

**USE OF GAMETES AND
EMBRYOS IN HUMAN
REPRODUCTIVE RESEARCH:
DETERMINING POLICY FOR
NEW ZEALAND**

RESEARCH TO SUPPLEMENT PUBLIC CONSULTATION
ON ACART'S DISCUSSION DOCUMENT

RESEARCH REPORT FOR

**ADVISORY COMMITTEE ON
ASSISTED REPRODUCTIVE
TECHNOLOGY**

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1 EXECUTIVE SUMMARY

This study was commissioned by the Ministry of Health on behalf of ACART (Advisory Committee on Assisted Reproductive Technology), to canvas views of New Zealanders on whether research involving the use of human gametes and embryos should be permitted in New Zealand, and if such research were permitted, what possible limitations should be applied.

This study used 10 mini groups of three to four people, with a total of 39 participants. They were selected from both metropolitan and rural New Zealand. The study comprised candidates selected on the basis of being "relatively informed individuals", but who would be unlikely to put forward public submissions or attend a public meeting or hui.

The selected candidates were chosen to include a cross section of society, with specific mini groups as shown:

- Young people
- Women
- People with experience of infertility
- People with experience of genetic disorders
- Ethnic selection: Chinese people
- Ethnic selection: Indian people

Maori and Pacific Island peoples were not included in this study because they were being consulted in wider public events such as hui and fono.

Research using human gametes and embryos inspired a wide-range of feelings and views. People from all demographic groups had differing perspectives, but overall there were four predominant perspectives.

The four perspectives were:

- **Strong Advocates** – strongly science focused; believed in progress through science; felt that positive contributions to society will come from science; full support for loose regulations around the science fraternity so as to maximise the momentum and progression of research; felt that New Zealand could lead the world in such research.
- **Pragmatic Advocates** – were still science focused; believed significant scientific and medical progress can result from this type of research; were aware of the risks and potential impacts on society from this form of research; wanted controls and regulations around the scientific research to ensure people who donate tissues to research were protected and treated respectfully; saw quality and validity as being very important; saw a little more of the donor side of the issue.
- **Cautious Evaluators** – had positive views on the potential of science; focused more on the potential impacts on the donors and the embryos as potential human life; struggled in supporting embryo research because of the destruction of the embryo; agreed with science needing to progress but emotionally uncomfortable with embryos being experimented on or destroyed; felt New Zealand needed to collaborate with other like minded countries for the benefit for the wider world community; felt strong regulations required, and concerned about risks; felt the purpose for the research should be only for worthy causes.
- **Strong Opposers** – strongly opposed to the use of embryos; felt the embryo is a life and should not be destroyed; felt the embryo had a soul as soon as it was fertilised; not opposed to science or progress; were supportive of adult stem cell research for its potential to alleviate suffering; concerned that the morals of society were slipping; felt the moral costs did not out-weigh the

benefits of this research; felt scientific research moving too fast and not enough attention to the long term effects of potential outcomes.

	Young people	Women	Experience of genetic disorders	Experience of infertility	Ethnic Chinese	Ethnic Indian	TOTAL
Strong Advocates	-	-	3	1	2	-	6
Pragmatic Advocates	6	-	3	2	-	3	14
Cautious Evaluators	2	4	-	1	1	-	8
Strong Opposers	-	4	1	4	2	-	11
TOTAL	8	8	7	8	5	3	39

The findings showed most people across all groups were not opposed to research in New Zealand using human gametes because they saw gametes as something that was being regularly discarded by the body and in themselves did not have the potential for life. Research on embryos, however, showed greatly varying views, ranging from absolutely supportive to absolutely against, with a spectrum of views in between.

With respect to the purpose of research on embryos, all groups, except the Strong Opposers, believed that the priority of research was to improve the quality of life for people who live with serious health conditions and research could potentially help reduce future human suffering. The Strong Opposers believed in alleviating suffering through the use of adult stem cell research instead of embryos. There were differing views within the groups on the other purposes of research, including infertility, cures for lifestyle diseases, and scientific knowledge.

Generally most of the people in all the groups agreed with using **donated gametes and non-viable embryos created via IVF**. All the groups except the Strong Advocates, believed that strong regulations were required to ensure that donors and the gametes and non-viable embryos were not exploited.

Suggested regulations included:

- Gametes and non-viable embryos must be donated
- Consents given
- Donors aware of what research is undertaken
- Gametes not used to create an embryo, clone or hybrid
- Guidelines reviewed and updated regularly to reflect the fast changing nature of scientific and medical research

Using **donated surplus viable embryos created via IVF** was generally acceptable to all groups except the Strong Opposers who were entirely against the use of embryos in research.

There were varying views, both positive and negative, on research using **embryos created specifically for research via IVF**. A positive point was that this type of research could continue more easily since there was an assured alternative supply of embryos and it was therefore a tool in advancing medical science. On the negative side, the general feeling was that women would not want to put themselves through the process of egg collection unless they believed strongly in the

outcome of the research, plus it was felt this would be morally wrong and viewed as 'playing God' and people objected to this.

Many of the people in all four groups were uncomfortable with **cloning and hybrid embryos** as a general concept. This was driven by a fear of 'tampering' with nature and the unknown, unpredictable and potentially serious outcomes.

On the topic of **genetic modification of gametes and embryos**, there was some sympathy for the notion of being able to remove a potential genetic defect so a child could be born without a debilitating disease. However there were concerns about the effects of a foreign body being introduced to an embryo, particularly from another species. It was also felt that there was not enough known or understood to predict the outcomes of changing the genetic makeup of a gamete or embryo. All groups were opposed to genetic modification to allow the potential selection of characteristics in children and/or anything that was motivated by financial gain.

In terms of **importing and exporting gametes and embryos**, some felt this was an important part of New Zealand contributing to the wider scientific world and in helping other countries that did not have the technology themselves. Others were concerned about:

- The potential for spreading disease
- Exploitation of third world countries in harvesting gametes and embryos
- The unknown origin of gametes and embryos affecting the validity of the research
- New Zealand gametes and embryos being used by other countries in ways that New Zealand was opposed to

In terms of incorporating different ethical, spiritual and cultural perspectives, people agreed there was no easy answer. Some people felt that due to the complex nature of the issues, in order to ensure informed decision-making it was important that education and consultation with Maori (including different iwi), would provide the basis of knowledge for them to incorporate their beliefs, values and needs into the policy¹.

Some people supported a policy that would allow individual choice, and others wanted a democratic consultation process. Others questioned the efficacy of a democratic process, when they believed that the New Zealand general public had very little knowledge of the area and appeared to base some of their views on popular science fiction or inaccurate information. These people were unsure that the government would be able to educate the public sufficiently without oversimplifying the information.

People were interested in the positions other countries have taken on this issue (when shown these), and at some level gained reassurance about the way they felt New Zealand should go.

The table below shows how the groups aligned with the different positions

¹ It should be noted that Maori were part of other consultation processes and were not included as participants in this study.

Position A	Position B	Position C	Position D
<p>The use of embryos in research is banned.</p> <p>The use of established human ESC in research is banned.</p>	<p>The use of embryos in research is banned.</p> <p>The use of established human ESC in research is not banned.</p>	<p>The use of surplus IVF embryos in research is not banned.</p> <p>The use of established human ESC derived from surplus embryos is not banned.</p>	<p>The use of embryos created for research and surplus IVF embryos is not banned.</p> <p>The use of established human ESC derived from such embryos is not banned.</p>
Where people were positioned			
Strong Opposers		Pragmatic Advocates Cautious Evaluators	Strong Advocates
Positions of countries			
<p>Republic of Ireland</p> <p>Austria</p> <p>Poland</p>	<p>Germany</p> <p>Italy</p>	<p>Canada</p> <p>Australia</p> <p>France</p> <p>Czech republic</p> <p>Denmark</p> <p>Finland</p> <p>Greece</p> <p>Hungary</p> <p>Norway</p> <p>Russia</p> <p>Spain</p> <p>Switzerland</p> <p>Taiwan</p>	<p>United Kingdom</p> <p>Singapore</p> <p>Belgium</p> <p>China</p> <p>India</p> <p>Israel</p> <p>Netherlands</p> <p>South Korea</p> <p>Sweden</p>

The ethnic specific groups of Chinese and Indian people were similar to the other groups in that their opinions ranged across the spectrum. Of note was that older Asians tended to be more supportive of research using embryos whilst the younger Asians in the sample were more cautious or opposed to using embryos. This was the reverse of what was noted in the other groups where generally the older people were cautious or opposed to using embryos whilst the younger people tended to be supportive of the concept.

However, as with all this research, it needs to be remembered that relatively small numbers of people were interviewed, so the results need to be interpreted in conjunction with all other research, submissions and expert advice being sought by ACART.

REGULATIONS

Whilst one group wanted very loose regulations on the use of gametes and embryos in research to allow quick growth and progress in the field, other groups wanted tight regulations that were respectful toward the donor, ensured valid research and would stop scientists from taking the

research too far (creating a clone person). If research on gametes and embryos is to go ahead the regulations that people wanted were:

- Gametes and embryos must be donated, not bought
- Donors must give consent to their gametes or embryos being used for research
- Donors must give consent to their gametes or embryos being imported or exported
- Donors would have access to information on research use and outcomes
- Gametes not to be used to create an embryo, clone or hybrid
- Guidelines reviewed and updated regularly to reflect the fast changing nature of scientific and medical research
- The embryos not to be allowed to grow past 14 days
- The embryo/cells from the embryo to be disposed of after a prescribed period of time
- Guidelines be set by suitably qualified and experienced people who have knowledge of overseas processes and regulations
- The system be closely monitored, audited and subjected to peer review
- Governed by a suitably appointed and experienced body or committee
- In depth knowledge (medical and family history) of the person/s who donated the gametes and embryos
- Import and export only to countries with similar policies to New Zealand
- Gametes and embryos are not bought or sold for profit
- Adhere to biohazard procedures

2 INTRODUCTION

The Ministry of Health, on behalf of the Advisory Committee on Assisted Reproductive Technology (ACART), wishes to canvas views on whether New Zealand should allow research involving the use of human gametes and embryos, and if so, the limitations of such research.

In the recent research conducted by TNS for the Bioethics Council, by way of nine focus groups among a broad cross-section of socio-demographic groups, the main pattern in the research outcomes was one of fragmentation, "there was virtually no consensus among any groups on any single issue relating to human embryo research". The study revealed that "the current awareness of human embryo research is so limited as to have a mythical quality, in that awareness is based more on fictional narratives and images than facts and actual scientific developments and capabilities". The authors of the research report noted that "It is prudent to be realistic about the extent to which the general public can be expected to become actively involved in the debate about how or whether human embryo research should be developed".

