C4.2.2000-775
2

494
Part II

2991001

Reproductive and Genetic Technologies

Prepared for:

Health Canada

by

POLLARA

October 26, 1999

350 Sparks Street, Suite 1210
Ottawa, ON K1R 7S8
Ph: (613) 237-4114
Fax: (613) 237-4305

POLLARA™
STRATEGIC PUBLIC OPINION & MARKET RESEARCH

Table of Contents

Introduction 2

Executive Summary 3

Detailed Report on Findings 4

Warm-up 4
In Vitro Fertilization (IVF) 5
Donor Insemination 5
Surrogacy Arrangements 6
Sex Selection 6
Embryo Research 6
Prenatal Diagnosis 7
Conclusion 7
Prohibition and Regulation 7
Commercialization 8
Paying Donors for Eggs or Sperm 8
Paying Surrogate Mothers 9
Commercialization Case 9
Use of Genetic Material 11
Genetic Material Case 11
New Legislation for RGTs 12
Importance of Legislation by Government of Canada 12
Wrap-up 14

Appendix A - Recruitment Guide
Appendix B - Moderator's Guide

Introduction

POLLARA is pleased to present the following report on a series of focus groups conducted on behalf of Health Canada.

A total of eight focus groups were held between Monday, September 20 and Thursday, September 23, 1999, in the following sequence and locations: Montreal, Toronto, Vancouver, and Halifax. Two groups were conducted in each location, with the two in Montreal constituting the French language groups and the rest being conducted in English.

Participants were recruited according to specific criteria to ensure an equal gender mix and a range of age and income distributions. A mix of people with and without children and those who know and do not know people who have had an infertility problem or been unable to conceive a child of their own was also established. In addition, participants were requited to ensure that those attending the first group in each location were somewhat in support of the proposed legislation to ban or regulate the use of certain reproductive and genetic technologies (RGTs). The second group in all locations was attended by those somewhat opposed to the proposed legislation.

In addition to the noted screener used to recruit, special recruiting was undertaken for two groups with those who were somewhat in support of RGT legislation in Toronto and in Montreal. A physically disabled person and a caregiver for a mentally disabled adult were recruited to participate in each of those groups. Furthermore, for both groups in Toronto and Vancouver, the participants were recruited to ensure 4 to 5 ethnic minority representation.

Three complete recruitment questionnaires - for general public, for physically disabled people and for caregivers for mentally disabled adults can be found in the Technical Appendix A.

Participants were fully informed of the audiotaping of their sessions, as well as the presence of client observers. All were assured that their individual identity would remain confidential in the reporting of the results.

Each session lasted approximately two hours and was attended on average by 10 participants. They were given financial reimbursement for their voluntary participation.

Senior POLLARA moderators conducted the discussion groups using a discussion outline designed in close consultation with client representatives. The copy of the moderator's discussion outline is provided in the Technical Appendix B of this report.

The moderator's discussion guide was designed specifically to elicit discussion and opinions on topics relevant to the RGTs.

This report provides a summary analysis and detailed description of overall focus group findings. Given the nature of the qualitative methodology, results to the research should be considered directional rather than statistically representative of the general adult Canadian public.

Executive Summary

The following sets out the summary of the focus group findings:

- Participants from both groups distinguished between reproductive and genetic technologies. They had a more positive outlook on reproductive technologies, especially donor insemination and in vitro fertilization. Surrogacy agreements were seen as positive, but potentially very complicated both legally and emotionally for the parties involved.
- Genetic technologies was viewed more negatively. Most agreed with prenatal diagnosis, with the condition that test results not be used as a basis for abortion. Sex selection induced negative responses. Participants were reluctant to form opinions about embryo research due to lack of knowledge. However, the word "research" was associated positively.
- Most people agreed that paying for eggs or sperm, and making surrogacy arrangements should be allowed, however, all should be regulated.
- Most of the participants supported the need to have government legislation of RGTs and were very surprised that none existed.
- Participants wanted guidelines to prevent abuse of these technologies. Although guidelines and legislation should be developed to prevent the market place from setting the standards in RGTs, they must not be too proscriptive and must allow research to continue.
- Participants agreed that Canada should have its own regulations and should learn from other countries, particularly European countries as opposed to the U.S.
- The regulatory body should include a broad cross-selection of Canadians. Regulations should be the same for all ethnic groups, but in its formulation there should be awareness that such differences exist. And, the regulations should allow room for personal choices.
- Ethical concerns must be included and addressed by the regulatory body on an on-going basis. To this end, many believed the public must be included via public forum or debates, to discuss and set these ethical guidelines.
- The welfare of children affected by RGTs was only addressed or raised as a concern when prompted.
- Allowing and promoting people to personalize issues while in the group discussions (eg. donation of sperm or eggs, and prenatal screening for diseases) encouraged a greater acceptance and understanding of the complexities of RGT. This in turn led to a greater likelihood of participants forming thoughtful and positive opinions about RGTs.

The national survey found that the more knowledgeable people were about RGTs the more supportive they were of the proposed legislation and regulation. However, there was little difference in the degree of support for legislation between participants in the two groups. By the time people were asked their opinion about the proposed legislation and regulation, the less knowledgeable participants of the second groups had significantly caught up with the participants from first groups in their level of knowledge about RGTs. It would appear that, the more people know about RGTs, are led or encouraged to personalize RGT scenarios and their complex nature, the more supportive of legislation and regulation they become.

Detailed Report on Findings

Warm-up

In order to create a common point of discussion, participants were asked to briefly identify the topic and top-of-mind opinions associated with RGTs. Consistent with the quantitative results, awareness of RGTs is high, with virtually all participants indicating that they were aware of at least some of them. When asked what came to participants' mind when they heard the words "reproductive and genetic technologies", participants mentioned a number of terms including: "in vitro fertilization", "multiple births", "test-tube babies" "surrogacy", "cloning", "taking genes and re-engineering them", "predictive testing", "sex selection", "abortion drugs", and "fertility drugs".

Most participants were initially split on their impressions of RGTs, with some viewing RGTs positively, and others viewing them negatively and the balance undecided, seeing both the good and the bad associated with them.

- The positive aspects included: infertile people's ability to have children, improved lifestyle, disease prevention, helping reproductive system, and improving human functions. Participants said it "could benefit those who want kids", "gene therapy is good", "finding cures", and "opportunity to discover new cures for diseases".

- However, some people viewed RGTs negatively. Even those who had positive opinions about RGTs had some concerns and saw problems that might arise in the future. The comments were "cloning is scary, like playing God - moving too far and too fast"; "can expect anything"; "worry about leftover embryos"; "rings an alarm bell, world is moving too quickly"; "too much knowledge is negative"; "who pays for it, if its personal choice? It shouldn't be government funding"; "meddling with nature"; and "trying to produce the perfect race". Some people mentioned that reproductive technologies should not be used, because of the world's increasing overpopulation and that adoption should be considered first.

Participants form the Halifax second group held the most positive opinions about RGTs. Their comments about RGTs were "aiding reproduction", "way to have children in the future", "improvement in lifestyle", "prevent diseases", the "more research the better", and "advanced science". However, one of their concerns was that RGTs control human genetics.

Participants from both the Toronto groups expressed more negative opinions about RGTs. Many participants associated RGTs with potential problems and danger of abuse. They mentioned "test-tube babies", "super humans", "one race", and "perfect children similar to Brave New World". A disabled person from Toronto added that RGTs were helping to "do away with people with disabilities", and "getting rid of people we don't like". The second group said more positive things about RGTs than their counterparts in the first group. The examples were "technology that helps reproductive system", and "improving human functions".

In Vitro Fertilization (IVF)

In general, IVF was seen as positive. Many thought that it helped couples who could not have children otherwise, and "allows everyone to experience being a parent".

On the negative side, some participants were concerned that only wealthy people would be able to afford IVF. Other concerns were that "it has a slim chance of success and causes multiple births". Some people were against it, saying it was an "unnatural" way to have children, and the world was overpopulated with "seven billion people already". A couple of the men from the Halifax second group did not know what IVF was.

The first group participants from Vancouver were all, except for one, against IVF. Typical negative comments included "playing God", "rich person's toy", "there are other options, like adoption, especially of orphans and becoming foster parents", "lots of problems associated with this, like multiple births", "it's ineffective, only about 10% chance", and "it's a last resort".

Donor Insemination

Donor insemination raised many concerns. Participants commented "sperm may not be tested for problems and diseases", "child's right to know", and "legal obligations of the donor". Others were concerned that people would try to choose the "ideal" father to have the perfect child, and that there would be many blond children with blue eyes. "But there are no guarantees." "People have to be more open minded... be prepared for differences, especially if the donor is not known." In addition, some participants said that society would have to re-examine its values. For example, the society would have to decide if a single woman could use donor insemination.

In spite of all the concerns, participants approved of this technique. They said it "could be good, if handled right", meaning a screening process for health risks, and legal controls in place. Other positive comments included "it's like choosing the father" and "it's a personal issue". A disabled person from Toronto was also positive about donor insemination.

Surrogacy Arrangements

Surrogacy arrangements created a lot of ambiguity in opinions. People did not say they were against it, but they stressed the fact that it was a very complex issue. There were too many people and emotions involved in such an arrangement. That might cause both legal and emotional problems.

Most participants viewed surrogacy arrangements positively and even more participants in both groups favoured it when "it's between close friends and family members". It was especially important to the representatives of ethnic groups. It "can be positive, when both parties know what they are doing". "Most people will do it for the money, but people pay to adopt also, and it is difficult to find children to adopt."

People realised the complexity of this issue especially the legal implications of RGT. Their concerns included "what if the surrogate mother changes her mind?", "how can you ensure the surrogate won't drink or smoke, etc.?", "need a contract". They acknowledged that "it is the most complex and the riskiest way to go" and that "you have to trust the surrogate mother".

There were also negative comments "it's uncomfortable and scary", "like leasing people", "the rich taking advantage", and "some doing it just for the money". Some people said that you should not go to such extent to try having a child. They reasoned that the "mother role is not the only thing that women can do", "adoption is a possibility", and considering many children that could use parents, this method seems "a long way to go".

Sex Selection

Almost all of the participants were against sex selection. They felt that it can be easily abused and cause unpredictable dangers. They also felt that it would be a harming factor while raising a child. Participants commented "this is true genetic manipulation", "it can lead to early abortions", "it starts with selecting eye colour, and then who knows where it can lead", "kids get "screwy"", since "it is privilege to have children" you should be "happy with what you get", and "leave it to nature".

