to seek clarification and explanation. This would help with understanding and trying to reduce people's fear of test results and treatments.

Reducing the financial barriers to accessing AHR would improve Māori access.

Some participants thought Māori health providers could help to bridge the gap between current services and Māori communities. A Māori provider could help with dissemination of information about infertility and AHR and could awahi Māori through the process of having their infertility assessed, considering the range of responses to infertility and referral to fertility services.

Another option would be for Fertility Services to have Māori staff that could do this. One suggestion was for services to have a kaiārahi, a person who could awahi Māori within the clinics.

7.0 SUMMARY OF THE RECOMMENDATIONS

Further Research is Needed:

- to determine the prevalence of infertility among Māori.
- to determine Māori need for gamete donation.
- to determine Māori access to and use of fertility services.
- to determine whether Māori seeking help with their fertility receive equitable access to services and equitable treatment.
- to explore Māori men's attitudes towards and experiences of infertility.
- to explore Māori men's attitudes towards sperm donation and identify barriers or support.
- to explore the attitudes and impacts on whānau of people who have donated.
- with whānau who have used AHR or with people born as a result of AHR to look for unintended negative impacts on them and their identity.
- from a Māori perspective to review the potential discriminatory effect of the current criteria for public funding of AHR.
- to analyse the differences in incidence of infertility, stage of diagnosis, fertility treatment accessed and outcome between Māori and non-Māori in New Zealand.
- looking into equitable access to AHR to also consider geographic spread of Māori. For example, do areas with high proportion of Māori such as Te Tai Tokerau and Tarawhiti have equitable access to fertility services?
- to investigate the experiences of Māori who have sought help with their fertility to assess their satisfaction with the service they received; and factors that contribute to decisions to pursue and end AHR treatment. Also, the research should determine whether the demographic profile of Māori who use AHR vs. those that choose not to use AHR is significantly different.
- to explore the subjective nature of the intrusiveness of AHR procedures with a view to developing a measure that could assist with tailoring of treatment supports to reduce barriers and drop-out for Māori.
- into Māori stories about whakapapa, whāngai, tomo and other arrangements that occurred to ensure people had children and heirs to help identify precedents, parallels and tikanga that could be used to guide Māori considering AHR.

Recommendations for Fertility Services

- MoH and Fertility Services should support a programme to raise awareness of Māori fertility, infertility and AHR among Māori communities.
- The MoH and fertility clinics should work together to raise Māori awareness and knowledge of AHR, including surrogacy.
- Information about infertility needs to be accessible to Māori. It would need to address the myths about Māori fertility rates.

- Information on how to support a whānau member who is experiencing infertility should be available and accessible to Māori whānau.
- Good information about the various pathways to parenthood in addition to AHR, including whāngai, adoption, co-parenting, and counselling and infertility support groups and services, needs to be made available to people prior to testing.
- Information on the different pathways to parenthood should include information on DIY AI and the things people need to consider, such as, the legal status of the parents and donor and how to protect against the spread of STIs.
- Fertility services need to ensure that Māori are equally aware of their existence and what they do.
- Information on fertility services and AHR procedures and technologies needs to be comprehensible by the full range of potential Māori clients, including those from lower socio-economic groups.
- Information about infertility, AHR and fertility services needs to be relevant and acceptable to Māori men as well, and needs to be comprehensible by the range of men including lower socioeconomic men.
- Māori seeking AHR should have access to information about the range of Māori views they may encounter, and they should have access to knowledgeable counsel about tikanga Māori and AHR.
- Fertility service providers need to understand about whakamā, and be committed to addressing practice that could contribute to whakamā. Fertility services working to be more accessible for Māori need to communicate clearly to potential Māori clients how some people feel afraid, shameful or embarrassed, for example, and they need to state clearly how they operate in order to reduce whakamā.
- It is recommended that fertility clinic staff involved in AI procedures are educated as to the barriers to Māori women's access to AHR, such as, whakamā, and fear that te whare tangata will not be shown due respect, and that fertility clinics review their procedures with a view to minimising fear, discomfort and whakamā for women clients.