In order to build on the work of the Bioethics Council and avoid duplication, ACART wished this current study to comprise "**relatively informed individuals**" who, nevertheless, would be unlikely to put forward public submissions or attend a public event such as public meetings, hui or fono.

The study was concerned with eliciting perspectives on the issues raised in ACART's discussion paper "Use of Gametes and Embryos in Human Reproductive Research: Determining Policy for New Zealand".

In accordance with the MoH brief for the research, the objectives of this study were to summarise the views New Zealanders express, in response to ACART questions concerning:

1. Research using gametes
2. Research using embryos
3. Purposes for conducting research
4. Sources of gametes and embryos
5. Genetic modification of gametes
6. Genetic modification of embryos
7. Import and export of gametes
8. Import and export of embryos
9. Incorporation of needs, values and beliefs of Maori into New Zealand policy position
10. Incorporation of different ethical, spiritual and cultural perspectives
11. Further comments not covered in issues above

3 METHODOLOGY

FOCUS GROUPS

For this research we used 10 mini-groups of between three and five respondents. Mini-groups are focus groups with fewer participating respondents. This structure combines the benefits of discussion while still maintaining a close rapport with a smaller group of people. Groups are usually 120 to 180 minutes long.

From these mini-groups we are able to elicit more in-depth responses than we would normally expect in a full-size focus group. Conducting this research using individual interviews or mini-group discussions allows much more scope to deal with sensitive cases should they arise. It also allows us to explore people's views people with more freedom than if they are in a larger group where others express strongly opposing views.

In larger focus groups of say six to eight participants, there is a risk of a "biased" sample, to the extent that there may be a risk of people not expressing contrary views.

LOCATION

These mini-groups were conducted in Auckland (representing an urban setting), Dunedin (representing a South Island setting), and Morrinsville (representing a rural setting).

	Auckland	Morrinsville	Dunedin
Young People		1 group x 4	1 group x 4
Women		1 group x 4	1 group x 4
Experience of infertility	1 group x 4		1 group x 4
Experience of genetic disorders	1 group x 4 1 group x 3		
Ethnic: Chinese	1 group x 5		
Ethnic: Indian	1 group x 3		

RECRUITMENT

ACART outlined for us the types of people they were interested in hearing from and these have been listed in the table above. We endeavoured to interview those who felt they were relatively informed on the subject of gametes and embryo research. Prior to attending the group participants received information and resources to ensure all people had a grasp of the concepts and issues to be discussed in the groups, without bias. (See the next section on Materials Received by Respondents for details.)

As well as being informed, criteria for recruitment of each of the groups included:

Young People	Women	Experience of genetic disorders	Experience of infertility	Ethnic: Chinese	Ethnic: Indian
Year 13 16-17 years old European ethnicity Biology or science student Unlikely to make a submission to the committee Not representing an organisation or business on this issue Male and female	Unlikely to make a submission to the committee Not representing an organisation or business on this issue 25-65 years old European ethnicity 4 with children 4 intending to have children in near future	European ethnicity Unlikely to make a submission to the committee Not representing an organisation or business on this issue Recruited from a list provided Male and female	Unlikely to make a submission to the committee Not representing an organisation or business on this issue 25-45 years old European ethnicity 4 with children 4 without children Male and female	Unlikely to make a submission to the committee Not representing an organisation or business on this issue 25-65 years old Chinese ethnicity Female	Unlikely to make a submission to the committee Not representing an organisation or business on this issue 25-65 years old Indian ethnicity Female

Mini-groups took place at a convenient location in each of the three centres and respondents were provided with a \$150 incentive to participate in the group. In total, there were n=39 respondents.

The research was carried out with the approval of the Multi-region Ethics Committee.

The guide used in the groups is in Appendix B.

4 RESPONDENT INFORMATION

Prior to the group discussion, respondents were sent information to consider and think about before attending the group.

This information booklet is attached in Appendix A, and contained:

- An outline of the questions the research was focusing on
- Explanation of the vocabulary and concepts
- Self-completion questionnaire to be filled in prior to attending the group

Materials used during the session are also attached in Appendix A as follows:

- A chart that outlined the different positions countries had taken on these issues
- A chart of the countries which related to these positions

To explore whether people's opinions would change after exposure to the group discussion, and having read more detailed information, ACART's full discussion paper "Use of Gametes and Embryos in Human Reproductive Research: Determining Policy for New Zealand" to take home.

People were asked to take several days to read it and fill in the submission forms at the back of the document and send them back to Phoenix Research in the pre-paid envelope supplied. This was done on the understanding that people could do as much or as little as they wished and that what they submitted would be for the purposes of the research and not a formal submission.

Of the 39 discussion papers distributed, 14 were returned. Views expressed in the submission forms did not differ from those they expressed in the groups.

5 GROUPING OF OPINIONS

OVERALL PERSPECTIVES

Research using human gametes and embryos inspired a wide range of feelings and views. People from all demographic groups had differing perspectives, but overall there were four predominant perspectives. These are outlined below and used throughout the body of the report to explain people's views.

STRONG ADVOCATES

These people were strongly science focused, they believed in progress through science and believed that science could and would make positive contributions to people and the country. These people tended to have had positive experiences of what science has done medically thus far and therefore had a positive emotional attachment to it.

The emphasis for these people was on speed; they wanted streamlined processes that allowed medical research to progress quickly and for results to be realised in a timely manner. These people had less of a focus on the need for regulations; in fact some wanted the regulations to be as wide as possible to facilitate experimentation. By having open policies it was felt that it might put pressure on other countries to follow suit, which people hoped would lead to more research, and more and quicker breakthroughs. A non-restrictive policy was perceived to positively encourage 'mavericks' who were felt to make the breakthroughs. Over-control was perceived to squash innovation and limit the potential for breakthroughs.

These people felt science and scientists needed to be valued; that they were seen to drive progress. Commercialisation was also seen to have value, as private facilities were felt not to have the controls that more public places did, i.e. universities.

"It shouldn't be over-controlled, there needs to be a balance. If the government over-controls and stops people wanting to spend money developing, in fact it's of no benefit to them. I think the ultimate way is for the government to do the funding through universities only, and therefore the universities might make money out of the research, but the universities don't usually make the progress because they are so heavily monitored."

(Person with experience of genetic disorders)

These people believed that there was an opportunity for New Zealand to lead and benefit financially through attracting international research funding in the area of research using embryos. They felt this was an area of research known for innovation and leading scientists. However, they suspected New Zealand would not take this up because decision making policy is expected to be too democratic. Public opinion was expected to be much more oppositional, due to perceived ignorance and religious and conservative attitudes.

It was believed that if New Zealand opposed this kind of research it would have a detrimental impact on New Zealand financially, with leading scientists leaving the country. It was thought that this stand would also give New Zealand a reputation of being backwards.

These people expected that huge progress would be made within this field over the next five years and they wanted New Zealand to be a part of it and not be left behind.

"I think New Zealand is quite a small country - we need to catch up and follow the world development and not always be behind. The whole world is developing so fast that New Zealand still coming from only the farms and land is always so behind the others and will get more behind. So you simply needs to look at what the other countries are doing and have at least one or two very powerful technologies. You can make a little bit of money out of farms, but even more if you have one technology, it can make New Zealand a lot of money like Canada, like America. So sometimes even though you are a small country but you need to know what happen in world."
 (Chinese person)

These people supported the use of embryos in research and were fairly trusting of the science and scientists.

Risk from the research, meaning unanticipated harm to people, was seen as inevitable and whilst all agreed that this needed to be avoided where possible they felt that sacrifices had to be made to gain the medical benefits and for science to progress.

For these people the pre-embryo was seen more as a group of cells than as a potential life. Their focus was more outcomes orientated than on the process of getting the outcome and there was little discussion about the moral or ethical issues of using the pre-embryos.

Make up of Strong Advocates	Number of people
Young People	0 out of 8
Women	0 out of 8
Experience of infertility	1 out of 8
Experience of genetic disorders	3 out of 7
Ethnic: Chinese	2 out of 5
Ethnic: Indian	0 out of 3
Total	6 out of 39

PRAGMATIC ADVOCATES

People in this group were science focused and generally believed in progress and that significant scientific and medical progress will be facilitated by this kind of research within their lifetime. These people were also very concerned that people who donate tissue to research be protected and treated respectfully. They saw the human side of the issue a little more than what was reflected in the Strong Advocates point of view.

"In particular, this means it is the obligation of scientists/researchers to keep donors, where requested, informed of when and how their donation is being used through the world and what the research results and outcomes, if any." (Person with experience of genetic disorders)

They saw the risks (i.e. unpredictability/unknown factors in long-term impacts of genetic engineering, cloning etc) as very real and were concerned about the potential for wider social impacts. Therefore

they were more pragmatic than the Strong Advocates in terms of considering the importance of the controls needed to surround the research.

"You have to have the freedom to do research but there has to be control over how that research is carried out and what is actually researched."

(Young person)

The focus of these people tended to be on the quality and validity of the research, wanting to ensure that the best possible gametes and embryos were used to ensure results were reliable and valid. Outcomes were focused on alleviating suffering, but they felt that strict controls were required.

These people were reasonably trusting of the world of science, but recognised that some abuse (not following regulations) would be inherent because of human nature. They felt that regulations are required to protect against the 'mavericks' in the industry. They felt that the benefits of the research would outweigh the expected abuse. They accepted that human sacrifices be made and would be worth it in the name of progress.

"Okay, look at super tankers, when they spill oil, I'm sorry to say but it isn't worth giving up oil and stopping the world using oil just to avoid the few thousand penguins dying, and then what about nuclear reactors, I'm sorry to say, but a few thousand people in Chernobyl being affected doesn't stop the benefit of nuclear power to the whole world."

(Person with experience of genetic disorders)

They believed that stem cell and embryo research has already been happening around the world and that it is not going to stop. Their belief was that New Zealand should join this trend and progress with the world otherwise it will be left behind. For these people it was about keeping up with progress and for New Zealand to make a positive contribution towards it. Pre-embryos were predominantly viewed as cells and not considered to represent a life yet.

Similar to the Strong Advocates, some of these people felt that if New Zealand did not go forward with this research it would have a negative impact on New Zealand financially and that the country would lose leading scientists to other more progressive countries.

These people tended not to have such a close personal connection to the benefits of science (i.e. hadn't received personal benefits), but believed in the potential positive results from research, from seeing past advances.

These people's levels of comfort increased and decreased depending on the issues being discussed. Some felt that time, experience and wisdom was important in scientific research and those risks increased if it was rushed.