Men from Halifax were more open to this idea. They were willing to tolerate exceptions in cases of genetic diseases that were related to gender, and in cases of unbalanced population that might cause dying out of a certain group of people. One person from Vancouver mentioned that there were cultural issues involved with sex selection.

Embryo Research

Although participants were not very knowledgeable about embryo research, the word "research" did create positive reactions. However, some felt they did not have enough information to have firm opinions be they negative or positive. High importance was given to the source of embryos in determining if research was positive or not. Participants viewed studying dead embryos or embryos' development without harming the embryo

more positively. They also wanted to make sure that research was being done for good purposes, such as the treatment of Parkinson's or other diseases. A few also expressed greater support when informed of the actual size of the embryos used in research.

Prenatal Diagnosis

Many people saw prenatal diagnosis as positive giving comments such as: "Just checking to see that the baby is okay"; "can save lives and help parents decide whether to keep a baby or not, to avoid serious handicaps," and "helps avoid family disasters." The physically handicapped participant from Montreal felt that parents should have a choice.

Many would want assurances that prenatal diagnosis would not be followed by abortion. A handicapped person from Toronto thought that prenatal testing leading to abortion was unacceptable, because society passes judgement on who should or should not live, which would be "one step away from killing human beings". A woman from Toronto who was taking care of her mentally disabled child shared his opinion. She said, "if they know you are going to be born disabled they might as well abort you".

Conclusion

To conclude the warm-up, participants were introduced to the definitions of RGTs and told which ones were practiced in Canada. The participants were then asked again to give their general opinion of RGTs. As in the national survey, people were more positive about reproductive technologies than genetic technologies.

They saw good and bad in each technology. Some people said that the technology in itself was not good or bad, "it's how you use it", and "it's a new science that we don't know". "You can't stop progress."

RGTs' advantages expressed were that they would help avoid illnesses and would make it possible for more people to have children. Typical comments included "its more positive and helpful"; "more accepted now"; "not so scary"; "should be available, be a choice for couples"; "it's very conservative"; "it's personal, it depends on the couple" and "it makes people's lives fuller".

Many risks were associated with RGTs, especially with genetic technologies. People feared abuse of technologies, immoral and unethical practises. Concerns were expressed by some that wealthier people would have greater access to RGTs than poorer Canadians. Genetic technologies were perceived by some participants to possibly cause side-effects that would only be discovered later, such as Dolly ageing faster than a normal sheep; "if there is research, there are monsters being created somewhere".

Most believed that RGTs are important and people should be given the choice of accessing these.

Prohibition and Regulation

Participants read and discussed two cases that dealt with prohibition and regulation of RGTs in order to identify and discuss relevant ethical considerations.

Commercialization

Paying Donors for Eggs or Sperm

Overall, participants were not strongly against paying female or male donors for their eggs or sperm. In some groups people started discussing how the eggs and sperm should be priced, if there should be a price ceiling, if price should be determined by the laws of supply and demand, and if eggs should cost more than sperm. They also mentioned the need to screen donors for illnesses. They voiced concern that in both cases the child is not going to be genetically the couple's own and that this could be problematic should the child wish to know his or her genetic make up.

Most people agreed with payment of egg donors. "If men get paid for their sperm now, why not pay women also?" Participants gave multiple reasons for paying for the eggs, such as "this is reasonable"; "it's invasive" therefore a woman should be compensated, "there's some discomfort", and some "health factors involved as a woman only has so many eggs".

Examples of reasons given for supporting paying for sperm donation included "still some blood tests and time involved for sperm donation"; "some inconvenience, with medical tests and questionnaires to fill out"; "no one forces anyone to do this, it's a free country so shouldn't oppose it". However, some individuals cautioned that they would only agree to support payment if it was "just a token amount" to prevent people making a business of it. Some thought that, as with egg donation there should be an upper limit to the amount paid.

However, not everybody liked the idea of paying donors for sperm. "If this is allowed, then no one will do it for free, which could then limit the supply." "I have problems with this because it's like selling your character." "Famous athletes can sell their sperm for more money." They were also "concerned about when the child wants to know". Some participants thought that paying for eggs should be allowed, but not for sperm. They thought that sperm donation to be different from egg donation in that "there are lots of sperm".

Some participants disagreed with this procedure or the payment. They commented that there should not be payment and that egg and sperm donation should be handled like either organ or blood donations. The point of view of free donations was a compelling one for some given the current free blood donor system and designated organ donation noted on people's drivers' licence. Some feared that paying for eggs or sperm would put a value on a human life, and could imply that "better" eggs or sperm from a "better" donor could be bought, but at a higher price. People were against that possibility.

For everyone, irrespective of payment versus donation, men and women should be treated the same.

Paying Surrogate Mothers

Most people from the second groups thought it was acceptable to pay surrogate mothers. "Everyone's happy as it's all consenting adults" and "fine if all agree". However, everyone mentioned there could be many legal problems. Most participants voiced opinion that if payment was allowed laws must be in place to protect all parties.

Potential problems mentioned were "what if the couple does not want the child?", and "should the surrogate mother be able to interact with the child?". Other concerns were: "too many complications"; "the price agreed upon may not be the final price paid"; "the surrogate may want to keep the baby"; "what if the surrogate wants more money when there are complications"; "what if the baby is mentally handicapped and no one wants it" and "everything must be put in the contract". Most thought there should be legally binding agreements, and careful screening of the surrogate to ensure she had a healthy nutritional lifestyle and was physically and psychologically healthy. As well many mentioned that counselling should be required to minimise risk of contractual complications.

Some first group participants were against payment of surrogates. They said that they would have never been able to be surrogate mothers for anyone except their very close relatives from whom they would not take the money. Others said that it was better to adopt a child than use such an arrangement. Some participants were against such agreements regardless of the money, "it's difficult to finance a child", "the child did not decide to be created to be sold... he/she could sue...the laws must be ready".

Commercialization Case

Participants read the commercialization case and were asked if a surrogate mothers would think through all the physical and emotional implications of what they were doing. Participants felt that surrogate mothers were most likely to think these through if they already have had children.

Although, surrogate mothers could think what pregnancy involves, most participants said that potential surrogate mothers could not understand what they were getting into in terms of being a surrogate mother. However, many participants commented that hopefully the surrogacy agency would provide counselling to her to help her think of all the issues. Many of the women participating in the focus groups mentioned that they themselves would not have been able to become surrogate mothers. They felt that they would bond during the pregnancy and would find it impossible as a result to give up a newborn baby.

Participants were also asked to discuss the role of money in surrogate arrangements. Most participants agreed that money for non-related or non-friends was the only motivator to become a surrogate mothers. Some surrogate mothers, they felt, took advantage of the situation to get more money out of the parents, and they perceived that others often decided to keep the child because they could not part with it once it was born. Most people agreed that surrogate mothers could not be expected to carry someone else's child unless it was for money.

As mentioned earlier, some participants thought that surrogacy arrangements would be most acceptable and work best within a family "The couple should know the surrogate mother" said one participant. Others added that it could also create problems if both mothers would be part of the child's life.

In the conclusion of the case discussion, the participants were asked if the child would mind knowing that his/her mother was paid to give birth to him/her. Some people indicated that they would not tell the child that it was the result of a surrogacy arrangement, stating that "it isn't an issue as the child doesn't need to find out as he/she would never ask about this". Some said the child does not have a right to know he had a surrogate mother and that it can know if its parents choose to tell it.

Most of the people, except the participants of the two Montreal groups, thought that the child would not mind "if it is presented in a right manner at the right time". Many thought the child would appreciate that its parents had made such efforts to bring him/her into the world. As well the child would also become aware that it was genetically related to its parents, and that the surrogate mother was just a "vehicle for growth". These positive minded participants believed an honest and understanding presentation of surrogacy would make it possible for a child to feel good about both the surrogate mother and its parents.

Many stated that you "need to be honest with the child", "tell them when they ask", and that you "need to pre-empt it and tell the child when they are still young". They thought that the child's reaction "depends on how the family handles it" and how it was brought up, "if they were raised in a loving and supportive family, then they'll take it much easier". Some individuals indicated that the child should take it "as a complement as their parents wanted them so much that they were willing to do this". The child should understand that "it's not always like a storybook and it's not their parents' fault that they couldn't conceive".

The majority in the Montreal groups and some participants from other locations felt that a child would mind knowing that its mother was paid to give birth to him or her. They thought that payment of money would cause self-esteem problems for the child. Others mentioned that the child might develop bad feelings towards its surrogate mother.

Use of Genetic Material

Genetic Material Case

The participants read the case about the posthumous use of sperm and were asked to give their opinions about the legality of using sperm and eggs from dead people.

Many participants felt strongly that written consent should not be required and that a spouse, or a member of the immediate family, should be able to request that sperm or eggs be taken from their relation.

They contended that if it would be between "husbands and wives, then it's okay" due to the contract of the marriage. These participants felt that "it has to remain a personal decision". "If a spouse is dead, it doesn't take anything away from them... it's not an issue." "Why protect a dead person?"

Some felt that it was like signing a consent form for organ donation. A few participants, however, saw a strong difference between saving a life through organ donation and creating a new life through sperm donation of someone dead. There were concerns about how the spouse would use the sperm or egg – would it be sold to someone else? What if there was a medical problem as a result of the illness that killed the donor?

A typical comment of those in support of the written consent were that it was "disrespectful of the dead", and "it is like organ donations". Some people thought that written consent was necessary to prevent abuse in cases when the deceased would have not wanted children or when having a child would influence inheritance distribution.

Participants from the first Toronto group were the biggest supporters of written consent. They believed that written consent would protect doctors and prevent what they considered to be a form of rape.

In the end, many people agreed that it should be dealt with on a case by case basis with exceptions to the rule, because it was such a personal decision.

The opinions about making a law to protect the dead from someone who wants to take their sperm were divided. Many people felt that written consent or something like a donor card should be enough and the government should not be involved. "Consent is crucial but the state must not be involved". "It's a personal matter and it would be like invading their privacy." Many felt that the donor card should stipulate if anyone could use genetic material or if solely the spouse could use it.

Some of those who felt that consent was important tended to feel that it should be enshrined in the law. Most agreed that if there was a law, doctors should be penalized through fines or temporary revocation of license if they do not abide by it. However, jailing such doctors was not seen as necessary or acceptable.