Recommendations for Health Professionals at Primary and at Secondary Care Level:

- Health professionals (both at primary and secondary healthcare level) should be encouraged to refer women to fertility services if they are at risk for infertility. This should include briefly asking women who have not had children by their late 20s (including single women and lesbian women) if they had aspirations to have children, and if so, whether they were aware that their fertility was going to decline more rapidly from that point on.
- Family Planning should review its role with regards to infertility.

Recommendations for Government:

- The law regarding parenthood when the child is conceived artificially outside of fertility clinics may need to be amended.

- The relevant family laws (and e.g. Human Assisted Reproductive Technology Act 2004) need to be reviewed with a view to extending better protection to the biological and intended parents of embryos carried by a surrogate and better clarification of the parental rights and responsibilities of surrogates. Like a sperm donor, a surrogate should not be legally recognised as the mother, unless she also donated her egg.
- It is recommended that AHR policies be reviewed with a view to addressing and removing barriers to AHR for Māori. For instance, if cost could be reduced by recommending that IVF with ICSI is used earlier in the process.
- The Government should review why there no Māori health providers are involved at any level in the delivery of fertility services to Māori.
- It is recommended that Government facilitate a process whereby iwi can be educated about AHR, fertility services and Māori fertility rates, and encouraged to consider the implications for them and their people who may experience infertility or want to use AHR and the resulting people born via AHR.
- Iwi need to be facilitated to discuss AHR, including PGD, with a view to setting policy, tikanga and guidelines for their people.
- Kaumātua and other experts in Māori tikanga should be asked to develop clear guidelines for Māori on AHR.
- Māori kaumātua and other experts on Māori tikanga should be involved in setting guidelines for Māori on the storage and disposal of gametes.

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10. GLOSSARY

aroha	love
awhi	support, help
e hia?	how many
hapū	pregnant
hau	soul, essence
hauora	health
he aha te kaupapa?	what's the purpose of it?
he mokopuna, he taonga	your grandchildren are your treasure
he wahine māori ahau, he māmā ahau hoki	I am a Māori woman, I am a mother
hōhā	a tiresome person, bored, annoyed
hui	meeting
iwi	tribe, bones
kai	food
kaiārahi	leader
Kaiarataki	leader, conveno
kaimahi	workers
kāore au he mokopuna	I have no grandchildren
kāore he hua ai	they had no children
karakia	prayer-chant
karanga	traditional greeting, call
kaumātua	elders
kaupapa	philosophy
kawa	protocols
ko wai koe?	who are you?
kōrero	talk
kūmara	sweet potato
mahi	work
mai ra no	since way back
makariri	cold
mākutu	curse
mamae	pain, hurt
mana	integrity, charisma
marae	space of traditional meetings
mātauranga	knowledge
mātua	parent
mauri	life principle
mirimiri	massage
mōkai	pet
mokopuna	grandchildren
motu	island
no hea koe?	where are you from?
non-Māori non-Pacific	predominantly Pākehā or white European New Zealanders
paepae	orator's bench
papa	floor/side
pepi	baby

pono	principle
pouri	sad
pōwhiri	welcome, opening ceremony
puku	belly
rangatahi	youth
rangatira	chief
rohe	territory, district
rongoā	treatment
rūnanga	council, institute
takatāpui	non-heterosexuals e.g. lesbian, gay, transsexual, intersex, bisexual
take	issue
tamariki	child, children
tamariki ora	children's health
tane	man
tangata (plural tāngata)	person
tāngata whenua	indigenous people of the land
tangihana	funeral, wake
taonga	treasures
tapu	sacredness
taurahere	link
te ao	the world
te taha wairua	the winged spirit
te whare tangata	the house of the people; woman's reproductive system
teina (plural tēina)	younger brother of boy, younger sister of girl,
tika	right
tikanga	the right way; custom; ethical system
tinana	body
tipuna (plural tīpuna)	ancestor grandparent
tohunga	expert, specialists
tomo	arranged marriage
tuakāna (plural tuākana)	older brother (of male), older sister (of female), senior
tutū	meddle
urupā	cemetery
wairua	spirit, soul
wānanga	learning institutions; educational hui
whakaaro	thinking
whakāhua roto	x-ray
whakamā	shy, feel ignominious, loss of mana
whakapapa	ancestry
whānau	family, extended family; birth
whanaungatanga	relationship, kinship
whāngai	adopt
whare	house
whare whakaira tangata	the house to create a new human being

11. APPENDICES

- A. Participant information sheet
- B. Participant consent sheet
- C. Participant demographic sheet
- D. Key informant interview schedule
- E. Flipchart/PowerPoint presentation for Interviews/Hui
- F. Hui Pānui: Health workers

Appendix A

Social & Community Health



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND
HEALTH SCIENCES

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Social & Community Health
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MAORI AND ASSISTED HUMAN REPRODUCTION: AN EXPLORATORY STUDY.