Make up of Pragmatic Advocates	Number of people
Young People	6 out of 8
Women	0 out of 8
Experience of infertility	2 out of 8
Experience of genetic disorders	3 out of 7
Ethnic: Chinese	0 out of 5
Ethnic: Indian	3 out of 3
Total	14 out of 39

CAUTIOUS EVALUATORS

These people focused on the possible positive outcomes of science and the impacts on the donors, and embryos as potential human life. For these people there was more of a struggle in supporting embryo research because of the destruction of the embryo. This presented a double bind situation for some because intellectually they agreed with science needing to progress and welcomed that in terms of alleviating human suffering, but emotionally they were uncomfortable with embryos being destroyed.

"I would have to say I agree, I don't like the idea of using embryos to do those things, if they said yes then I think there should be parameters that they are allowed to use them in and it should be for the betterment of mankind. Again I like the idea of fixing problems, but I don't like the idea of using embryos to get there. So I go round and round in circles. It's a good idea, but how do you do it." (Person with experience of infertility)

Risks were acknowledged as being very real, and concerns revolved around the impacts on both the individual and society as a whole. These people tended to be less trusting of science and concerned about possible abuse inherent in human nature. They struggled to perform risk benefit analysis, feeling that they often didn't have enough information about the process to really decide if the outcome out-weighed the risks and practicalities of the research (destroying embryos).

These people were compassionate toward suffering and hoped that research could alleviate it. They did not believe in research for its own sake; they wanted a more specific, targeted approach.

Like the Pragmatic Advocates, this group was also concerned that there was not enough known by science about the long term impacts of genetic modification, cloning and use of hybrid embryos to really evaluate whether this research should go ahead.

Some felt that other sources should be looked at before using embryos, and that embryos should only be used if there was no other way of finding out what was required.

These people did not have strong positive or negative emotional experiences with science/medical research and therefore had a more distant emotional connection with the possibilities. They did not talk about a strong emotive attachment to the pre-embryo, but did see it emotionally and cognitively as a potential life.

These people wanted very strong regulations set in place to ensure that only research that was really worthy (would alleviate suffering) would be allowed and that 'mavericks' would be kept in check so that the donors and pre-embryos would not be exploited.

"I think more strict. If it was going to be done you would want really strict guidelines of at what point it should be stopped. Like how much they'd let the tissue grow or what they are going to put it in or like the usage of this technology would have to be really strictly guide-lined."

(Person from woman's group)

These people saw New Zealand as having the potential to make a valuable contribution in this research field and wanted New Zealand to take a collaborative approach with other like-minded countries. This was to ensure that research was not duplicated, and that facilities and findings were shared to benefit the wider world community.

Make up of Cautious Evaluators	Number of people
Young People	2 out of 8
Women	4 out of 8
Experience of infertility	1 out of 8
Experience of genetic disorders	0 out of 7
Ethnic: Chinese	1 out of 5
Ethnic: Indian	0 out of 3
Total	8 out of 39

STRONG OPPOSERS

These people generally were not opposed to science and the progress that scientific research could make medically, but not at any cost. They were opposed to the use of embryos on moral, ethical and religious grounds. They viewed the embryo as having a soul and/or the potential for life from the moment it became fertilised and felt that using it for research was destroying a life.

"I'm a Christian, and so to bring a bit of balance to it, I'm not against medical scientific research in any way shape or form, so long as it doesn't take human life - and as far as stem cell research is concerned, they can take stem cells from animals, they can take stem cells from adults, as you were saying yourself - I'm against them taking stem cells from embryos. I'm of the opinion that once an egg is fertilised, it's human life. If it's not human life, why does it grow, why does it multiply, why does it multiply again? It won't if they want the master cell, the ones that really develop the personality, probably the sex, what that person's going to be like - medical science refers to the first 14 weeks as tissue, I don't - they just refer to it as tissue - if it's tissue, tissue hasn't got life. The fact that it multiplies, to me says it's got life in it - I would go further to say that once an egg is fertilised that a new spiritual being has been created, and I ask the question, have we, as men and women, scientists, got the right to destroy that? Because when you do stem cell research on an embryo, you destroy the embryo, and I don't think it makes any difference whether that has been taken out of the womb,

or whether it's been done in the lab, once you fertilise an egg you've created a baby now." (Person with experience of genetic disorders)

These people were concerned that the morals of society were slipping and felt that this was opening the door to further 'acts against humanity'. The benefits of this research were not seen to out-weigh the moral costs and fundamentally it went against what these people felt was important.

Many people felt that research using adult stem cells was showing promise, and that this area should be pursued instead. They saw this area of work as having potential to alleviate human suffering. There was concern that this area would not be fully pursued if using embryos and embryonic stem cells were approved.

"I just think, what I know of the embryonic research that they've done on all of the diseases and conditions, they don't have as positive results as what adult stem cell research has." (Person from women's group)

Some of these people felt a distrust of the government, society and scientists. They were concerned that politics, money and scientific 'mavericks' would influence decisions rather than decisions being made based on what the public majority wanted.

These people were concerned about how this research using human embryos would affect society and the human race as a whole, both morally and physically. This issue was likened by some to issues they felt surrounded abortion and what Hitler did to people in World War II. The Strong Opposers, similar to the Cautious Evaluators, felt that scientific research was moving fast and that there was not enough attention being paid to the bigger picture and what the long-term effects of the outcomes might be.

Make up of Strong Opposers	Number of people
Young People	0 out of 8
Women	4 out of 8
Experience of infertility	4 out of 8
Experience of genetic disorders	1 out of 7
Ethnic: Chinese	2 out of 5
Ethnic: Indian	0 out of 3
Total	11 out of 39

6 RESEARCH USING GAMETES

Most people across all the groups were not opposed to research in New Zealand using human gametes. This was because people saw gametes as something that was being discarded by the body regularly and not in itself as having the potential for life.

"They are apart. You can't have anything until you mix them up."
(Young person)

"This is not a viable human baby, so I think research should be permitted."
(Person from women's group)

Gametes were perceived as belonging to an individual and therefore it being up to the individual as to whether they are used in research or not, as opposed to an embryo, which for some was seen as being an independent life and people making decisions over it.

"They belong to an individual and if they want to donate them, it is up to them." (Person with experience of infertility)

All groups felt that approval for use of gametes in research was conditional on clear regulations for their use. The Strong Advocates group wanted limited regulations whilst other people wanted these regulations to be crafted both for the donor and for the gametes. They wanted the regulations to include a consent process for the donors, which would ensure that they knew what research they were allowing their gametes to be used for. People felt it was crucial that there were clear guidelines that would prohibit the use of gametes in creating embryos. Some people were particularly uncomfortable with the idea of unknown people's eggs and sperm being put together to form an embryo, and for the donors not to be aware of what was being done, and worst case scenario to find out later that they were 'parent' to a child they didn't know about, created with the gametes of someone they didn't know.

People wanted the regulations to be reviewed regularly, to ensure that they were up-to-date. There would also need to be a specified length of time in which these gametes were used and then destroyed.

"...but when it's gametes there's no problems with it unless they are joined up." (Young person)

"Sperm/egg need to be kept separate and used only for the purposes that do not involve fertilisation of any kind." (Person from women's group)

Also of importance to a few people was the quality of the gametes used in research. They wanted to ensure that the research was as reliable and valid as possible and that the gametes used in the research were the best available. For them this meant careful regulations around where the gametes came from, ensuring that enough was known about the donor's health and genetic background to rule out any genetic or medical abnormalities in the gamete.

There was also concern that no money be involved in donating gametes. Most people were concerned that there was a possibility of vulnerable people being taken advantage of by being offered money for their gametes. The concern focused particularly on women and their eggs.

A few people from the Strong Opposers group felt a strong distrust and cynicism about the research staying within prescribed parameters. They felt that it was too risky, that the gametes would be used to create embryos or hybrids and therefore were against research using gametes.

7 RESEARCH ON EMBRYOS

In this area people's views varied, ranging from absolutely supportive of research using embryos to absolutely against, with a spectrum of views in between.

The Strong Advocates were strongly in favour of research using embryos. Their focus was on what the outcomes of the research might achieve and how it had the potential to alleviate suffering and further New Zealand's standing in the scientific community. These people saw the embryo as a collection of cells and were not opposed to them being used for research.

This group didn't want the research to be regulated. Many felt the fewer regulations the better, because it allowed scientists to go as far as they could and would drive progress and discoveries.

Pragmatic Advocates also agreed with embryos being used for research. Their focus was for this research to produce outcomes that would alleviate suffering, but they were also concerned that the donors be respected and informed. In general, these people believed it was ethical and responsible to use embryos and gametes in the pursuit of improving future quality of life, as long as constraints were in place to ensure research was motivated by good intentions, for the good of humanity and couldn't be abused by individuals or organisations in pursuit of personal rewards (scientific kudos/trophy hunting or financial gain).

"I think as long as it is done in a controlled environment and being careful and have set guidelines to work by, then medical science makes so many huge bounds and leaps forward and personally I don't really want it to stop. I want them to go ahead and make more progress but of course within a controlled environment." (Person with experience of infertility)

All agreed on the need for tight controls and supervision of any research carried out on embryos. They felt that this would entail a transparent process with audit trail, peer supervision and spot inspections. Research needed to be driven by the good of humanity rather than for the benefit of an individual or an organisation and thus be protected from 'maverick' behaviour. Also wanted were controls which would ensure the quality of the research and research results - would it be scientifically robust?

Cautious Evaluators were saying a cautious 'yes' to research that used embryos and also wanted very strict guidelines. These people tended to feel that it was important to be able to seek ways to alleviate suffering, but were a little uncomfortable about the use of embryos. Guidelines and regulations which facilitated donors giving informed consent (knew what the research was for, what it would entail, and received feedback on results) made these people feel more comfortable with the concept. They also wanted to ensure that the embryos were not exploited and that the research was worthwhile, and worthy of the sacrifice. These people felt that they would need more information to help them decide about their absolute position. They felt that alleviating suffering made this worthwhile, while things such as cosmetic improvements wouldn't be.

Most of the Strongly Opposed people were strongly against the use of viable embryos in research. They saw this as destroying a life, or potential life, and that science and humanity did not have that right.

There were a couple of people who opposed the use of both viable and non-viable embryos in research. This was due to a strong distrust of human nature and a concern that non-viable embryos

would not be accurately assessed and viable embryos might mistakenly (or not) be pronounced as non-viable in order to maintain supply.

One person in the Strongly Opposed group was clear that whilst they were themselves against the use of embryos in research, they wouldn't want to stop others having the choice.

8 PURPOSES OF RESEARCH

Three of the groups, the Strong Advocates, Pragmatic Advocates and Cautious Evaluators all believed that the priority for research was to improve the quality of life for people who live with serious conditions and help reduce future human suffering. For most this meant supporting research for the purposes of prevention of hereditary disease and for the treatment of human disease and injury.