Opinions were divided on the implications of using sperm and eggs from dead people. Many participants felt it was acceptable with prior consent. Many said it was like organ donation, but after some discussion, people started to consider the "strings attached" – who would use it and for what purpose. Some men said, "I would feel honoured", and "I would feel appreciated" in the case where his wife would use it to have their children.

Others would not want someone using their reproductive material without their written consent. "I could be walking down the street and run into a child who looks just like my dead husband." One woman commented that she doesn't know how this would work, and questioned the willingness of her husband's new wife to carry his dead wife's child.

Some participants were against it in principle and saying it was unnatural: "when you're dead, you're dead.... It gets dangerous if you open too many doors", and "people would try to prolong life artificially to get around the law."

To finish the discussion of this case, participants were asked their views regarding what the child would think in the case where its parent was dead before its birth. Participants did not bring up concern about the welfare of the child on their own. Some thought that a child would have some problems, that it would be raised by a single parent and would question its existence. However, others mentioned that similar situations occur everyday. "Problems can be avoided if the situation is explained in the right environment and upbringing."

New Legislation for RGTs

The purpose of the following discussion was to identify what drives opinions on the Government of Canada's proposed legislation for a comprehensive and balanced regulatory framework. Consistent with the quantitative survey results, a majority of participants from the first groups, who were recruited based on being somewhat supportive of the idea of legislation, supported the prospect of federal government legislation of RGTs. Many participants from the second groups, who were recruited to be participants somewhat opposed to legislation, also grew to agree that legislation would be very important.

Importance of Legislation by Government of Canada

Most of the participants from the first groups thought that the federal government should regulate RGTs and expressed surprise that there was no legislation. This view was expressed by all the participants in both of the Montreal groups. Some Halifax participants thought that the federal government should just set guidelines to then be implemented by the provinces. A few of the participants were more ambivilent and less likely to give clear cut opinions.

Many participants felt that it was important that the Government of Canada puts in place legislation to regulate and oversee RGTs, to prevent abuse. "Especially with all the changes coming up in this area." Other comments were "if nothing is in place, it is like opening a can of worms", and "there should be controls, or else it would get out of hand".

A handicapped person from Toronto was a strong supporter of regulation saying it was "very important, people such as myself could be killed before we're born".

Furthermore, some believed one consistent federal legislation would be necessary to avoid people having to travel to a different province or country (eg. the U.S.) to have access to RGTs.

However, even among the supporters of the idea of legislation, the feeling was that it should not be prescriptive but should "prevent abuse". Concerns voiced included "it should not hinder research", and "it should allow for exceptions". They believed that while the public should be protected "the door should be kept open for scientific research to continue". However, many expressed the view that scientists should not be charged with the setting of regulations.

The few who dissented to the idea of legislation, thought that it would be too difficult to develop and implement as it would have to be too broad, especially given the personal nature of the issue. To this end they felt that the government would "need lots of public input". Examples of comments included, "having a child is the most personal decision you can make"; "personal choice should be allowed"; "have to look at it case by case for moral standards", and "if you ask 1,000 people, you'll get 1,000 opinions".

Most of the participants from the first groups thought that Canada should set its own unique guidelines and consider the experience of other countries. They reasoned however, that Canadian guidelines should not be the same as those set in other countries because, "we have a different culture and it should be based on our culture"; "what's acceptable there may not be okay for Canada"; "they may have higher or lower standards than us", and "the legislation should be responsive so as to work out the bugs". Some thought that the European experience would be a better model than that of the U.S.

Based on the opinion of most of the participants, they would want government legislation to cover safety, health, ethical, and moral issues. Some participants felt, however, that ethics and morals change so fast and are so different for various people that it would be difficult to address and would need to be updated frequently - "It will no longer apply in five years".

Many thought that an advisory body should include representatives from almost all fields. Representation from the general public was perceived to be the most important. Also, participants mentioned doctors and scientists, as well as lawyers, bureaucrats and ethicists to oversee the processes. Some participants mentioned that couples who used fertility treatments should also be involved as an information source.

Ethical concerns identified included "how far along to allow the fetus to evolve"; "sex selection"; "genetic manipulation, such as blue eyes, 6 feet tall, etc."; "where do you draw the line?"; "exposure to counselling, finding out what you're getting into"; "whose rights are stronger, the surrogate mother or the genetic parents?"; "what happens to leftover embryos?" and "right to privacy and the rights of the child to know his/her genetic heritage".

Participants from Halifax and Vancouver, were asked if the composition of an advisory body on ethics should include people from a variety of ethnic backgrounds . These participants were aware that different cultures might view RGTs differently. For example, participants raised the issue that "boys are favoured in certain cultures". However, participants still believed that there should be only one law for all Canadians "the majority should rule".

Some people said that cultural issues should also be addressed in the legislation. You "should look at the big picture and include all issues". Others were concerned that "ethics are so different for different people" that it might be difficult to incorporate this into the legislation.

Participants from the second groups shared most of the views of the participants from the earlier groups. However a few mentioned that "MP's are not smarter than we are", and that some people would "find a way to get around the law". Some people considered the laws to be important to regulate health, safety, quality, screening processes, and equal access to the technologies. Some mentioned that ethics and morality were constantly changing and that therefore, they would be difficult to regulate.

Wrap-up

Participants were asked to say which of the following messages was the most important when regulating RGTs, and to explain their choice.

1. That the health of Canadians will be safeguarded by regulating certain practices and banning others.
2. That human reproductive materials, such as sperm, eggs and embryos, will be treated with respect
3. That the welfare of all persons, especially women using these technologies and children who are born as a result of them, will be protected.
4. That certain standards – ethical and practical – will be set up and followed to ensure safe practice and a consistent approach to difficult ethical issues.

Objective	**1st Group Votes**					**2nd Group Votes**					**Total**				
	H	M	T	V	***All***	H	M	T	V	***All***	H	M	T	V	***All***
#1	1	4	-	7	***12***	-	-	3	2	***5***	1	4	3	12	***20***
#2	-	-	2	3	***5***	-	3	1	5	***9***	-	3	3	8	***13***
#3	-	1*	-	-	***1****	-	-	2	1	***3***	-	1*	2	1	***4***
#4	8	4	6	-	***18***	10	7	3	1	***21***	18	11	9	1	***39***

* Physically disabled person vote

** A disabled person from Toronto did not vote because he did not think that "health of Canadians" was inclusive of his definition of health.

The most popular overall was # 4: the most important message when it comes to regulating RGTs is that certain standards - ethical and practical – should be set and followed to ensure safe practice and a consistent approach to difficult ethical issues. The most homogeneous response was received from groups in Halifax, while people from the second group in Toronto voted evenly for all 4 options.

Following are the reasons for choosing or not choosing a certain objective:

1: Pros: Implies involvement of other parties such as advisory board
Without health you have nothing!
Covers everyone
Cons: Exists in Canada already
Too vague
Too school teacher like

2: Pros: Basis for all others
Highlights respect – thinking through
Does not mention vague word – "ethics"
Cons: Just a minimum, # 4 includes it

3: Pros: Protects women who are more vulnerable to exploitation
Practical and direct
Cons: Excludes parts of society, who are not women or children
Word "welfare" is vague
Not the state should be responsible for children

4: Pros: Most comprehensive

APPENDIX A
Recruitment Guide

FINAL

General Recruitment Screener – Health Canada Focus Groups

Good afternoon/evening. My name is _____, and I am calling from POLLARA, the national public opinion research firm. I would like to invite you to attend a discussion group on _____ to discuss current events. If you qualify and attend this group, you will receive $50.00 for participating. However, I have to ask you a few questions to be sure that you qualify.

Are you familiar with the concept of a focus group?

YES - *CONTINUE*
NO -> A focus group consists of eight to ten participants and one moderator. During a two-hour session, participants are asked to discuss a wide range of issues related to the topic being examined.

Would you be interested in attending this session?

Yes -> I would like to ask you a few brief questions to see if you qualify. Your responses will remain confidential.
No (*THANK AND TERMINATE)*

1. RECORD GENDER

   Male
   Female

   (Ensure an equal number of male and female participants)

2. Have you ever participated in a focus group for which you received a sum of money?

   Yes -> How long ago was that? *(TERMINATE IF WITHIN PAST 6 MONTHS, OTHERWISE GO TO Q3)*
   No -> SKIP TO Q5

3. How many focus groups have you attended in the past 5 years?

   RECORD _____ *(IF "6" OR MORE, THANK AND TERMINATE, OTHERWISE GO TO Q4)*

4. And what were the topics discussed?

_____

(IF CONNECTED TO STANDARD OR PROJECT RELATED OCCUPATION OR TOPIC, TERMINATE)

5. Have you or any member of your household ever worked for any of the following? (READ LIST)

   An advertising agency
   A market research firm
   The media
   A public relations firm
   The Government of Canada
   The medical field, for example a doctor's office or hospital

   (IF YES TO ANY, THANK AND TERMINATE)

6. What is the highest level of education that you have completed? (READ LIST)

Elementary School
High School
Community College
Some University
Complete University

(*Ensure a good mix*)

7. Which of the following categories best represents your household's annual total income?

Under $25,000
$25,000 to $44,000
$45,000 to $59,000
$60,000 to $75,000
$75,000 or more

(*Ensure a good mix*)

8. To which of the following age groups do you belong?

18-24
25-34
35-44
45-54
55+

(*Ensure a good mix*)

9. Have you ever had children?

Yes
No

(*Ensure a good mix*)

10. Do you know anyone, among your immediate family or your close friends, who has had an infertility problem or been unable to conceive a child of their own?

Yes
No

(Ensure a good mix)

Reproductive and genetic technologies include a wide range of activities, both old and new. Reproductive technologies attempt to produce a pregnancy by such processes as in vitro fertilization, donor insemination and surrogacy arrangements. Genetics-based technologies include sex selection, embryo research and prenatal diagnosis. Many of these reproductive and genetic technologies are currently practised in Canada.

11. The federal Department of Health (Health Canada) is currently considering introducing legislation to ban or regulate the use of certain reproductive and genetic technologies in order to ensure the best practices are used. Using a scale from 1 to 10, where 1 means very opposed and 10 means very supportive, how would you rate your level of support or opposition to this legislation?