PARTICIPANT INFORMATION SHEET

Ko Ngatokimatawhaorua te waka. Ko Hokianga te awa. Ko Nga Puhi Nui Tonu te iwi. Ko Marewa Glover toku ingoa. Tena koutou, tena koutou, tena koutou katoa. I am a researcher in the Department of Social and Community Health at the University of Auckland. Supporting me in this research are Dr Lorna Dyall of the Department of Maori Health, also at the School of Population Health, University of Auckland and Adjunct Professor Dr Ken Daniels from the Department of Social Work, University of Canterbury. Henare Mason and Waiora Port are the kaumatua overseeing this research. The research is funded by Nga Pae o te Maramatanga, The National Institute of Research Excellence for Maori Development and Advancement.

This research aims to find out what different Maori think about infertility and the services and technologies that have developed to assist human reproduction. We want to understand better what are the supportive influences and barriers that might exist for Maori who could benefit from assisted human reproduction.

I will be interviewing about 12 people who could be considered to be key informants on the topic of Maori infertility and assisted human reproduction in New Zealand. I invite you to participate in this study as a key informant. Your participation is entirely voluntary and you are free to withdraw from the study up to 3 months following the interview/hui. You may do this without having to give any reason, and without suffering negative repercussions of any sort.

I also will be running six hui to gather the views of Maori kaumatua/kuia, rangatahi, Maori health workers, Maori who may have used or wanted to use fertility services, Maori women and their partners and takataapui. The hui will involve the presentation of information on assisted human reproduction to encourage informed discussion of the meaning, implications and benefits for Maori of the various technologies and services currently available or that are potentially going to be available in the future.

There are no right or wrong opinions and you don't have to have experienced infertility, or needed or accessed fertility services to take part in the study. Interviewees and hui participants will not be required to speak about their personal experience of assisted human reproduction, although any information you choose to contribute will be treated respectfully and anonymously. Due to the nature of hui confidentiality cannot be guaranteed. Participants will be asked to respect the privacy of other participants and to treat the korero as confidential to the hui.

The discussions could touch on culturally sensitive or personally sensitive matters. If the discussions trigger uncomfortable feelings, such as, unresolved grief, you are welcome to talk to me or the kuia or kaumatua about your feelings. I am a psychologist with counselling experience and I would be happy to listen to your concerns and/or refer you to specialist services that could help. I can be contacted on (09) 373 7599 extn. 86044 or if you are outside of Auckland you can contact me on 0800 285 284.

The interviews and hui will be tape recorded and notes will be taken. At any point during the interview/hui you can ask for the recorder to be turned off or for particular comments to not be written down. Notes and tapes from interview and hui will be stored in a locked filing cabinet for 6 years and then destroyed using the University document destruction service. The information will not be kept for use in any future research projects.

If you agree to participate in the research you need only do so once. An interview will take about 35 minutes to 45 minutes. The interviews will be conducted at a time and place convenient to you (for example, at your work place). Hui will be run in accordance with tikanga Maori and most will be run from approximately 10am to 3pm, unless the participant group stipulates an alternative time, such as, after hours. Hui will be held at a community based venue, such as, a marae or health centre. Morning tea and lunch will be provided. Petrol vouchers are available as reimbursement for travel if required.

The interviewer/hui facilitator and note taker can understand intermediate level te reo Maori, so the interviews will be conducted mainly in English, but you may respond in Maori if you wish. Te reo Maori versions of this information sheet and the consent form are available if you want a copy.

If you agree to participate in this research please read and sign the consent form (to be supplied) and return it to the researcher. Thank you very much for your time and help in making this study possible. If you would like to receive a copy of the summary report of the results please add your name to the separate list being circulated for that purpose.