However, young people in the Pragmatic Advocates group felt research into cures for lifestyle diseases were a lesser priority as people should be motivated to make lifestyle changes and not rely on medicine to fix something that could have been prevented.

The Strong Opposers, whilst against using embryos in research, felt that great gains had been made in adult stem cell research and felt that this line of research should be supported. These people also supported research that alleviated human suffering.

The Strong Advocates and Pragmatic Advocates considered research for scientific knowledge a lesser priority, but supported it because they viewed this as necessary in laying the building blocks for aiding the higher priority research. The Cautious Evaluators tended to not make a clear differentiation between specialised research and research for scientific knowledge.

The Strong Opposers, whilst not supporting research on embryos, supported research for the purpose of increasing scientific knowledge and, like some in the Pragmatic Advocates group, believed that it took time for wisdom and breakthroughs to be made in this area.

Many people in all three groups agreed that research into fertility and infertility was also worthwhile. The IVF process was perceived as very expensive, lengthy, traumatic and often unsuccessful, and many respondents supported the concept of improving this and making IVF more financially accessible.

Research to support fertility and infertility, was seen as providing couples/women with the same opportunities for having children as unaffected couples, both in terms of being able to identify and select embryos that are unaffected by disorders and in helping couples who suffer from infertility.

For a couple of people in the Pragmatic Advocates group, research into infertility was seen as less important. They felt that infertility issues were age related and were a result of people choosing to have children later. They felt that people could choose to have children earlier, rather than relying on IVF. As such, these people felt that the focus should be on couples who genuinely have no chance of conceiving naturally.

"I think it's ok to enable women, to conceive a child, where they aren't able to conceive it naturally – the embryonic research should only ever be for that benefit and not to help that huge percentage of women that have trouble conceiving due to age. Because to me, when I look at all the stories on tv with IVF, and I know there's a slant in there, but it's always about a woman, 45 who suddenly decides to have children and you know fertility is going to be a problem and they go and spend thirty, forty or fifty thousand dollars or whatever the cost of IVF – I sort of think to myself, well sorry that's their choice. So if embryonic research is going to be used to foster IVF research in order to allow women to make lifestyle choices, or their partners, that's a lifestyle choice, don't ask for any public funding under any circumstances."
(Person with experience of genetic disorders)

The Strong Opposers had diverse views about the area of research for fertility and infertility. For some this area was really important and they supported that whilst not supporting research on embryos. For others in this group it was not felt to be a priority. These people took the view that there was a reason that some people did not conceive and that this had to be accepted. Another view was that adopting the parent-less babies in the world was a priority before using science to create more.

One person in the Pragmatic Advocates group felt that research into IVF would be important because it would earn money.

Respondents all mentioned that funding was finite and that policy would somehow need to ensure that funds were used in the most appropriate ways (i.e. directed towards areas of the highest need with the best potential to benefit mankind).

9 SOURCES OF EMBRYOS

GAMETES AND DONATED NON-VIABLE EMBRYOS

Generally most people in each group agreed with using donated gametes and non-viable embryos. These were the sources that most people perceived to be most acceptable to the New Zealand general public. Neither of these sources were seen as having the ability to independently develop into a child and therefore fewer moral issues are attached to their use.

Two people opposed the use of these sources. One of the Pragmatics did so because they did not believe that it could be guaranteed that the embryos would be non-viable and that once this door was opened regulations would slip so that viable would come closer and closer to being non-viable.

The other person who opposed the research was from the Strong Opposers group and was against the use of these sources because of the likelihood of regulations being broken by human nature. It was felt that the chance of someone creating embryos, clones or hybrids out of the gametes was very high and therefore it was better not to allow the opportunity.

All the groups except for the Strong Advocates believed that regulations would be required to ensure that donors and the gametes and non-viable embryos were not exploited. These regulations were:

- The gametes and non-viable embryos must be donated
 - ♦ People did not want there to be an opportunity for people to sell their gametes and embryos and for it to become a money making venture or be set up to exploit the vulnerable.
- Consent given by donor or both donors of an embryo
 - ♦ People wanted to ensure that no gamete or non-viable embryo was used without the donor's permission. Some cited previous cases where body tissue had been used without consent and were insistent that this be avoided in the future.
- Donors are made aware of what research is being done on it
 - ♦ Some respondents felt it was important that donors knew, or had the option of knowing what research their donation would be used for and what the outcome of that research was. Some likened it to donating an organ and wanting to know that it had done some good. For others it was about acknowledging the need for hope.

"I believe this could be solved by potential policy. There's no legislation at the moment. If they would ask, would you like a copy of the report. Would you like to be kept informed of all the research in this area. When you have a condition, that gives a lifeline to people. I don't think it's covered. There's nothing in the policies to make sure it goes right."

(Person with experience of genetic disorders)

- Gametes are not used to create an embryo, clone or hybrid
 - ♦ Many respondents wanted to protect against actions that they considered to be maverick-like or abusive. These were using the donated gametes to create an embryo, clone or hybrid without the knowledge of the donor and against regulations they hoped would prohibit such creations.

- Guidelines are reviewed and up-dated regularly to reflect the fast changing nature of scientific medical research
 - ♦ A few people were concerned that the language and intent set out in regulations would become outdated quickly in an environment that was developing rapidly. These people wanted to ensure that the original intent of the regulations was kept by ensuring that language was kept up-to-date.
 - ♦ The Strong Advocates believed that the wider the regulations could be, the better, because it allowed science to follow whatever path it required in order to come up with positive outcomes.

DONATED SURPLUS EMBRYOS CREATED VIA IVF

Using donated surplus embryos created via IVF was acceptable to all the Strong Advocates, most of the Pragmatic Advocates and some of the Cautious Evaluators. The Strong Opposers were against the use of embryos.

Embryos were seen by the Strong Advocates and most of the Pragmatic Advocates group, as cells, and therefore they did not feel there were any moral issues in using them in research. Many felt that it was a waste of cells to destroy them and felt that using them for research was a responsible way of bettering mankind and reducing wastage.

"For me it's almost recycling them. It sounds terrible but you've got this product that is serving a purpose and if it is no longer required for that purpose, you are then making the most of what is already there. It's a resource that's already available that you can then do research on. Rather than creating things just to do research on. It's an efficient use of resources because it's already there, it's already available and it's going to be destroyed in ten years anyway. Use it while it's there."

(Person from women's group)

Some people felt that starting with donated surplus embryos was a reasonable way to begin in this area of research, rather than specifically making embryos for research when not much was known about the field in New Zealand.

For some in the Cautious Evaluators group to feel that it was acceptable to use viable surplus donated embryos, would be dependent on the purpose of the research. They felt if the research was worthy (i.e. reduce suffering and for the benefit of mankind) and that there was no other way of gaining that knowledge, then it would be acceptable. These people were uncomfortable with the concept of the embryo being destroyed. They struggled with their compassion for the suffering and their belief that scientific progress was important, against the feeling that the embryo being destroyed was a potential human being. For these people there was no one right answer. One person felt that it would be acceptable if stem cells could be removed without damaging the embryo.

One young person in the Pragmatic Advocates group was against using this source for research because they believed the embryos were not created for this purpose, and if the embryo was not going to be used to have children then it should be destroyed. This person was more comfortable with the idea of embryos being created specifically for research.

Some people in the Pragmatic Advocates group were concerned that by providing an option to donate surplus embryos to research there might be a decrease in resources made available to couples with issues of infertility. This did not stop them from agreeing in principle, but they wanted the other option presented to couples as well, and the system be monitored for any negative effect on the IVF resources.

People in the Pragmatic Advocates group were unsure of the effect using frozen embryos would have on the outcomes of research. They were very firm in their belief that in order to have robust and valid outcomes there needed to be an assurance that factors such as embryos being frozen, did not unknowingly affect the research. They supported the use of the best possible embryos in order to gain the best possible results, and felt that if the frozen embryos affected the research outcomes then they should not be used, or used carefully.

The people in the Strong Opposers group were against the use of donated surplus viable embryos created via IVF. They believed that the embryo had a soul or potential for life and that it therefore should not be used for research. This went against their morals, and knowing that the embryos would be destroyed after ten years, if not used, did not change their standpoint.

Both the Pragmatic Advocates and Cautious Evaluator groups felt that strict guidelines would be required to decrease the possibility of human error and the possibility of abuse in using this source for research.

Regulations that were suggested were:

- Both donors would have to consent
 - ♦ People wanted to ensure that both parties involved knew and were agreeable to the embryo being used for research.
- Donors would have access to information on use and outcomes
 - ♦ People wanted donors to be able to know what research the embryo was going to be used for and what the outcome of that research would be. They felt that this was important feedback to receive and acknowledge the contribution the donor was making to the research. For some this served as a way of making people feel comfortable with the process.
- The embryos would not be allowed to grow past 14 days
 - ♦ Some people in both groups wanted to ensure that the embryos were not allowed past the time science had identified the embryo as being multiplying cells. This was because some people were uncomfortable with the embryo being destroyed and wanted to ensure it was done before features denoting human life began.
- That the embryo/cells from the embryo be disposed of after a prescribed period of time
 - ♦ Some people in the Cautious Evaluators group did not want people to have their stem cell lines going on 'forever'. This felt too limitless for some. They felt more comfortable with the idea that donated tissue would stop being used at a certain point.
- Guidelines be set by suitably qualified and experienced people who have knowledge of overseas processes and regulations
 - ♦ Some people in both the Pragmatic Advocates and Cautious Evaluator groups felt that they did not understand enough about the details of research or the way the embryo would be used to be able to protect both the donors and embryos from being exploited. They felt

that this would need to be done by people who had a thorough knowledge of the area and New Zealand's culture, and who had experience with these processes overseas. People felt that this was the best way of trying to anticipate and prevent difficulties before they actually arose.

- The system be closely monitored, audited and subjected to peer review
 - ♦ Some people in both the Pragmatic Advocates and Cautious Evaluator groups wanted to ensure that research results were accurate and robust and that scientists had very little opportunity of going off in their own direction (protecting against 'mavericks'). For this reason some people wanted checking and random testing that protocols were being followed.
- Governed by a suitably appointed and experienced body or networked committee
 - ♦ Some people also wanted to ensure that there was a committee of people from diverse backgrounds, but who were knowledgeable in this area, overseeing what sort of research was being carried out and again that regulations were being adhered to. People wanted to ensure that the purpose of research was something that would benefit mankind and would alleviate suffering. Some people in the Strong Advocates and Pragmatic Advocates group did not want a large committee, nor a committee made up of people who had little knowledge of the area. The Strong Advocates felt that this would slow down the process and not allow research to move ahead. Some people in the Pragmatic Advocates group felt that a committee that drew only on knowledgeable people would work, as this would ensure that progress was made.