"1" or "2"/Very opposed (THANK AND TERMINATE)
"3", "4", or "5"/Somewhat opposed *(GROUP 2)*
"6", "7", or "8"/Somewhat supportive *(GROUP 1)*
"9" or "10"/Very supportive (THANK AND TERMINATE)

I would like to invite you to attend the session on:

MONTREAL:	Monday, September 20, 1999 at 6pm	GROUP 1 (recruit 10 for 8 to show)
	Monday, September 20, 1999 at 8pm	GROUP 2 (recruit 12 for 10 to show)
TORONTO:	Tuesday, September 21, 1999 at 6pm	GROUP 1 (recruit 10 for 8 to show)
	Tuesday, September 21, 1999 at 8pm	GROUP 2 (recruit 12 for 10 to show)
VANCOUVER:	Wednesday, September 22, 1999 at 6pm	GROUP 1 (recruit 12 for 10 to show)
	Wednesday, September 22, 1999 at 8pm	GROUP 2 (recruit 12 for 10 to show)
HALIFAX:	Thursday, September 23, 1999 at 6pm	GROUP 1 (recruit 12 for 10 to show)
	Thursday, September 23, 1999 at 8pm	GROUP 2 (recruit 12 for 10 to show)

which will be held at _____. Please arrive 15 minutes prior to this time for registration.

As I said earlier, if you attend, you will receive a participation fee of $50.00. (IF 6PM SESSION: Sandwiches and beverages will also be provided to you.)

Could I please have your:

Name: _____
Address:_____
Telephone # (Residence)_____
Telephone # (Business)_____

PLEASE NOTIFY OUR OFFICE BY CALLING _____ SHOULD YOU HAVE ANY DIFFICULTY ATTENDING THE DISCUSSION GROUP. THANK YOU.

FINAL
Toronto and Montreal Mentally Disabled Caregiver Recruitment Screener – Health Canada Focus Groups

Good afternoon/evening. My name is _____, and I am calling from POLLARA, the national public opinion research firm. I would like to invite you to attend a discussion group on _____ to discuss current events. If you qualify and attend this group, you will receive $50.00 for participating. However, I have to ask you a few questions to be sure that you qualify.

Are you familiar with the concept of a focus group?

YES - *CONTINUE*
NO -> A focus group consists of eight to ten participants and one moderator. During a two-hour session, participants are asked to discuss a wide range of issues related to the topic being examined.

Would you be interested in attending this session?

Yes -> I would like to ask you a few brief questions to see if you qualify. Your responses will remain confidential.
No (*THANK AND TERMINATE)*

1. Are you the primary caregiver for an adult family member who currently suffers from a permanent mental disability, such as Down's Syndrome, Schizophrenia, who requires full-time care but is not living in an institution?

   Yes *(GROUP 1 FOR TORONTO & MONTREAL)*
   No (*THANK AND TERMINATE)*

2. Have you ever participated in a focus group for which you received a sum of money?

   Yes -> How long ago was that? *(TERMINATE IF WITHIN PAST 6 MONTHS, OTHERWISE GO TO Q3)*
   No -> SKIP TO Q5

3. How many focus groups have you attended in the past 5 years?

   RECORD _____ *(IF "6" OR MORE, THANK AND TERMINATE, OTHERWISE GO TO Q4)*

4. And what were the topics discussed?

_____

(IF CONNECTED TO STANDARD OR PROJECT RELATED OCCUPATION OR TOPIC, TERMINATE)

5. Have you or any member of your household ever worked for any of the following? (READ LIST)

   An advertising agency
   A market research firm
   The media
   A public relations firm
   The Government of Canada
   The medical field, for example a doctor's office or hospital
   (IF YES TO ANY, THANK AND TERMINATE)

I would like to invite you to attend the session on:

MONTREAL: Monday, September 20, 1999 at 6pm GROUP 1 (recruit 1 for 1 to show)

TORONTO: Tuesday, September 21, 1999 at 6pm GROUP 1 (recruit 1 for 1 to show)

which will be held at _____. Please arrive 15 minutes prior to this time for registration.

As I said earlier, if you attend, you will receive a participation fee of $50.00. Sandwiches and beverages will also be provided to you.

Could I please have your:

Name: _____
Address:_____
Telephone # (Residence)_____
Telephone # (Business)_____

PLEASE NOTIFY OUR OFFICE BY CALLING _____ SHOULD YOU HAVE ANY DIFFICULTY ATTENDING THE DISCUSSION GROUP. THANK YOU.

FINAL

Toronto and Montreal Physically Disabled Recruitment Screener – Health Canada Focus Groups

Good afternoon/evening. My name is _____, and I am calling from POLLARA, the national public opinion research firm. I would like to invite you to attend a discussion group on _____ to discuss current events. If you qualify and attend this group, you will receive $50.00 for participating. However, I have to ask you a few questions to be sure that you qualify.

Are you familiar with the concept of a focus group?

YES - *CONTINUE*
NO -> A focus group consists of eight to ten participants and one moderator. During a two-hour session, participants are asked to discuss a wide range of issues related to the topic being examined.

Would you be interested in attending this session?

Yes -> I would like to ask you a few brief questions to see if you qualify. Your responses will remain confidential.
No (*THANK AND TERMINATE)*

1. Do you currently suffer from a permanent physical disability which you have had all your life?

   Yes *(CONTINUE)*
   No (*THANK YOU, UNFORTUNATELY TO QUALIFY FOR THE GROUPS WE CAN ONLY ACCEPT SOMEONE WHO HAS HAD A DISABILITY ALL THEIR LIFE)*

2. Have you ever participated in a focus group for which you received a sum of money?

   Yes -> How long ago was that? *(TERMINATE IF WITHIN PAST 6 MONTHS, OTHERWISE GO TO Q3)*
   No -> SKIP TO Q5

3. How many focus groups have you attended in the past 5 years?

   RECORD _____ *(IF "6" OR MORE, THANK AND TERMINATE, OTHERWISE GO TO Q4)*

4. And what were the topics discussed?

_____

(IF CONNECTED TO STANDARD OR PROJECT RELATED OCCUPATION OR TOPIC, TERMINATE)

5. Have you or any member of your household ever worked for any of the following? (READ LIST)

   An advertising agency
   A market research firm
   The media
   A public relations firm
   The Government of Canada
   The medical field, for example a doctor's office or hospital

   (IF YES TO ANY, THANK AND TERMINATE)

I would like to invite you to attend the session on:

MONTREAL: Monday, September 20, 1999 at 6pm GROUP 1 (recruit 1 for 1 to show)

TORONTO: Tuesday, September 21, 1999 at 6pm GROUP 1 (recruit 1 for 1 to show)

which will be held at _____. Please arrive 15 minutes prior to this time for registration.

As I said earlier, if you attend, you will receive a participation fee of $50.00. Sandwiches and beverages will also be provided to you.

Could I please have your:

Name: _____
Address:_____
Telephone # (Residence)_____
Telephone # (Business)_____

PLEASE NOTIFY OUR OFFICE BY CALLING _____ SHOULD YOU HAVE ANY DIFFICULTY ATTENDING THE DISCUSSION GROUP. THANK YOU.

RECRUITMENT SPECIFICATIONS FOR ALL LOCATIONS

GROUP 1 (6:00 p.m.): "6" - "8"/Somewhat supportive of Health Canada legislation (Q12)
MTL/TOR: Confirm 10 respondents for 8 to show (we do NOT want more than 10 to participate)
MTL/TOR: Also confirm 1 caregiver for mentally disabled adult + 1 adult physically disabled since birth
(CONFIRM THAT FACILITY IS ACCESSIBLE TO PHYSICALLY DISABLED)
VAN/HAL: Confirm 12 respondents for 10 to show (we do NOT want more than 10 to participate)
Ensure good mix of those with/without children; and those who know/don't know someone infertile
Ensure good mix of genders, age, household income and education (in this order of importance)
Incentive of $50

GROUP 2 (8:00 p.m.): "3" - "5"/Somewhat opposed to Health Canada legislation (Q12)
Confirm 12 respondents for 8-10 to show (we do NOT want more than 10 to participate)
Ensure good mix of those with/without children; and those who know/don't know someone infertile
Ensure good mix of genders, age, household income and education (in this order of importance)
Incentive of $50

FINAL

Questionnaire général de recrutement - Groupe de discussion de Santé Canada

Bonjour, bonsoir, ici _____de POLLARA, l'entreprise nationale de recherche en opinion publique. J'aimerais vous inviter à participer à un groupe de discussion le _____ pour discuter de sujets d'actualité. Si vous êtes admissible et participez à ce groupe, vous recevrez 50,00 $ en guise de remerciement. Je dois cependant vous poser quelques questions pour m'assurer que vous êtes admissible.

Le concept de groupe de discussion vous est-il familier?

«OUI» - CONTINUEZ
«NON» - EXPLIQUEZ : «*Un groupe de discussion est formé de huit à dix participants et d'un animateur ou d'une animatrice. Pendant les deux heures que dure le groupe, on demande aux participants de discuter de toute une gamme d'enjeux liés au sujet étudié.*»

Seriez-vous intéressé à participer à ce groupe de discussion?

OUI - J'aimerais vous poser quelques brèves questions pour savoir si vous êtes admissible. Vos réponses demeureront confidentielles.
NON - (REMERCIEZ ET TERMINEZ)

1. INSCRIVEZ LE SEXE

   Homme
   Femme

   (Recrutez un nombre égal d'hommes et de femmes)

2. Avez-vous déjà participé à un groupe de discussion pour lequel vous avez été rémunéré?

   OUI Quand?_____ (SI MOINS DE SIX MOIS, REMERCIEZ ET TERMINEZ, AUTREMENT ALLEZ À Q3)

   NON - PASSEZ À Q5

3. À combien de groupes de discussion avez-vous participé depuis 5 ans?