Should you have any concerns or complaints arising from your participation in this research you may contact Dr Marewa Glover or Dr Peter Adams (Head of Discipline), through the Department of Social and Community Health, School of Population Health, University of Auckland, Private Bag 92019, Auckland, phone 373 7599 extn. 86538. If you have any queries about ethical matters relating to this project, you may contact The Chair of the University of Auckland Human Participants Ethics Committee, Office of the Vice Chancellor, Research Office, Level 2, 76 Symonds Street, Auckland, Private Bag 92019, Auckland, or phone 373 7599 extn. 87830.

Approved by the University of Auckland Human Participants Ethics Committee on 20 July 2005 for a period of three years. Reference 2005/296.

Appendix B

Social & Community Health



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND
HEALTH SCIENCES

CONSENT TO PARTICIPATE IN RESEARCH

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Morrin Road, Glenn Innes

Telephone: 64 9 373 7599 extn 86044
Facsimile: 64 9 303 5932
www.health.auckland.ac.nz/population-health

Project: Maori and assisted human reproduction: An exploratory study.

Researcher: Dr. Marewa Glover

I have had this research project explained to me and I understand it. I have been able to ask questions of the researcher and have them answered. I understand that I am free to withdraw from the study up to 3 months following my interview. I may do this without having to give any reason, and without suffering negative repercussions of any sort.

I understand and consent to the use of a tape recorder and that notes will be taken during my interview. I understand that these will be marked with a code number only and not my name, and that they will be kept strictly confidential. They will be stored in a locked filing cabinet for 6 years and then destroyed. The information will not be kept for use in any future research projects.

I agree that anything I say during the interview may be quoted or cited in presentations, reports or publications arising from this research. Such quotations will be anonymous, with any potentially identifying details removed or changed. I reserve the right to stipulate certain areas of conversation or details I talk about as not available to be used as part of the research findings.

I would like to check the transcript of my interview. Yes/No

I would like to receive a summary report of the results. Yes/No

I agree to take part in this research.

Signed: _____

Name: _____
(please print clearly)

Date: _____

**Approved by the University of Auckland Human Participants Ethics Committee
on 20 July 2005 for a period of 3 years. Reference 2005/296.**

Appendix C

MAORI AND ASSISTED HUMAN REPRODUCTION: AN EXPLORATORY STUDY.

INFORMATION ABOUT PARTICIPANTS

This form asks information that will help us to assess whether we succeeded in gathering the views of Maori of different ages, who live in different areas; some might work, some might be self-employed or raising children fulltime, looking for work or retired; some might have experience of fertility services while others know very little about the topic. This information is anonymous and will not be used to identify you in any way. Thank you for participating.

Tick which apply:

Male Female

How old are you? _____

Town/City of Residence: _____

Do you work outside the home? Yes No

If YES: is this employment paid or unpaid? Paid Unpaid

On a course

Fulltime Part-time

Casual

What is your occupation? _____

Do you receive an income benefit? Yes No

If YES: which benefit do you receive?

Unemployment Domestic Purposes Superannuation

Invalids Sickness Widows

Are you eligible for a Community Services Card? Yes No

How much do you know about Assisted Human Reproduction? (tick all that apply)

- Very little
- Only what I've read in the papers or heard on the radio or television
- I have read pamphlets, books or other information on the topic
- I have extensive knowledge of the subject from a personal, clinical or policy perspective

Reproductive history:

- 1. I/We haven't tried to get pregnant and have children yet, but intend to do so in the future
- 2. I never had the opportunity to have children but I would have liked to have had children
- 3. I/We have had personal difficulties conceiving or hanging on to a pregnancy
- 4. I/We have tried different methods to improve my/our chances of conceiving/carrying to term
- 5. I/We have used fertility services
- 6. I/We have had (insert number)_____ child/children without assistance
- 7. I/We have had (insert number)_____ child/children with assistance
- 8. I/We have assisted others (as a donor/surrogate) to have a child/children

Other

Appendix D

MAORI AND ASSISTED HUMAN REPRODUCTION: An Exploratory Study

Key Informant Interview Schedule

Date _____

Key informant type (e.g. Policy, Organisational, Practice, Perspective)

What is your background experience with regard to Maori 'infertility' and the various responses to infertility?

Attitudes to Infertility

What are your personal views on infertility?