EMBRYOS CREATED SPECIFICALLY FOR RESEARCH VIA IVF

The Strong Advocates felt that it was acceptable to use embryos created specifically for research via IVF. They saw the embryos as cells and felt that this would be an alternative way to ensure there was a supply for research.

The Pragmatic Advocates and Cautious Evaluators groups had more of a mix of views on this source. For some, it was acceptable because they felt that the embryo was created for research and it would never have the chance to develop and therefore did not have the potential for 'life'. It was therefore a tool in advancing medical science.

Others took the opposing view. They were uncomfortable with embryos being created for research, they found it difficult to articulate their discomfort, but did not feel that it was moral to create something and then destroy it.

"That doesn't sit comfortably with me either. It doesn't seem, it seems very, as you say, the purpose of life, creating it and disposing of it. ..."
(Person from women's group)

"It reminds me of the people back in the Second World War, they used to pin them down and do terrible things to them in the name of research."
(Person with experience of infertility)

Many in the Pragmatic Advocates group felt that this was an acceptable source, but that it should not be the first port of call. They felt that there would be enough embryos from IVF donations. These people also wondered about the practicalities of such a process. The general feeling was that women

would not put themselves through the process of egg collection unless they believed strongly in the outcome of the research.

The Strong Opposers group was against the use of embryos in research and against embryos being created to be used in research. This was felt to be morally wrong by some, because once the egg is fertilised it has a soul and this would then be destroyed. It was viewed as 'playing God' and people objected to it.

Among the people who supported this source, regulations and guidelines were talked about as being important to ensure that donors and gametes/embryos were treated with respect. Most often articulated was the need for donors to be made aware that their gametes would be used to create embryos and that they give consent to this. Regulations already mentioned in the previous sections were also touched on and would also need to be applied.

CLONING (SOMATIC CELL NUCLEAR TRANSFER) AND HYBRID EMBRYOS

Many of the people in all four groups were uncomfortable with cloning and hybrid embryos as a general concept. This was driven by fear of 'tampering' with nature and the unknown, with unpredictable and potentially serious outcomes.

Research involving cloning of animals was perceived by some in the Strong Advocates, Pragmatic Advocates and Strong Opposers groups as not being particularly successful so far. These people felt that there was a need to gather more knowledge and wisdom over time before starting to do this type of research on human embryos/eggs.

A few Strong Advocates were not opposed to research on cloning as a viable source of stem cells. Other Pragmatic Advocates believed that this source should be put on hold and then reconsidered in the future once more is known.

Some Pragmatic Advocates and Cautious Evaluators felt that cloning was an acceptable way of manufacturing stem cells and saw it as creating 'cells' of themselves rather than seeing them as embryos or potential people.

Some other people in the Cautious Evaluators and Pragmatic Advocates were against using cloning as an alternative. These people drew no distinction between the different types of cloning and believed that it would lead to human clones being created. These people feared that this technology would be abused and felt that currently, it was best to put it on hold until there were ways to ensure no abuse took place. Concerns here were that clones would be created to harvest organs or limbs, that people would have their clone walking around in public and that this would fundamentally change society.

Hybrid embryos were also seen by many as unacceptable. Many people, including some of those in the Strong Advocates group felt inherently uncomfortable with differing species being genetically crossed. For some the image of humans with rabbit ears or crocodile tails came to mind when this subject was discussed.

Some in the Pragmatic Advocates group felt the same about hybrid embryos as they did about the cloning. They felt that there was not much known about the outcomes of this type of research and that this area needed time and knowledge before looking at whether it should be used in New Zealand.

Many people across the groups grappled with trying to understand how this type of source would be useful to the research and what unanticipated risks might arise from the use of them. Some felt that there would be sufficient embryos for research without using this technology.

Many of the people across most of the groups felt that the New Zealand general public would not be well informed on cloning and hybrid embryos and would be likely to reject them as a source of embryos. They felt that these sources could be put on hold until the public were better educated and then have their use re-examined.

People in the Strong Opposers group were against both cloning and hybrid embryos. They felt that it was an unnatural process and was tampering with nature, which was feared to bring negative consequences.

People who were not against using this technology felt that clear regulations would need to be in place, and that people in the field would need to craft those guidelines, including the regulations already mentioned in the previous sections.

10 GENETIC MODIFICATION OF GAMETES AND EMBRYOS

When people discussed the issue of genetic modification of gametes and embryos they made very little distinction between the tissues used. Their focus was more on the issue of genetic modification. Opinions between use of the embryo and use of the gamete did not differ, so they are addressed together in this section.

Most Strong Advocates supported the genetic modification of embryos and gametes for the purpose of reducing suffering. They felt that by being able to remove a defective cell, a child could be born without a debilitating disease and that this would be valuable. There was one person in this group who objected to anything being inserted into the embryo or gamete and stipulated that for them it was about removing a cell. They were concerned about the effects of a foreign body being introduced to an embryo, particularly from another species.

Some of the Pragmatic Advocates, and a few of the Cautious Evaluators, were supportive of the principle of genetic modification, but only where it had the potential to alleviate serious suffering. Others from these groups were against genetic modification. They felt there was not enough known or understood to be able to predict the outcome of changing the genetic make up of a gamete or embryo and the outcomes could have consequences that could potentially affect someone for life.

All groups were opposed to genetic modification which allowed people to select characteristics in their children, and anything that was motivated by financial gain. Some people struggled with the idea of genetically modifying a gamete if it was going to be combined to create an embryo. They wondered someone would modify a gamete rather than an embryo.

Some people from all three of these groups were opposed to genetic modification because they felt it was fundamentally changing the make up of the potential person with unpredictable consequences. Some questioned how New Zealand could allow gametes and embryos to be genetically modified when it would not allow food to be genetically modified.

The people in the Strong Opposers group were also against genetic modification for the reasons already outlined, and because some believed that every life had the right to live life as it was created, even if this life had a serious disorder. A few people took the view that people with disorders added to the texture and flavour of society, and that these people could still live very worthwhile and fulfilling lives and had the potential to make a positive contribution to society. Some felt that society needed to accept and embrace difference and imperfection rather than seeking perfection. These people saw tampering with genes at the gamete and embryo level as 'playing God' and were opposed to that.

11 IMPORT AND EXPORT OF GAMETES AND EMBRYOS

Similar to the genetic modification section, people felt the same way about gametes and embryos with respect to importing and exporting. Therefore they are discussed together in this section.

The people in the Strong Advocates group believed that importing and exporting gametes and embryos was necessary if New Zealand is serious about contributing to this area of research on a world level. These people felt that New Zealand should operate at a world level, sharing and collaborating with other countries and adhering to international checks and peer reviews, which were perceived to add robustness to New Zealand research. The importance of this for these people was faster progress in scientific research.

Pragmatic Advocates were not opposed to the import and export of gametes and embryos but were concerned that there would be opportunities for abuse. There was particular concern about women in third world countries being coerced or exploited in the process. Regulations (which are outlined further on in this section), a clear knowledge of where the embryos or gametes are imported from, and a non-profit approach, were thought to help prevent this.

Also seen as a potential problem was the unknown quality of gametes and embryos being imported, which could affect the quality and robustness of the research. For people relying on the outcomes of this research, quality and robustness of research outcomes was very important.

The Cautious Evaluators group had mixed responses to importing and exporting gametes and embryos. They were reluctant to allow importing and exporting because of similar concerns to the Pragmatic Advocates about setting up a market for exploitation. These people were also concerned about increasing the ability to cross contaminate.

For some of the Cautious Evaluators, the import and export would be worthwhile if New Zealand could help countries that didn't have the technology to do it themselves, or if New Zealand could contribute and share in the findings of other worthy causes.

The people in the Strongly Opposed group were opposed to import and export of gametes and embryos. Some people felt that New Zealand should not use other countries/people's gametes and embryos if New Zealand was not prepared to use their own. They felt that it implied that New Zealand didn't value people from other countries as much as their own.

For others it was the fundamental opposition to the use of embryos that made them opposed to embryos being exported and imported.

Generally there was concern that there was more potential for viruses to spread world wide. People felt that New Zealand possibly wouldn't have enough embryos and gametes to be able to export them. People also felt that exporting would have to take place between like-minded countries so that New Zealand's policies would be upheld in other countries. People did not like the idea of donors agreeing to donate under one set of guidelines and then having their gametes or embryos used for something different if they were exported.

People proposed the following regulations:

- Donors' consent
 - ◆ People felt it was important that donors were made aware that their gametes and embryos were going to be exported and gave consent for this to happen.

- In-depth knowledge of source of gametes and embryos
 - ♦ People wanted to ensure that gametes and embryos of 'good quality' were used for research. They wanted to ensure that the health of the donor was known and a medical history was taken, so that researchers were very well informed about the condition of the gamete or embryo.
- Import and export to countries that have similar policies to New Zealand
 - ♦ People felt that it was important for donors, gametes and embryos to be protected. They wanted to ensure that any imported embryos or gametes be collected and handled in similar ways to those collected in New Zealand. They also wanted any gametes or embryos exported from New Zealand to be handled in a similar way. They did not want New Zealand working with countries that had policies that did not reflect New Zealand's values.
- Not for profit
 - ♦ Of great concern to many people was the potential for a black market to develop for gametes and embryos, and that people, particularly third world women, could be exploited. Many people felt that donors should not be paid for donating their gametes and embryos, to try and prevent any exploitation.
- Biohazard precautions
 - ♦ People wanted to ensure that there was as little chance as possible of viruses or disease spreading as a result of the import or export of gametes and embryos. They wanted systems in place to manage this.

12 INCORPORATION OF THE NEEDS, VALUES AND BELIEFS OF MAORI

People's reactions to this topic were predominantly that they felt that all New Zealanders' needs, values and beliefs needed to be taken into account and incorporated into policy.

Most people felt that a carefully executed education and consultation plan would be of most use, not just for Maori, but for all those living in New Zealand. Specifically for Maori, some people felt that approaching the different tribes and discussing the issues with them would be the way to find out their views, and from that work on how these could be incorporated into a policy.

Another suggestion was to personalise the issue as this was felt to help make the issue real and relevant to people, rather than a more abstract concept.

Some felt that the policy needed to reflect the right of people to make their own choice.

13 INCORPORATION OF DIFFERENT ETHICAL, SPIRITUAL AND CULTURAL PERSPECTIVES

Many people felt that there was no easy answer to this question. As with incorporation of needs, values and beliefs of Maori, some people felt that wide education on the issues and consultation with a variety of community groups and cultures would help to get a feeling for people's views. This would provide a base on which to begin the work of incorporating all the different ethical, spiritual and cultural perspectives. Another suggestion was to hold a nationwide survey. Some people felt it was important that information be released in a number of languages to help aid understanding.