   INSCRIVEZ _____ (SI «SIX OU PLUS» REMERCIEZ ET TERMINEZ, AUTREMENT ALLEZ À Q4)

4. Et de quels sujets avez-vous discuté dans ces groupes?

_____

(SI SUJETS LIÉS AUX OCCUPATIONS HABITUELLES OU RELATIVES AU PROJET, REMERCIEZ ET TERMINEZ)

5. Est-ce que vous ou un membre de votre famille avez déjà travaillé pour un des types d'entreprises suivantes? (LISEZ LA LISTE)

Une agence de publicité	❑
Une entreprise d'études de marché	❑
Un média	❑
Une agence de relations publiques	❑
Le gouvernement du Canada	❑
Le domaine de la santé, comme dans un cabinet de médecin ou un hôpital	❑

(SI «OUI» REMERCIEZ ET TERMINEZ)

6. Quel est le plus haut niveau de scolarité que vous avez terminé?

École élémentaire
École secondaire
Cégep ou collège communautaire
Quelques années d'université
Diplôme universitaire
(Bonne répartition)

7. Laquelle des catégories suivantes reflète le mieux le revenu annuel total de votre ménage?

Moins de 25 000 $
De 25 000 $ à 44 000 $
De 45 000 $ à 59 000 $
De 60 000 $ à 75 000 $
De 75 000 $ ou plus

(Bonne répartition)

8. À quel groupe d'âge appartenez-vous? LISEZ LA LISTE

18 à 24 ans	❑
25 à 34 ans	❑
35 à 44 ans	❑
45 à 54 ans	❑
55 ans et plus	❑

(Bonne répartition)

9. Avez-vous déjà eu des enfants?

Oui
Non

(Bonne répartition)

10. Connaissez-vous quelqu'un dans votre famille immédiate ou dans votre cercle d'amis intimes qui a eu des problèmes d'infertilité ou qui a été incapable de concevoir son propre enfant?

Oui
Non

(Bonne répartition)

Les techniques de reproduction et de génétique incluent toute une gamme d'activités, à la fois anciennes et nouvelles. Les techniques de reproduction tentent de produire une grossesse au moyen de procédés comme la fécondation in vitro, l'insémination par donneur et les arrangements de mères porteuses. Les techniques génétiques incluent la détermination du sexe, la recherche sur les embryons et les diagnostiques prénataux. Beaucoup de ces techniques de reproduction et de génétique sont pratiquées présentement au Canada.

11. Le ministère fédéral de la Santé (Santé Canada) songe actuellement à présenter une loi pour interdire ou réglementer l'utilisation de certaines techniques de reproduction et de génétique pour faire en sorte que seules les meilleures pratiques soient utilisées. Sur une échelle de 1 à 10, où 1 signifie «très opposé» et 10 signifie «très favorable», quelle cote accorderiez-vous à votre niveau de d'appui ou d'opposition à cette législation?

Très opposé
Assez opposé
Assez favorable
Très favorable

J'aimerais vous inviter à participer au groupe du :

MONTRÉAL : Lundi 20 septembre 1999 à 18:00 GROUPE 1
Lundi 20 septembre 1999 à 20:00 GROUPE 2

qui aura lieu au _____. Veuillez vous présenter 15 minutes avant l'heure pour vous inscrire.

Comme je l'ai déjà mentionné, si vous participez, vous recevrez 50.00 $ en guise de remerciement. (GROUPE DE 18:00 : «De plus, des sandwichs et des boissons seront servis»)

Pourrais-je avoir :
Votre nom : _____
Votre adresse : _____

Votre numéro de téléphone [domicile] _____
[travail] _____

VEUILLEZ COMMUNIQUER AVEC NOUS AU _____ S'IL VOUS EST IMPOSSIBLE D'ASSISTER AU GROUPE. MERCI.

FINAL

Questionnaire de recrutement pour les aidants de personnes handicapées mentalement-
Groupe de discussion de Santé Canada à Montréal et à Toronto

Bonjour, bonsoir, ici _____de POLLARA, l'entreprise nationale de recherche en opinion publique. J'aimerais vous inviter à participer à un groupe de discussion le _____ pour discuter de sujets d'actualité. Si vous êtes admissible et participez à ce groupe, vous recevrez 50,00 $ en guise de remerciement. Je dois cependant vous poser quelques questions pour m'assurer que vous êtes admissible.

Le concept de groupe de discussion vous est-il familier?

«OUI» - CONTINUEZ
«NON» - EXPLIQUEZ : «*Un groupe de discussion est formé de huit à dix participants et d'un animateur ou d'une animatrice. Pendant les deux heures que dure le groupe, on demande aux participants de discuter de toute une gamme d'enjeux liés au sujet étudié.*»

Seriez-vous intéressé à participer à ce groupe de discussion?

OUI - J'aimerais vous poser quelques brèves questions pour savoir si vous êtes admissible. Vos réponses demeureront confidentielles.
NON - (REMERCIEZ ET TERMINEZ)

1. Êtes-vous l'aidant principal d'un membre adulte de votre famille souffant présentement d'un handicap mental permanent, comme la trisomie ou la schizophrénie, et qui a besoin de soins à temps plein mais ne vit pas en institution?

   Oui (GROUPE 1 POUR TORONTO ET MONTRÉAL)
   Non (REMERCIEZ ET TERMINEZ)

2. Avez-vous déjà participé à un groupe de discussion pour lequel vous avez été rémunéré?

   OUI Quand?_____ (SI MOINS DE SIX MOIS, REMERCIEZ ET TERMINEZ, AUTREMENT ALLEZ À Q3)

   NON - PASSEZ À Q5

3. À combien de groupes de discussion avez-vous participé depuis 5 ans?

   INSCRIVEZ _____ (SI «SIX OU PLUS» REMERCIEZ ET TERMINEZ, AUTREMENT ALLEZ À Q4)

4. Et de quels sujets avez-vous discuté dans ces groupes?

_____

(SI SUJETS LIÉS AUX OCCUPATIONS HABITUELLES OU RELATIVES AU PROJET, REMERCIEZ ET TERMINEZ)

5. Est-ce que vous ou un membre de votre famille avez déjà travaillé pour un des types d'entreprises suivantes? (LISEZ LA LISTE)

Une agence de publicité	❑
Une entreprise d'études de marché	❑
Un média	❑
Une agence de relations publiques	❑
Le gouvernement du Canada	❑
Le domaine de la santé, comme dans un cabinet de médecin ou un hôpital	❑

(SI «OUI» REMERCIEZ ET TERMINEZ)

J'aimerais vous inviter à participer au groupe du :

MONTRÉAL : Lundi 20 septembre 1999 à 18:00 GROUPE 1

qui aura lieu au _____. Veuillez vous présenter 15 minutes avant l'heure pour vous inscrire.

Comme je l'ai déjà mentionné, si vous participez, vous recevrez 50.00 $ en guise de remerciement. De plus, des sandwichs et des boissons seront servis.

Pourrais-je avoir :
Votre nom : _____
Votre adresse : _____

Votre numéro de téléphone [domicile] _____
[travail] _____

VEUILLEZ COMMUNIQUER AVEC NOUS AU _____ S'IL VOUS EST IMPOSSIBLE D'ASSISTER AU GROUPE. MERCI.

FINAL

Questionnaire de recrutement pour les personnes handicapées physiquement-
Groupe de discussion de Santé Canada à Montréal et à Toronto

Bonjour, bonsoir, ici _____de POLLARA, l'entreprise nationale de recherche en opinion publique. J'aimerais vous inviter à participer à un groupe de discussion le _____ pour discuter de sujets d'actualité. Si vous êtes admissible et participez à ce groupe, vous recevrez 50,00 $ en guise de remerciement. Je dois cependant vous poser quelques questions pour m'assurer que vous êtes admissible.

Le concept de groupe de discussion vous est-il familier?

«OUI» - CONTINUEZ
«NON» - EXPLIQUEZ : «*Un groupe de discussion est formé de huit à dix participants et d'un animateur ou d'une animatrice. Pendant les deux heures que dure le groupe, on demande aux participants de discuter de toute une gamme d'enjeux liés au sujet étudié.*»

Seriez-vous intéressé à participer à ce groupe de discussion?

OUI - J'aimerais vous poser quelques brèves questions pour savoir si vous êtes admissible. Vos réponses demeureront confidentielles.
NON - (REMERCIEZ ET TERMINEZ)

1. Souffrez-vous présentement d'un handicap physique permanent que vous avez eu toute votre vie?

   Oui (CONTINUEZ)
   Non (REMERCIEZ : «MALHEUREUSEMENT, POUR CE GROUPE NOUS NE POUVONS ACCEPTER QUE LES GENS AYANT TOUJOURS EU UN HANDICAP.»)

2. Avez-vous déjà participé à un groupe de discussion pour lequel vous avez été rémunéré?

   OUI Quand?_____ (SI MOINS DE SIX MOIS, REMERCIEZ ET TERMINEZ, AUTREMENT ALLEZ À Q3)

   NON - PASSEZ À Q5

3. À combien de groupes de discussion avez-vous participé depuis 5 ans?

   INSCRIVEZ _____ (SI «SIX OU PLUS» REMERCIEZ ET TERMINEZ, AUTREMENT ALLEZ À Q4)

4. Et de quels sujets avez-vous discuté dans ces groupes?

_____

(SI SUJETS LIÉS AUX OCCUPATIONS HABITUELLES OU RELATIVES AU PROJET, REMERCIEZ ET TERMINEZ)

5. Est-ce que vous ou un membre de votre famille avez déjà travaillé pour un des types d'entreprises suivantes? (LISEZ LA LISTE)

Une agence de publicité	❑
Une entreprise d'études de marché	❑
Un média	❑
Une agence de relations publiques	❑
Le gouvernement du Canada	❑
Le domaine de la santé, comme dans un cabinet de médecin ou un hôpital	❑

(SI «OUI» REMERCIEZ ET TERMINEZ)

J'aimerais vous inviter à participer au groupe du :

MONTRÉAL : Lundi 20 septembre 1999 à 18:00 GROUPE 1

qui aura lieu au _____. Veuillez vous présenter 15 minutes avant l'heure pour vous inscrire.

Comme je l'ai déjà mentionné, si vous participez, vous recevrez 50.00 $ en guise de remerciement. De plus, des sandwichs et des boissons seront servis.

Pourrais-je avoir :
Votre nom : _____
Votre adresse : _____

Votre numéro de téléphone [domicile] _____
[travail] _____

VEUILLEZ COMMUNIQUER AVEC NOUS AU _____ S'IL VOUS EST IMPOSSIBLE D'ASSISTER AU GROUPE. MERCI.

APPENDIX B
Moderator's Guide

Moderator's Guide (Used in Montreal only)
RGT Polling - Phase 3
(September 15, 1999)

I. Introduction (5 Minutes)

1. Introduction by moderator.

- "Focus groups sometimes allow us to get more detail on topics and issues than we can from telephone surveys (thought, feelings, and opinions). As well, focus groups let us show people a questionnaire or some advertisement that we want the participants to read and then evaluate."