What do you think are the Maori views on infertility?

Is it important for Maori to have good fertility? Why?

(e.g. for individual hauora (wairua & hinengaro); whakapapa; relative to other Maori health priorities; in relation to increasing Maori population? What are the Maori rights and responsibilities with regard to AHR?)

Attitudes to Assisted Reproductive Services and Technologies

Is it important for Maori to have access to services and technologies that can help people who find themselves unable to get pregnant when they want to? Why?

(e.g. again an individual hauora issue; could be a Treaty issue such as equitable access. If necessary, ask: What, if any, are the issues associated with access for Maori to AHR services?)

Now, I'm going to run through a range of treatment options and technologies that are being used or are proposed in the field of Assisted Human Reproduction. For each of these, what would be the positive or negative take (issues) for Maori? Particularly, could you tell me of any opinions Maori have expressed about them.

[Refer to flipchart]

(If applicable) What could be done to address the issues you have raised?

Attitudes to AHR Policy

With regards to the development of policy on AHR and the formulation or changing of legislation, are there any 'issues' for Maori?

(e.g. access to the policy development process, consultation with Maori. If necessary, ask What, if any, changes to current policy or legislation are needed?)

Comments on aims of this study

We are proposing to run six hui on AHR. The hui will involve the presentation of information on assisted human reproduction to encourage informed discussion of the meaning, implications and benefits for Maori of the various technologies and services currently available or that are potentially going to be available in the future.

a. Who do you think we should be seeking comment from?

b. Are there any questions other than those I have asked you, that you think should be put to the hui?

Other comments

Is there anything else I should have asked you?

Is there anything you would like to add to what you've already said about Maori infertility and AHR?

Appendix E

Flipchart/PowerPoint presentation for Interviews/Hui

Slide 1

**Maori and
Assisted Human Reproduction:
An Exploratory Study**

Dr Marewa Glover
Social & Community Health
School of Population Health

THE UNIVERSITY
OF AUCKLAND
FACULTY OF MEDICAL
AND HEALTH SCIENCES

Ngā Pae o te
Māramatanga

Slide 2

What is infertility?

- A typical fertile couple in their mid-to-late 20s having regular sex has about a 20-25% chance of conceiving each month. After 6 months at least three-quarters of such couples will be pregnant, and after a year at least 90%.
- Infertility is usually defined as not becoming pregnant after a year of trying.
- European studies show 15-20% of couples experience infertility at some time.
- About half of infertility is male based and about half female based.

2

Glover et al (2005) Maori & AHR

Slide 3

What do you think about infertility?

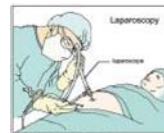
- *What have you heard about traditional/pre-European Maori views on and responses to infertility?*
- *Is it important for Maori to have good fertility?*
- *Is it important for Maori to have access to services and technologies that can help people who find themselves unable to get pregnant when they want to?*

3

Glover et al (2005) Maori & AHR

Slide 4

Assessing infertility




- Hormone tests for the woman
He whakamatau taiaki mo te wahine
- Sperm test for the man
He whakamatau keha mo te tane
- Laparoscopy or,
He mahi pokanga ngawari
- x-ray (hysterosalpingogram) to check tubes
He whakaahua whakaroto hei titro I te whare tangata

4

Glover et al (2005) Maori & AHR

Slide 5

Ovulation induction




- Drugs to stimulate ovulation
He pire, he werohanga ranei hei whakaterere i te mate o te wahine
- Drugs to stimulate production of more than one egg
Kainga ai e te wahine etahi rongoa taiaki kia maha ake nga kakano e pakari mai ana i te marama o te maimoatanga
- Drugs can be used to bring on ovulation

Glover et al (2005) Maori & AHR




5

Slide 6

Gamete donation



- Sperm donation
 - using own donor
 - using an anonymous donor*
- Egg donation
 - using own donor
 - using an anonymous donor*
- Embryo donation
 - using an anonymous donor*




* Donors can no longer remain anonymous to the child.

Glover et al (2005) Maori & AHR

6

Slide 7

Gamete Storage



- Sperm, eggs and embryos can all be frozen and thawed for later use.