Two people felt that it was important to have a policy that allowed people the choice to participate.

Some people in the Strong Advocates group believed that the New Zealand general public was not sufficiently informed or interested enough about these issues to make effective decisions on policy. Others felt that as a result of limited education about the issues the general public would make decisions based on fear and concepts that were science fiction.

These people questioned the efficacy of decisions based on fear and misinformation and also questioned how effective information and education would be. They were concerned that the issue may be over-simplified in the process of education. Some of these participants felt the quality, or lack of information sent to them prior to the groups, supported this view. They felt it provided an over-simplified view and failed to sufficiently inform people of the issues, the risks, developments/progress thus far, potential benefits and time-frames so that people could make an informed decision and weigh the risks against the potential benefits.

"I don't think they can, because I think to go through the whole gambit of philosophic issues, financial issues, political issues, no questionnaire is going to be able to do that. But we need everybody to think about all the possibilities about this, 'cos everything's got a cost factor to it – whether it's emotional, physical, or financial." (Person with experience of genetic disorders)

Some felt that a democratic decision making process was not appropriate because of the belief that people lack accurate information and because the process would be slow and hold back development. Instead it was felt that the decision making process should be left to people who were well informed and knowledgeable about subject.

Some of the people in the Pragmatic Advocates group agreed with the Strong Advocates concerns that the New Zealand public would not be well informed and that meant decisions could be made on the basis of faulty information. These people did not feel a committee would work because debating the issues from a wide range of differing perspectives would stall any movement. They felt that using a group of experts who were outcome-driven would provide a balance of momentum and structure.

Most of the people in the Cautious Evaluators group and Strong Opposers group felt that a democratic process was important and the public needed to be well educated on the issues before their opinions were sought.

Some people felt cynical as to whether people's opinions would be listened to and incorporated when policy was being formulated, with some giving the example of the recent 'anti-smacking bill' which, for them, showed that the government was not listening to the public.

14 OTHER FINDINGS

OTHER COUNTRIES' POSITIONS

Many of the participants were interested to see the positions different countries took on these issues. Some expressed surprise at the positions some countries had taken, whilst others were not, and felt that the positions reflected their sense of those countries.

For some participants in the Pragmatic Advocates group, and particularly in the Cautious Evaluators group, this table at some level, gave them reassurance about the way they felt New Zealand should go.

For participants in the Strong Advocates group, seeing what everyone else was doing, and the fact that the majority of countries allow embryonic research at some level, reinforced their view that New Zealand needed to allow the research in order to stay up with the world and its natural progression.

The table below shows how the groups generally aligned with the positions.

Position A	Position B	Position C	Position D
<p>The use of embryos in research is banned.</p> <p>The use of established human ESC in research is banned.</p>	<p>The use of embryos in research is banned.</p> <p>The use of established human ESC in research is not banned.</p>	<p>The use of surplus IVF embryos in research is not banned.</p> <p>The use of established human ESC derived from surplus embryos is not banned.</p>	<p>The use of embryos created for research and surplus IVF embryos is not banned.</p> <p>The use of established human ESC derived from such embryos is not banned.</p>
Where people were positioned			
Strong Opposers		Pragmatic Advocates Cautious Evaluators	Strong Advocates
Positions of countries			
<p>Republic of Ireland</p> <p>Austria</p> <p>Poland</p>	<p>Germany</p> <p>Italy</p>	<p>Canada</p> <p>Australia</p> <p>France</p> <p>Czech republic</p> <p>Denmark</p> <p>Finland</p> <p>Greece</p> <p>Hungary</p> <p>Norway</p> <p>Russia</p> <p>Spain</p> <p>Switzerland</p> <p>Taiwan</p>	<p>United Kingdom</p> <p>Singapore</p> <p>Belgium</p> <p>China</p> <p>India</p> <p>Israel</p> <p>Netherlands</p> <p>South Korea</p> <p>Sweden</p>

ASIAN GROUPS

The opinions of the Indian and Chinese people did not differ hugely from the other groups interviewed in that their opinions ranged across the spectrum. Of note was that older Asians tended to be more supportive of research using embryos whilst the younger Asians in the sample were more cautious or opposed. This was the reverse of what was noted in other groups, where generally the older people were cautious or opposed to using embryos whilst the younger people tended to be supportive of the concept. The interviewers wondered if this was due to the older people's experience of growing up in their countries of origin whilst the younger people interviewed had grown up in New Zealand.

It was hypothesised that China and India, as developing countries, had witnessed a vast amount of progress over the last 10 to 15 years, and that science and technology were viewed as drivers for this. With science and progress being seen as having status in those countries it is possible that immigrants may bring this view with them. Conversely, young people who have grown up in New Zealand and not been personally influenced by development may be more reflective about the issues.

THE ROLE OF INFORMATION

Many people remarked that before participating in the groups they had felt they had a clear idea of where they stood on the issues, and after being part of the group discussion their views had changed somewhat. For most this wasn't a radical change from being opposed to being in support of the use of embryos; it seemed more to be a developing or fleshing out of their views. For some the grouped acted as a way for them to arrive at being able to think about and articulate what they felt at a more emotive level.

Also noted by some people in the group was the growing complexity of the issue. These people said they had come into the group feeling sure about where they stood on the general issues, but found that as the questioning became more specific, the more they found the topic complex, the more they felt they didn't know and the more information they felt they required. This seemed to have the effect of increasing some people's confusion and doubt their confidence in their views. It also resulted in their becoming more guarded in their responses.

The information that most people felt was required, appeared to be from the 'science perspective' of the debate. People wanted to know:

- Pros and cons of using gametes and embryos
- Why this research was being considered and what was expected to be gained
- What had succeeded so far
- What had failed
- What the potential benefits are
- What are the likely time frames
- Who would benefit
- What are the risks, known and unknown

Without specific information some people relied upon popular media and science fiction to inform their views on the issues.

15 CONCLUDING COMMENTS

Unlike most studies Phoenix Research engages in, we have not provided conclusions and recommendations for this study. The objective of this research is to provide public perspectives that can be used by ACART along with other available information from other research, submissions and expert opinion.

It should also be noted that this was a qualitative study and as such involved relatively small numbers of people. The qualitative approach was appropriate to enable us to adequately investigate the issue and understand people's views, however there is a need for some caution in generalising the findings. It is therefore appropriate that they will be used as one source of information in the ACART process.

This group of more informed members of the public does appear to have had clearer and more differentiated views than the general public included in the TNS research. However, there is still a diversity of views that reinforce the difficulty of developing policy in this area. While the understanding of public views has been aided by identifying the four different groups in this study, the characteristics of these groupings reinforces the fact that it will not be possible to develop policy that will satisfy all groups.

APPENDIX A - INFORMATION BOOKLET AND INTERNATIONAL POSITIONS

UNDERSTANDING VOCABULARY AND DEFINITIONS

**Please read before coming
to the group discussion**

Purpose of Group
Discussion

Public Consultation to
Assist Formulation of
Policy for New Zealand

TOPIC

Use of gametes and embryos in human reproductive research

Current legal position

- Does **not prohibit** research using viable embryos

BUT

- Requires that policy be developed with public consultation before any such research proceeds
- Currently permits research which uses
 - ♦ Non-viable embryos created during fertility treatment
 - ♦ Imported human embryonic stem cell lines

Questions

Should human...

- Sperm } (gametes)
- Eggs } (gametes)
- Embryonic stem cell lines
- Embryos which are
 - In-vitro
 - Viable
 - Less than 14 days development
 - Either created or donated for research with the informed consent of the sperm/egg/embryo donor

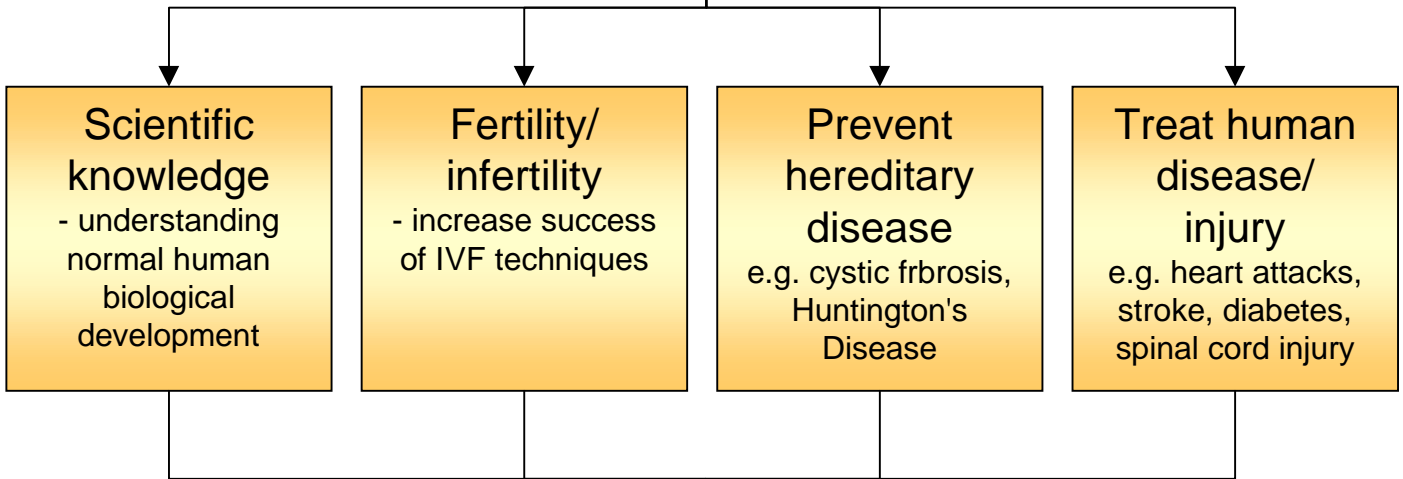
... be used for research purposes?