- "We are not here to reach a consensus. Everyone will have an opportunity to participate. There are no right or wrong answers - you help me by giving me your opinions."

- "Proceedings are observed by the client and are audio-taped for purposes of reporting.

- "The individuals participating will not be identified by name in any of the reporting."

- [If requests are made on who the client is, Health Canada will be identified at the **End** of the focus group discussion.]

- "The discussion will last about 2 hours"

2. Round table introductions.

II. Warm-up (20 Minutes)

Objective: To briefly identify the topic and top-of-mind opinions associated with reproductive and genetic technologies (RGTs).

1. Before we get into depth on the topic, I want you to tell me what comes to mind when I say the words "human reproductive and genetic technologies"? 1a
Probe: What do you associate with these words? Why? 1c 1b

1a-1i'

What comes to mind when you hear: **[Probe for each: "positive/negative" & "why"]**
* in vitro fertilization 1d d'
* donor insemination 1e e'
* surrogacy arrangements 1f f'
* sex selection 1g g'
* embryo research 1h h'
* prenatal diagnosis 1i i'

15

2. **Background to be read to participants:** Reproductive and genetic technologies include a wide range of activities, both old and new. Reproductive technologies attempt to produce a pregnancy by such processes as in vitro fertilization, donor insemination and surrogacy arrangements. Genetics-based technologies include sex selection, embryo research and prenatal diagnosis. Many of these reproductive and genetic technologies are currently practiced in Canada. **[Note: Place definitions on flip chart for full view of participants]**

Probe: Generally speaking, what is your opinion of RGTs? Is it positive or negative? Why?

III. Discussion on Prohibition and Regulation (55 Minutes)

Objective: To identify what drives opinions on commercialization, research using human genetic material and stem cell/ therapeutic cloning research.

[Moderator: Discuss each and probe for each why they hold such opinions]

1. Commercialization

a) Paying female donors for their eggs. Why? Why not?

b) Paying the male donors for their sperm. Why? Why not?

c) Allowing payment to a surrogate mother who carries a child for someone else.

Read Commercialization Case:

In 1993, a woman was paid $20,000 to carry a child for another woman. As recently as last year a female Harvard graduate woman was paid $25,000 for donating her eggs to a couple.

Usually, in cases of surrogacy and egg donation, woman are paid much less than these figures, but still they are compensated. Take for example the case of Shelly who agreed to carry a child for Bob and Janet Smith. Janet had tried for 7 years to conceive and carry a child but because of severe endometriosis (abnormal lining of the uterus) she continued to miscarry. Finally, at the age of 40, her doctor advised her that the only way she and Bob could have children of their own, was to find a surrogate who could carry a child for them.

Through a surrogacy agency Bob and Janet met a number of women who were eligible to be surrogates. After interviewing all of them separately, they decided on Shelly. She seemed reliable, was mature and had already had 3 children. It was therefore unlikely,

12

they reasoned, that she would want to keep the baby after birth. The reasons that Shelly gave for wanting to be a surrogate was that she wanted to help others who couldn't have children to experience the joys of parenthood. As well, as a single mother, she was finding it financially difficult so the decided price of $15,000 would come in handy. She also asked for extra medical insurance as she wanted a private hospital room when she went in to hospital.

Shelly, Bob and Janet had to undergo a number of tests over the next few months. Bob and Janet eventually underwent in vitro fertilisation and produced 10 healthy embryos. Three of these were implanted into Shelly's uterus. She became pregnant with twins. Bob and Janet realised that the extra risks to Shelly's health would have to be compensated - not just financially but extra trips to the doctor's would be required and child care of Shelly's children would have to be arranged in case she needed to stay in the hospital for longer.

Shelly did have twins, although prematurely. Bob and Janet ended up paying her $20,000 and had to carry the costs of $10,000 in private medical bill.

Probe: If surrogate mother is paid for her services, do you think she still thinks through the physical/emotional implications of what she is doing? Will they be motivated by money alone?

4a→c 4a 4b

Do you think a child would mind knowing that its mother was paid to give birth to it? 4c

2. Use of Genetic Material

Read Use of Genetic Material Case:

In Britain in 1995, a 30 year old man named Stephen Blood fell into a coma as a result of a sudden case of meningitis. At his wife's request, doctors removed sperm from Stephen while he was comatose via electro ejaculation.

Mr. Blood died a few days later and his sperm was kept in a storage tank until doctors could clarify what they were legally allowed to do with his sperm. As Mr. Blood had not given his written consent to the taking or storage of his sperm, it was against British law for the doctors, or Mrs. Blood, to keep his sperm in storage and also it was against the law to use it in treatment.

Mrs. Blood was distraught to discover that, according to British law, she could not use her husband's sperm. Although she and Stephen had spoken of having children one day, because there was nothing in writing she would never be allowed to use his sperm and could therefore not hope to have a baby born genetically related to her dead husband.

3

Mrs. Blood applied eventually for judicial review of the law and its refusal to allow her to use her dead husband's sperm. However, without written consent, the law said that she could not have access to his sperm. Mrs. Blood took her case to court and it eventually was heard by the Appeal Court of the High Court of Great Britain.

In the end, the Courts upheld the law but the regulatory body allowed Mrs. Blood to take the sperm abroad for treatment.

Probe:
- How important is written consent? Should there be room to make exceptions to rules?
- Should it be enshrined in law? Should doctors be penalised if they do not abide by the law? What if they are put in prison?
- What about the implications of using sperm and eggs from dead people to create an embryo and possibly a child? Should that be allowed? Why? Why not? How do you think the child would feel knowing that one of its parents was dead before he/she was born?

IV. Discussion of Instituting New Legislation for RGTs (30 Minutes)

Objective: To identify what drives opinions on the Government of Canada instituting legislation for a comprehensive and balanced regulatory frame work for RGTs.

1. How important is it to you that the Government of Canada to put in place legislation to regulate and oversee reproductive and genetic technologies? Why do you think it is/is not important?

2. If other countries have legislation or government guidelines in this area, how important do you think it is for Canada to have something in place as well?

3. In your opinion, should the regulations and standards be mainly concerned with health and safety or should ethical issues also be dealt with by this legislation?

Probe:
- What ethical concerns would you want them to focus on? Why?
- If there were to be an ethical advisory body, who should be involved? Ethicists? Scientists? Canadians who have used fertility treatment? Bureaucrats? Practitioners?

V. Wrap-up (10 Minutes)

Probe for what they think are the most important messages when it comes to regulating this area:

- that the health of Canadians will be safeguarded by regulating certain practices and banning others

- 9b that human reproductive materials, such as sperm, eggs and embryos, will be treated with respect
- 9c that the welfare of all persons, especially women using these technologies and children who are born as a result of them will be protected
- 9d that certain standards - ethical and practical - will be set up and followed to ensure safe practice and a consistent approach to difficult ethical issues

VI. Thank and Terminate

Moderator's Guide
RGT Polling - Phase 3
(September 15, 1999)

I. Introduction (5 Minutes)

1. Introduction by moderator.

- "Focus groups sometimes allow us to get more detail on topics and issues than we can from telephone surveys (thought, feelings, and opinions). As well, focus groups let us show people a questionnaire or some advertisement that we want the participants to read and then evaluate."

- "We are not here to reach a consensus. Everyone will have an opportunity to participate. There are no right or wrong answers - you help me by giving me your opinions."

- "Proceedings are observed by the client and are audio-taped for purposes of reporting.

- "The individuals participating will not be identified by name in any of the reporting."

- [If requests are made on who the client is, Health Canada will be identified at the **End** of the focus group discussion.]

- "The discussion will last about 2 hours"

2. Round table introductions.

II. Warm-up (20 Minutes)

Objective: To briefly identify the topic and top-of-mind opinions associated with reproductive and genetic technologies (RGTs).

1. Before we get into depth on the topic, I want you to tell me what comes to mind when I say the words "human reproductive and genetic technologies"?
Probe: What do you associate with these words? Why?

What comes to mind when you hear: [**Probe for each: "positive/negative" & "why"**]
* in vitro fertilization
* donor insemination
* surrogacy arrangements
* sex selection
* embryo research
* prenatal diagnosis

2. **Background to be read to participants:** Reproductive and genetic technologies include a wide range of activities, both old and new. Reproductive technologies attempt to produce a pregnancy by such processes as in vitro fertilization, donor insemination and surrogacy arrangements. Genetics-based technologies include sex selection, embryo research and prenatal diagnosis. Many of these reproductive and genetic technologies are currently practiced in Canada. [**Note: Place definitions on flip chart for full view of participants**]

Probe: Generally speaking, what is your opinion of RGTs? Is it positive or negative? Why?

III. Discussion on Prohibition and Regulation (55 Minutes)

Objective: To identify what drives opinions on commercialization, research using human genetic material and stem cell/ therapeutic cloning research.

[Moderator: Discuss each and probe for each why they hold such opinions]

1. Commercialization

a) Paying female donors for their eggs. Why? Why not?
b) Paying the male donors for their sperm. Why? Why not?

c) Allowing payment to a surrogate mother who carries a child for someone else.

Read Commercialization Case:

In 1993, a woman was paid $20,000 to carry a child for another woman. As recently as last year a female Harvard graduate woman was paid $25,000 for donating her eggs to a couple.

Usually, in cases of surrogacy and egg donation, woman are paid much less than these figures, but still they are compensated. Take for example the case of Shelly who agreed to carry a child for Bob and Janet Smith. Janet had tried for 7 years to conceive and carry a child but because of severe endometriosis (abnormal lining of the uterus) she continued to miscarry. Finally, at the age of 40, her doctor advised her that the only way she and Bob could have children of their own, was to find a surrogate who could carry a child for them.

Through a surrogacy agency Bob and Janet met a number of women who were eligible to be surrogates. After interviewing all of them separately, they decided on Shelly. She seemed reliable, was mature and had already had 3 children. It was therefore unlikely,

they reasoned, that she would want to keep the baby after birth. The reasons that Shelly gave for wanting to be a surrogate was that she wanted to help others who couldn't have children to experience the joys of parenthood. As well, as a single mother, she was finding it financially difficult so the decided price of $15,000 would come in handy. She also asked for extra medical insurance as she wanted a private hospital room when she went in to hospital.