Ka totokahia ana nga keha, kakano, kahu ranei

7

Glover et al (2005) Maori & AHR

Slide 8

Artificial Insemination *Ka whakaurua te keha ki roto o te whare tangata*



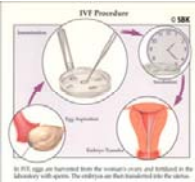
- Done at home
- Assisted inseminations

8

Glover et al (2005) Maori & AHR

Slide 9

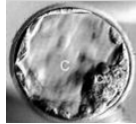
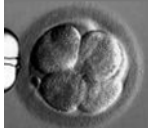
IVF



© SBK

In IVF, eggs are harvested from the woman's ovary and fertilised in the laboratory with sperm. The embryos are then transferred into the uterus.

- In vitro fertilisation (IVF)
- If an egg is successfully fertilised it is inserted high in to the uterus by a Doctor
- Transfer at 3 days or 5 days




Glover et al (2005) Maori & AHR

9

Slide 10

ICSI



© SBK

Sperm aspirated into pipette Sperm inserted into ooplasm Sperm expelled into ooplasm


- Intra Cytoplasmic Sperm Injection
 - the sperm is injected into the fluid part of the cell
- A single sperm is injected into each egg
 - He weronga I tetahi keha ki roto o ia kakano*
- Used when sperm count is low or sperm inhibited by antibodies.
- Sperm can be retrieved direct from testes using a fine needle.

Glover et al (2005) Maori & AHR

10

Slide 11

Pre-Implantation Genetic Diagnosis




- Involves taking a single cell from a developing embryo and analyzing its genetic makeup.
- This is done to find chromosomal and genetic disorders or diseases (e.g. Cystic Fibrosis, Down's syndrome, chromosomal abnormalities that can cause miscarriage or prevent pregnancy).

11

Glover et al (2005) Maori & AHR

Slide 12

IVF Surrogacy *Whare whakaira tangata*



- The infertile woman undergoes most of the steps of an IVF treatment, but the embryos are transferred to a friend or whanau member who is called the surrogate. The infertile couple adopt the child after birth.

12

Glover et al (2005) Maori & AHR

Slide 13

AHR Policy Development

- *With regards to the development of policy on AHR and the formulation or changing of legislation, are there any 'issues' for Maori?*

13

Glover et al (2005) Maori & AHR

Slide 14

Whakamutunga

- Is there anything you would like to add to what's already been said about Maori infertility and AHR?

14

Glover et al (2005) Maori & AHR

Acknowledgements

- This project is funded by Nga Pae o te Maramatanga
- The research team supporting this project includes Adjunct Professor Ken Daniels, Dr Lorna Dyll, Alvie McCree, Henare Mason and Waiora Port
- Some of the te reo Maori was downloaded from www.fertilityassociates.co.nz
- The pictures were found using www.google.com

Appendix F

Hui Panui

PANUI PANUI PANUI PANUI PANUI PANUI PANUI

Maori Fertility & Assisted Reproduction Hui: Maori Health Workers Views



**Wednesday 29 March, 10.00am at Ruapotaka Marae
106 Line Rd, Glen Innes, Auckland**

**Is Infertility among Maori increasing?
Why don't more Maori donate sperm, eggs or embryos?
Are Maori using In Vitro Fertilisation?
Have you heard of Pre-Implantation Genetic Diagnosis?
What are your views on Reproductive Surrogacy?**

Your views as a Maori Health / Sexual Health Worker are wanted for a study on Maori attitudes to infertility and the services and technologies that have developed to assist with human reproduction.

The hui will involve the presentation of information to encourage informed discussion of the meaning, implications and benefits for Maori of the various fertility services now available.

There will be a series of hui to gather the views of different groups of Maori. Other hui will be run for Kaumatua/Kuia, Rangatahi (16-24yrs), Maori who may have used or wanted to use fertility services, Maori who have thought about helping others to have children and Takataapui (gay, lesbian, transsexuals and bisexuals).



**To register and receive an
information sheet please contact
Dr Marewa Glover
Principal Investigator
University of Auckland
(09) 373 7599 extn 86044
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**Powhiri: 10.00am
Kapu Ti: 10.30am
Mihimihi: 10.45am
Korero: 11.00am
Kai (lunch): 12.30pm
Korero ano: 1.00pm
Expected close: 2.30pm**