If so:

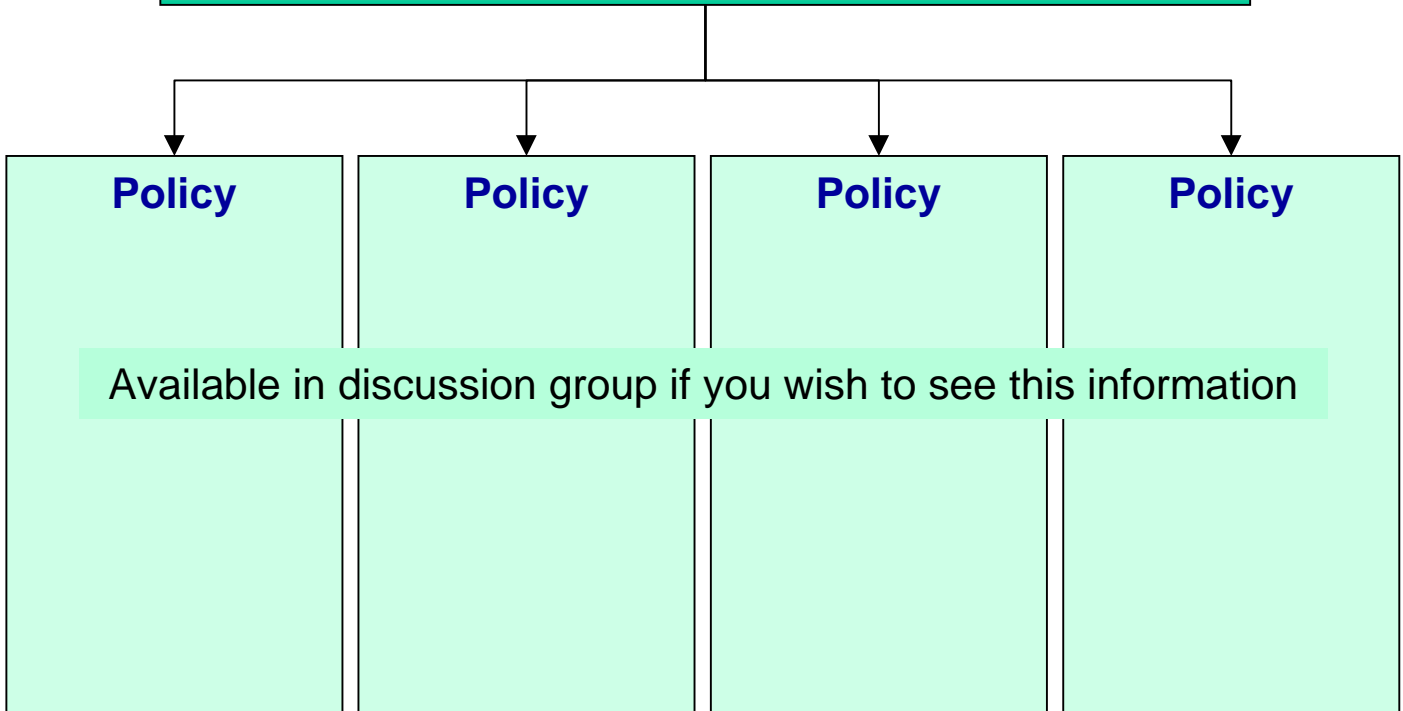
- What are the ethical, spiritual, cultural considerations of using sperm, eggs or embryos for research?
- Is it acceptable to use embryos from some sources but not others?
- Should the import/export (into/out of New Zealand) of sperm, eggs or embryos for research be allowed?
- Should what is happening overseas influence our thinking?

**FUTURE
NEW ZEALAND POLICY**

RESEARCH PURPOSES



Most countries in the developed world have a policy on research using embryos
Positions fall into four main groups



What are gametes and embryos?

Gamete is the name given to an egg or sperm before they are combined (fertilisation) and their cells begin to multiply.

Embryo is the name given to the fertilised egg in its first eight weeks (while its cells are multiplying), after which time the nervous system and organs begin to form and it becomes a foetus. In the first 14 days after fertilisation, the embryo is often called a **pre-embryo**.

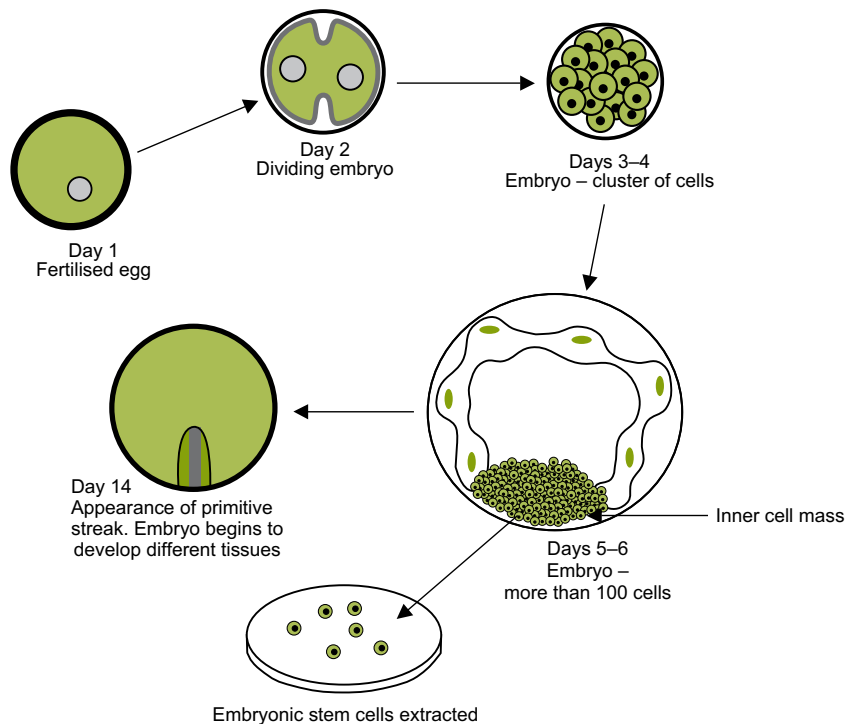
Stem cells

Stem cells are some of the very first early cells of the pre-embryo. They can divide over and over again and develop into many kinds of tissue. They are the 'master' cells that can develop into any of the many different types of cells in the human body.

Five days after fertilisation, the pre-embryo is made up of more than 100 cells. Some go on to become the embryo, known as the inner cell mass, but most become support tissue (such as the placenta). It is the cells from the inner cell mass that are the source of embryonic stem cells.

The most useful cells for scientists doing stem cell research come from the very early stage embryo – in the first 14 days. Embryonic stem cells are not embryos and cannot become human beings, but they hold the potential to form the many different types of cells in the human body. Researchers believe these cells help us to understand human development and diseases, and may one day lead to improved treatment and cures.

Embryo development and extraction of embryonic stem cells



Even in societies that allow research on human embryos, embryos older than 14 days are not allowed to be used. In New Zealand, the HART Act prohibits the use of embryos for research or transfer into a woman (following IVF) after the 14th day of development.

In vitro fertilisation (IVF) – laboratory fertilisation

- In vitro fertilisation is when an egg is fertilised with sperm outside the body in a laboratory.
- Only about 60 percent of eggs fertilised *in vitro* develop into usable embryos, and of these only 50–70 percent become usable for implantation into a woman’s uterus, where further loss is likely to occur. This is much the same rate of development, implantation and loss as with non-assisted reproduction.
- Some embryos produced for IVF treatment are **not viable** – meaning they do not have the potential to form a living individual. In New Zealand such embryos have already been approved for use in research.
- Sometimes embryos grown for IVF are left over after successful treatment. Currently in New Zealand these embryos may be stored or donated to others for reproductive purposes. In the future, these embryos could be donated for use in research. However, in New Zealand there is no policy in place for using such embryos in research and so at the moment, such research cannot happen until the government makes a decision.

Cloning

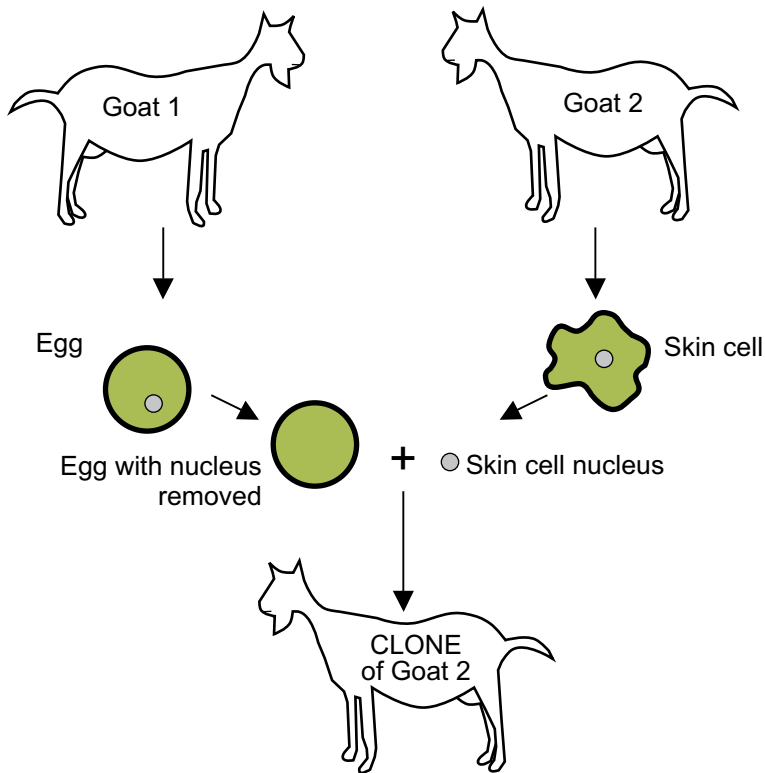
Embryo splitting

Embryo splitting is considered the most conservative of the human cloning techniques. Identical twins are an example of embryo splitting. One egg fertilised by one sperm splits, and forms two separate embryos after fertilisation, each with exactly the same genetic make-up. Embryo splitting could be used in the future to obtain embryos for use in research.

Reproductive cloning

You've probably heard of Dolly the sheep. Cattle, mice, pigs, cats, dogs, rabbits and goats have been also been cloned from body cells of the adult animal.

Goat example: With its nucleus removed, an egg taken from Goat 1 is put with the nucleus taken from Goat 2's cell (eg, skin cell). Goat 1's egg, with its new nucleus from Goat 2, can now develop into a goat that is a clone of Goat 2.



Therapeutic cloning

The same method of nucleus removal and combination is used to make a pre-embryo. The aim is to produce **stem cells** for research, not to produce a cloned human being.

Hybrid embryos

Hybrid embryos have genetic material from two different species. A human nucleus could be transferred into a rabbit egg to produce a human-rabbit hybrid that could be used as a source of human-like stem cells or as a model of human disease (for studying). The human nucleus could come from, say, a skin cell, and there would be no need for human egg donation as the egg could come from an animal. In New Zealand it is prohibited to implant a cloned or hybrid embryo into a human.

Other sources of stem cells for research

As well as from embryos (which are then destroyed), stem cells can be sourced from:

- cells removed from embryos during a cell biopsy that tests for disease
- frozen embryos that fail to thrive after thawing (may be already damaged)
- adult stem cells.

While there is some debate, most scientists agree that so far, pre-embryos are the best place to find stem cells to use for further research into human development and curing diseases. However, adult stem cells could also be of use in this research. There is considerable research effort in this area, and new ideas for sources of stem cells are being developed on a regular basis.

Please complete at home and bring to group discussion

1. Write down the first images, feelings and thoughts that you had after receiving the phone call about participating in this research. It can be anything at all.