Shelly, Bob and Janet had to undergo a number of tests over the next few months. Bob and Janet eventually underwent in vitro fertilisation and produced 10 healthy embryos. Three of these were implanted into Shelly's uterus. She became pregnant with twins. Bob and Janet realised that the extra risks to Shelly's health would have to be compensated - not just financially but extra trips to the doctor's would be required and child care of Shelly's children would have to be arranged in case she needed to stay in the hospital for longer.

Shelly did have twins, although prematurely. Bob and Janet ended up paying her $20,000 and had to carry the costs of $10,000 in private medical bill.

Probe: If surrogate mother is paid for her services, do you think she still thinks through the physical/emotional implications of what she is doing? Will they be motivated by money alone?

Do you think a child would mind knowing that its mother was paid to give birth to it?

2. Use of Genetic Material

Read Use of Genetic Material Case:

In Britain in 1995, a 30 year old man named Stephen Blood fell into a coma as a result of a sudden case of meningitis. At his wife's request, doctors removed sperm from Stephen while he was comatose via electro ejaculation.

Mr. Blood died a few days later and his sperm was kept in a storage tank until doctors could clarify what they were legally allowed to do with his sperm. As Mr. Blood had not given his written consent to the taking or storage of his sperm, it was against British law for the doctors, or Mrs. Blood, to keep his sperm in storage and also it was against the law to use it in treatment.

Mrs. Blood was distraught to discover that, according to British law, she could not use her husband's sperm. Although she and Stephen had spoken of having children one day, because there was nothing in writing she would never be allowed to use his sperm and could therefore not hope to have a baby born genetically related to her dead husband.

Mrs. Blood applied eventually for judicial review of the law and its refusal to allow her to use her dead husband's sperm. However, without written consent, the law said that she could not have access to his sperm. Mrs. Blood took her case to court and it eventually was heard by the Appeal Court of the High Court of Great Britain.

In the end, the Courts upheld the law but the regulatory body allowed Mrs. Blood to take the sperm abroad for treatment.

Probe:
- How important is written consent? Should there be room to make exceptions to rules?
- Should it be enshrined in law? Should doctors be penalised if they do not abide by the law? What if they are put in prison?
- What about the implications of using sperm and eggs from dead people to create an embryo and possibly a child? Should that be allowed? Why? Why not? How do you think the child would feel knowing that one of its parents was dead before he/she was born?

3. Stem Cell/Therapeutic Cloning Research

Read:

Frank and Deborah were undergoing IVF at a fertility clinic. The scientists produced a number of embryos. There were so many in fact that they transferred 3 to Deborah's uterus and placed the rest in a freezer to be stored in case Deborah and Frank wanted to use these later.

Nine months later, Deborah gave birth to triplets. Feeling that they had completed their family and would not want to use these embryos to try for more children, they donated the embryos to a research laboratory. The scientists decided to use some of Deborah and Frank's embryos in research that they were doing involving embryos and stem cells.

Embryonic stem cells are the master cells from which the fetus develops. These can give rise to any kind of cell in the body, from brain cells to liver cells. These embryonic stem cells arise early after conception and are the ancestral cells for all of the body's tissue, such as muscle, bone, nerves and skin.

The researchers who used these embryos reported on their research last November. This included experiments that showed the cells might be a rich source of new tissue to treat diseases in which brain cells are destroyed, including Parkinson's and Alzheimer's diseases.

After removing some of the stem cells the embryos cannot be placed back in the freezer so they are no longer viable - ie they cannot develop into humans. However the cells can

be multiplied and used for a variety of purposes.

Probe: Should this be allowed? Why? Why not?
Probe: Do you think such research should be permitted using these embryos? Why? Why not?
[want to see if focus groups get into ethical discussion around this issue - give some time to flesh out if possible]

IV. Discussion of Instituting New Legislation for RGTs (30 Minutes)

Objective: To identify what drives opinions on the Government of Canada instituting legislation for a comprehensive and balanced regulatory frame work for RGTs.

1. How important is it to you that the Government of Canada to put in place legislation to regulate and oversee reproductive and genetic technologies? Why do you think it is/is not important?

2. If other countries have legislation or government guidelines in this area, how important do you think it is for Canada to have something in place as well?

3. In your opinion, should the regulations and standards be mainly concerned with health and safety or should ethical issues also be dealt with by this legislation?

Probe:
- What ethical concerns would you want them to focus on? Why?
- If there were to be an ethical advisory body, who should be involved? Ethicists? Scientists? Canadians who have used fertility treatment? Bureaucrats? Practitioners?

V. Wrap-up (10 Minutes)

Probe for what they think are the most important messages when it comes to regulating this area:

- that the health of Canadians will be safeguarded by regulating certain practices and banning others
- that human reproductive materials, such as sperm, eggs and embryos, will be treated with respect
- that the welfare of all persons, especially women using these technologies and children who are born as a result of them will be protected
- that certain standards - ethical and practical - will be set up and followed to ensure safe practice and a consistent approach to difficult ethical issues

VI. Thank and Terminate

Guide de l'animateur (Montreal seulement)
Sondage sur les TRG - troisième étape
(15 septembre 1999)

I. Introduction (5 minutes)

Introduction habituelle
Si les participants le demandent, dites à la **fin** du groupe que le client est Santé Canada.

II. Mise en situation (20 minutes)

Objectif : Identifier brièvement le sujet et les opinions spontanés associés aux techniques de reproduction et de génétique (TRG).

1. Avant que nous commencions à étudier le sujet plus en détail, j'aimerais que vous me disiez à quoi vous pensez lorsque je vous dis les mots «techniques de reproduction et de génétique»?
Sondez : Qu'associez-vous à ces mots? Pourquoi?

   À quoi pensez-vous lorsque je dis : **[Sondez pour chacun : «positif/négatif» et «pourquoi»]**
   *La fécondation in vitro?
   *L'insémination par donneur?
   *Les arrangements de mères porteuses?
   *La détermination du sexe?
   *La recherche sur les embryons?
   *Les diagnostiques prénataux?

2. **Définition à lire aux participants** :

   Les techniques de reproduction et de génétique incluent toute une gamme d'activités, à la fois anciennes et nouvelles. Les techniques de reproduction tentent de produire une grossesse au moyen de procédés comme la fécondation in vitro, l'insémination par donneur et les arrangements de mères porteuses. Les techniques génétiques incluent la détermination du sexe, la recherche sur les embryons et les diagnostiques prénataux. Beaucoup de ces techniques de reproduction et de génétique sont pratiquées présentement au Canada.
   [Note : Placez les définitions sur le chevalet pour que les participants puissent bien les voir.]

   Sondez : En général, que pensez-vous des TRG? En avez-vous une opinion positive ou négative? Pourquoi?

III. Discussion sur la prohibition et la réglementation (55 minutes)

Objectif : Identifier ce qui sous-tend les opinions sur la commercialisation, la recherche utilisant le matériel génétique humain et la recherche sur le clonage des cellules souches ou le clonage thérapeutique.

[Animatrice : Discutez de chaque point et sondez pour savoir pourquoi les participants ont de telles opinions.]

1. <u>La commercialisation</u>

   a) Payer les femmes donnant leurs ovules. Pourquoi? Pourquoi pas?
   b) Payer les hommes donnant leur sperme. Pourquoi? Pourquoi pas?

   c) Permettre qu'une mère porteuse soit payée pour porter l'enfant de quelqu'un d'autre.

<u>Lisez le cas de commercialisation :</u>

En 1993, une femme a reçu 20 000 $ pour porter l'enfant d'une autre femme. L'an dernier, une femme diplômée de Harvard a reçu 25 000 $ en échange du don de ces ovules à couple.

Habituellement, dans les cas de mères porteuses et de dons d'ovules, les femmes reçoivent beaucoup moins d'argent que dans les deux cas précédents, mais elles sont tout de même rémunérées. Prenons par exemple le cas de Shelly, qui a accepté de porter un enfant pour Bob et Janet Smith. Janet avait essayé pendant sept ans de concevoir et de porter un enfant, mais en raison d'un cas aigu d'endométriose (anomalie de la tunique muqueuse de l'utérus) elle les avait toujours perdus. Finalement, à l'âge de 40 ans, son médecin lui a dit que la seule façon pour elle et Bob d'avoir leur propre enfant serait de trouver une mère porteuse qui pourrait porter l'enfant pour eux.

Par l'intermédiaire d'une agence de mères porteuses, Bob et Janet ont rencontré un bon nombre de femmes qui pouvaient être mères porteuses. Après les avoir toutes reçues individuellement en entrevue, ils ont choisi Shelly. Elle semblait fiable et posséder une maturité d'esprit et elle avait déjà trois enfants. Il était donc peu probable, pensait le couple, qu'elle veuille garder l'enfant après sa naissance. Shelly disait qu'elle voulait être mère porteuse pour aider les gens ne pouvant pas avoir d'enfants à connaître les joies d'être parent. De plus, en tant que mère célibataire, elle avait des difficultés financières et la somme de 15 000 $ qui était

offerte lui donnerait un coup de main. Elle a aussi demandé une assurance médicale supplémentaire pour avoir une chambre privée à l'hôpital.

Shelly, Bob et Janet ont dû passer toute une série de tests au cours des mois qui ont suivi. Bob et Janet ont finalement passé par le processus de fécondation in vitro et produit 10 embryons sains. Trois de ces embryons ont été implantés dans l'utérus de Shelly. Elle est devenue enceinte de jumeaux. Bob et Janet se sont rendus compte que Janet devrait être dédommagée pour les risques de santé accrus - pas seulement financièrement mais il faudrait faire plus de visites chez le médecin et il faudrait prendre les mesures nécessaires pour faire garder les enfants de Shelly si elle devait rester à l'hôpital plus longtemps.

Shelly a accouché de jumeaux, mais prématurément. Bob et Janet lui ont versé 20 000 $ et ont dû acquitter des frais médicaux de 10 000 $.

Sondez : Si une mère porteuse est payée pour ses services, croyez-vous qu'elle pense quand même aux implications physiques et émotionnelles de ce qu'elle fait? Croyez-vous que les mères porteuses seront motivées par l'argent seulement?

Croyez-vous que ça dérangerait un enfant d'apprendre qu'on a payé sa mère pour le mettre au monde?

2. Utilisation du matériel génétique

Lisez le cas d'utilisation de matériel génétique :

En Grande-Bretagne en 1995, un homme de 30 ans nommé Stephen Blood est entré dans un coma suite à un cas subit de méningite. À la demande de sa femme, les médecins ont prélevé du sperme de Stephen par électro-éjaculation.