2. Write down what you imagine the percentage of people in New Zealand is who would say "yes" to research on gametes and embryos, the percentage of people who would say "maybe" and the percentage of people who would say "no".

%
 Yes
 Maybe
 No

3. What do you imagine these people might be taking into account when they are making their decision. The "yes people", the "maybe people" and the "no people".

	Issues people taking into account
Yes people	
Maybe people	
No people	

4. What thoughts, feelings and images popped into your mind while you were reading the information booklet?

5. How do you think your feelings, images and thoughts changed (if at all) after reading the Information Booklet?

6. Write down three questions that you have after reading the information booklet.

International positions on embryo research

Position A	Position B	Position C	Position D
The use of embryos in research is banned.	The use of embryos in research is banned.	The use of surplus IVF embryos in research is not banned.	The use of embryos created for research and surplus IVF embryos is not banned.
The use of established human ESC in research is banned.	The use of established human ESC in research is not banned.	The use of established human ESC derived from surplus embryos is not banned.	The use of established human ESC derived from such embryos is not banned.

International positions on embryo research

Position A	Position B	Position C	Position D
<p>Republic of Ireland Austria Poland</p>	<p>Germany Italy</p>	<p>Canada Australia France Czech republic Denmark Finland Greece Hungary Norway Russia Spain Switzerland Taiwan</p>	<p>United Kingdom Singapore Belgium China India Israel Netherlands South Korea Sweden</p>

APPENDIX B - GROUP GUIDE

GROUP DISCUSSION GUIDE FOR FORMULATION OF POLICY ON RESEARCH USING GAMETES AND EMBRYOS

OBJECTIVES: To elicit participants views on the formulation of policy

1. Research using gametes
2. Research using embryos
3. Purpose for conducting embryo research
4. Sources of gametes and embryos
5. Genetic modification of gametes
6. Genetic modification of embryos
7. Import and export of gametes
8. Import and export of embryos
9. Incorporation of needs, values and beliefs of Maori into New Zealand policy position
10. Incorporation of different ethical, spiritual and cultural perspectives
11. Further comments not covered in issues above

PRIOR TO ATTENDING GROUP

Participants will...

- Read attached vocabulary and definitions booklet
- Complete self-completion form (below) - bring to group discussion

**Please complete at home
and bring to group discussion**

1. Write down the first images, feelings and thoughts that you had after receiving the phone call about participating in this research. It can be anything at all.

2. Write down what you imagine the percentage of people in New Zealand is who would say "yes" to research on gametes and embryos, the percentage of people who would say "maybe" and the percentage of people who would say "no".

%
Yes _____
Maybe _____
No _____

3. What do you imagine these people might be taking into account when they are making their decision.
The "yes people", the "maybe people" and the "no people".

Issues people taking into account	
Yes people	
MAYBE P E O P L E	
No people	

4. What thoughts, feelings and images popped into your mind while you were reading the information booklet?

5. How do you think your feelings changed (if at all) after reading the Information Booklet?

5. Write down three questions that you have after reading the information sheets booklet, pages 3-8.

WELCOME (AT GROUP DISCUSSION)

- Explain purpose of research
- Explain no right or wrong answers, interested in everybody's views and opinion
- Not here for a consensus, everybody has differing perspectives and we would like to hear them all
- Explain where facilities are located
- Explain recording, for our purposes, to ensure we gather accurately all the details we discuss today
- Confidential, will not be identified in the report, and taping is only for researchers

INTRODUCTIONS

Please introduce yourself to the group and tell us a little about yourself and what you enjoy doing

NEW ZEALAND POLICY

Talking today about the need to make policy in New Zealand on the use of gametes and embryos in research. As you will have read (in The Vocabulary and Definitions booklet), there is a need for policy governing the use of gametes and embryos in research in New Zealand.

Discuss self-completion sheet Question 1:

What were your top-of-mind thoughts about this when you completed the sheet at home?

PURPOSE OF RESEARCH

- What have we seen or heard about that is currently happening with research using embryos in New Zealand or overseas?
- Where did we see or hear that?
- How much attention do we pay to it - how important or not is it to us? New Zealanders in general?
- What do we imagine is the "average"/"typical" attitude of New Zealanders towards this?

SPECIFIC PURPOSES OF RESEARCH

Discuss Sheet Q2 to 5

Let's talk specifically about research being conducted for the purpose of increasing scientific knowledge - understanding normal human biological development

- What does this mean to us?
- What kind of knowledge might this be?
- How was this different or not say ten years ago?
- How is scientific knowledge important or not to us now?
- What about in the future, what do we imagine scientific knowledge will be like in ten years time?
- How do we feel about research for this purpose?

Let's talk about research being conducted for the purpose of fertility/infertility - to increase success of IVF techniques

- What does this mean to us
- How might this be important or not to us now
- How different or not was this ten years ago
- What do we imagine about this kind of research in the future, say ten years from now

Let's talk about research being conducted for the purpose of preventing hereditary diseases, e.g. cystic fibrosis, Huntington's Disease, etc.

- What does this mean to us?
- How might this be important or not to us?
- How different or not was this area of research ten years ago?
- What do we imagine about this kind of research in the future, say ten years from now?

What about research being conducted for the purpose of treating human disease and injury, e.g. heart attacks, stroke, diabetes, spinal injury

- What does this mean to us?

- How might this be important or not to us?
- How different or not was this area of research ten years ago?
- What do we imagine about this kind of research in the future, say ten years from now?

Can we think of any other research that might use human embryos

- What does this mean to us?
- How might this be important or not to us?
- How different or not was this ten years ago?

What do we imagine about this in the future, say ten years from now?

OVERALL

Thinking about research using human embryos overall, what makes us comfortable (or not) with research

- What makes that so?
- Where does "trust" come into it?
- Who or what do we trust (or not)?

What implications does our trust (or lack of it) have for policy development?

RESEARCH IN NEW ZEALAND

Thinking now about New Zealand and whether embryos, sperm and eggs should be used for research in our country, let's get more specific about the sources of these.

On the piece of paper in front of you written down what percentage of people in NZ would say "yes", "maybe", "hold/moratorium" and "no" (for each of 5 sources)

Self-completion sheet re each source:

Rate: Yes, Maybe, On hold/moratorium, No

- Donated non-viable embryo's created via IVF treatment
- Donated viable surplus embryos created via IVF treatment
- Embryos created via IVF specifically for research purposes
- Embryos created via somatic cell nuclear transfer (SCNT) specifically for research purposes
- Hybrid embryos created for research purposes
- Donated gametes

QUESTIONS

Complete Self-completion - but do not discuss yet

- What comes to mind when we think about research that uses?
- Tell me about that?
- What would make it more/ less ok?
- How does where thecomes from impact or not on how we feel?
- What things do we consider when we are thinking about this issue?

- What would make us strongly agree or strongly disagree with this happening

Discuss self-completion:

On the piece of paper in front of you written down what percentage of people in NZ would say "yes", "maybe", "hold/moratorium" and "no" (for each of 5 sources)

- Characterise these people
- What things might these people take into account when making this decision?
- Where would we put it? - in the category of "yes", "maybe", put decision "on hold/moratorium" or "no"?
- What are the conditions that would need to be put in place for there to be yes on this?
- What would you want people formulating this policy to know/think about when thinking about how to regulate this area?
- If it is "no", what would make it a "maybe" for you?

GENETIC MODIFICATION

Now thinking about the genetic modification of gametes and embryos

- What comes to mind when we think about genetic modification of GAMETES?
- Tell me about that?
- What would make it more/ less ok?
- How does where thecomes from impact or not on how we feel?
- What things do we consider when we are thinking about this issue?
- What would make us strongly agree or strongly disagree with this happening
- On the piece of paper in front of you written down what percentage of people in NZ would say "yes", "maybe", "hold/moratorium" and "no"
- Characterise these people
- What things might these people take into account when making this decision
- Where would we put it? - in the category of "yes", "maybe", put decision "on hold/moratorium" or "no"?
- What are the conditions that would need to be put in place for there to be yes on this?
- What would you want people formulating this policy to know/think about when thinking about how to regulate this area
- If it is "no", what would make it a "maybe" for you

Repeat above for embryos

IMPORTING AND EXPORTING

Go through questions for both: *Gametes and Embryos*

- How do we feel about ... being imported into New Zealand?
- What are some of the things you would be wondering about in evaluating this?

- What would you need to make a decision?
- Where would you put this on our "yes", "maybe", "hold/moratorium ", "no" scale?
- What kind of conditions would you like to have around this?
- How do we feel about ... being exported from New Zealand?
- What are some of the things you would be wondering about in evaluating this?
- What would you need to make a decision?
- Where would you put this on our "yes", "maybe", "hold/moratorium ", "no" scale?
- What kinds of conditions would there need to be put on this?

NEW ZEALAND COMPARED WITH OTHER COUNTRIES

- How do you imagine New Zealand being similar or different to other countries in the future re embryo research?
- Which countries might New Zealand be most similar to on this issue?
- Which countries might New Zealand be most different to on this issue?
- What do we want other countries to understand about New Zealand?
- How would this be reflected in the choices on this issue?

Show card with four positions on research on gametes and embryos and explain

- What first ideas/images come to mind when you look at this?
- Where do you feel New Zealand might sit on this

Show card with four positions linked to countries

- Where would you ideally like New Zealand to sit?
- What would need to happen for it to sit here? And here? How would that make us feel about New Zealand?

PARTNERSHIP

One of the principles that ACART must consider is: "The needs, values and beliefs of Maori should be considered and treated with respect."

- How can this principal be incorporated into the policy position
- What are your views on how this principal could inform ACART's advice to the minister and if research does proceed in some form, how it could be reflected in guidelines?
- How might other different ethical, spiritual and cultural perspective in society be considered and treated with respect
- What are your views on how this principal could inform ACART's advice to the minister and if research does proceed in some form how it could be reflected in the guidelines?

OTHER

Any other comments?

Probe any other issues that are discussed

- If you were having to advise on this issue, taking into account everything that we have been talking about today, what would your advise be?
- How could a policy be crafted to take into account peoples differing views
- What would the key elements in it be for you
- What are definite no go areas for you?

CLOSURE

Collect up self-completion sheets

Explain:

- *"Homework"*
 - ♦ Homework will be given out to participants as a way of summarising their thoughts, views and feelings
 - ♦ The homework will be the full ACART paper and submission forms
 - ♦ Will ask participants to read the paper and fill in the forms
 - ♦ They can do as much or as little as they like, and are not obligated to do it
 - ♦ They will be given a courier bag so that they can courier it back at the end of the week
- *Hand out copies of ACART paper and submission form*
- *Courier bag to return completed submission*