M. Blood est mort quelques jours plus tard et son sperme a été gardé dans un réservoir de stockage le temps que les médecins clarifient ce qu'ils pouvaient légalement faire du sperme. Comme M. Blood n'avait pas consenti par écrit à la conservation et à l'utilisation de son sperme, il était interdit par les lois britanniques que les médecins, ou Mme Blood, gardent ou utilisent le sperme pour un traitement.

Mme Blood a été bouleversée d'apprendre que, selon la loi britannique, elle ne pouvait pas utiliser le sperme de son mari. Bien qu'elle et Stephen aient parlé d'avoir des enfants un jour, comme il n'y avait rien par écrit, elle ne pourrait jamais utiliser son sperme et ne pouvait espérer avoir un enfant ayant un lien

génétique avec son défunt mari.

Mme Blood a fini par demander une révision judiciaire de la loi lui interdisant d'utiliser le sperme de son mari. Cependant, sans le consentement écrit, la loi stipulait qu'elle ne pouvait pas avoir accès au sperme de son mari. Mme. Blood a présenté sa cause devant les tribunaux et a finalement été entendue par la cour d'appel de la cour supérieure de la Grande-Bretagne (Appeal Court of the High Court of Great Britain).

En fin de compte, la cour décida de maintenir la loi mais décida de lui permettre d'emporter le sperme de son mari à l'étranger pour l'utiliser dans un traitement.

Sondez :

- Dans quelle mesure le consentement est-il important? Devrait-on permettre des exceptions à la règle?
- Le consentement devrait-il être enchâssé dans la loi? Les médecins devraient-ils être punis s'ils ne respectent pas la loi? Et s'ils étaient mis en prison?
- Qu'en est-il des conséquences de l'utilisation du sperme ou des ovules de personnes décédées pour créer un embryon et peut-être même un enfant? Cela devrait-il être permis? Pourquoi? Pourquoi pas? D'après vous, comment réagirait un enfant en apprenant qu'un de ses parents était mort avant qu'il naisse? *(Marie, ne devrait-on pas dire «avant qu'il soit conçu?»)*

IV. Discussion sur l'établissement d'une nouvelle législation pour les TRG (30 minutes)

Objectifs : Identifier ce qui sous-tend les opinions par rapport à l'établissement par le gouvernement du Canada d'une législation définissant un cadre de travail législatif complet et équilibré pour les TRG.

1. Dans quelle mesure est-il important pour vous que le gouvernement du Canada adopte une législation pour réglementer et superviser les techniques de reproduction et de génétique? Pourquoi pensez-vous que c'est important / que ce n'est pas important?

2. Si les autres pays ont des législations ou des directives gouvernementales dans ce domaine, dans quelle mesure croyez-vous qu'il soit important que le en Canada ait aussi?

3. D'après vous, les normes et les règlements devraient-ils toucher surtout la santé et la sécurité ou la législation devrait-elle également englober les questions morales?

Sondez :

- Sur quelles questions morales devrait-on s'attarder? Pourquoi?
- S'il y avait un organisme de conseil moral, qui devrait y participer? Les éthiciens? Les scientifiques? Des Canadiens ayant utilisé des traitements de fertilité? Des bureaucrates? Des praticiens?

V. Conclusion (10 minutes)

Sondez pour savoir quels sont les messages que les participants estiment être les plus importants en ce qui concerne la réglementation de ce domaine :

- Que la santé des Canadiens sera préservée en réglementant certaines pratiques et en en interdisant certaines autres;
- Que le matériel de reproduction humain, comme le sperme, les ovules et les embryons, sera traité avec respect;
- Que le bien-être de toutes les personnes, surtout des femmes utilisant ces techniques et des enfants nés suite à leur utilisation, sera respecté;
- Que certaines normes, morales et pratiques, seront établies et observées pour assurer une pratique sûre et une approche uniforme aux questions éthiques difficiles.

VI. Remerciez et terminez.

Guide de l'animateur
Sondage sur les TRG - troisième étape
(15 septembre 1999)

I. Introduction (5 minutes)

Introduction habituelle
Si les participants le demandent, dites à la **fin** du groupe que le client est Santé Canada.

II. Mise en situation (20 minutes)

Objectif : Identifier brièvement le sujet et les opinions spontanés associés aux techniques de reproduction et de génétique (TRG).

1. Avant que nous commencions à étudier le sujet plus en détail, j'aimerais que vous me disiez à quoi vous pensez lorsque je vous dis les mots «techniques de reproduction et de génétique»?
Sondez : Qu'associez-vous à ces mots? Pourquoi?

   À quoi pensez-vous lorsque je dis : **[Sondez pour chacun : «positif/négatif» et «pourquoi»]**
   *La fécondation in vitro?
   *L'insémination par donneur?
   *Les arrangements de mères porteuses?
   *La détermination du sexe?
   *La recherche sur les embryons?
   *Les diagnostiques prénataux?

2. **Définition à lire aux participants** :

   Les techniques de reproduction et de génétique incluent toute une gamme d'activités, à la fois anciennes et nouvelles. Les techniques de reproduction tentent de produire une grossesse au moyen de procédés comme la fécondation in vitro, l'insémination par donneur et les arrangements de mères porteuses. Les techniques génétiques incluent la détermination du sexe, la recherche sur les embryons et les diagnostiques prénataux. Beaucoup de ces techniques de reproduction et de génétique sont pratiquées présentement au Canada.
   [Note : Placez les définitions sur le chevalet pour que les participants puissent bien les voir.]

   Sondez : En général, que pensez-vous des TRG? En avez-vous une opinion positive ou négative? Pourquoi?

III. Discussion sur la prohibition et la réglementation (55 minutes)

Objectif : Identifier ce qui sous-tend les opinions sur la commercialisation, la recherche utilisant le matériel génétique humain et la recherche sur le clonage des cellules souches ou le clonage thérapeutique.

[Animatrice : Discutez de chaque point et sondez pour savoir pourquoi les participants ont de telles opinions.]

1. La commercialisation

a) Payer les femmes donnant leurs ovules. Pourquoi? Pourquoi pas?
b) Payer les hommes donnant leur sperme. Pourquoi? Pourquoi pas?

c) Permettre qu'une mère porteuse soit payée pour porter l'enfant de quelqu'un d'autre.

Lisez le cas de commercialisation :

En 1993, une femme a reçu 20 000 $ pour porter l'enfant d'une autre femme. L'an dernier, une femme diplômée de Harvard a reçu 25 000 $ en échange du don de ces ovules à couple.

Habituellement, dans les cas de mères porteuses et de dons d'ovules, les femmes reçoivent beaucoup moins d'argent que dans les deux cas précédents, mais elles sont tout de même rémunérées. Prenons par exemple le cas de Shelly, qui a accepté de porter un enfant pour Bob et Janet Smith. Janet avait essayé pendant sept ans de concevoir et de porter un enfant, mais en raison d'un cas aigu d'endométriose (anomalie de la tunique muqueuse de l'utérus) elle les avait toujours perdus. Finalement, à l'âge de 40 ans, son médecin lui a dit que la seule façon pour elle et Bob d'avoir leur propre enfant serait de trouver une mère porteuse qui pourrait porter l'enfant pour eux.

Par l'intermédiaire d'une agence de mères porteuses, Bob et Janet ont rencontré un bon nombre de femmes qui pouvaient être mères porteuses. Après les avoir toutes reçues individuellement en entrevue, ils ont choisi Shelly. Elle semblait fiable et posséder une maturité d'esprit et elle avait déjà trois enfants. Il était donc peu probable, pensait le couple, qu'elle veuille garder l'enfant après sa naissance. Shelly disait qu'elle voulait être mère porteuse pour aider les gens ne pouvant pas avoir d'enfants à connaître les joies d'être parent. De plus, en tant que mère célibataire, elle avait des difficultés financières et la somme de 15 000 $ qui était

offerte lui donnerait un coup de main. Elle a aussi demandé une assurance médicale supplémentaire pour avoir une chambre privée à l'hôpital.

Shelly, Bob et Janet ont dû passer toute une série de tests au cours des mois qui ont suivi. Bob et Janet ont finalement passé par le processus de fécondation in vitro et produit 10 embryons sains. Trois de ces embryons ont été implantés dans l'utérus de Shelly. Elle est devenue enceinte de jumeaux. Bob et Janet se sont rendus compte que Janet devrait être dédommagée pour les risques de santé accrus - pas seulement financièrement mais il faudrait faire plus de visites chez le médecin et il faudrait prendre les mesures nécessaires pour faire garder les enfants de Shelly si elle devait rester à l'hôpital plus longtemps.

Shelly a accouché de jumeaux, mais prématurément. Bob et Janet lui ont versé 20 000 $ et ont dû acquitter des frais médicaux de 10 000 $.

Sondez : Si une mère porteuse est payée pour ses services, croyez-vous qu'elle pense quand même aux implications physiques et émotionnelles de ce qu'elle fait? Croyez-vous que les mères porteuses seront motivées par l'argent seulement?

Croyez-vous que ça dérangerait un enfant d'apprendre qu'on a payé sa mère pour le mettre au monde?

2. Utilisation du matériel génétique

Lisez le cas d'utilisation de matériel génétique :

En Grande-Bretagne en 1995, un homme de 30 ans nommé Stephen Blood est entré dans un coma suite à un cas subit de méningite. À la demande de sa femme, les médecins ont prélevé du sperme de Stephen par électro-éjaculation.

M. Blood est mort quelques jours plus tard et son sperme a été gardé dans un réservoir de stockage le temps que les médecins clarifient ce qu'ils pouvaient légalement faire du sperme. Comme M. Blood n'avait pas consenti par écrit à la conservation et à l'utilisation de son sperme, il était interdit par les lois britanniques que les médecins, ou Mme Blood, gardent ou utilisent le sperme pour un traitement.

Mme Blood a été bouleversée d'apprendre que, selon la loi britannique, elle ne pouvait pas utiliser le sperme de son mari. Bien qu'elle et Stephen aient parlé d'avoir des enfants un jour, comme il n'y avait rien par écrit, elle ne pourrait jamais utiliser son sperme et ne pouvait espérer avoir un enfant ayant un lien

génétique avec son défunt mari.

Mme Blood a fini par demander une révision judiciaire de la loi lui interdisant d'utiliser le sperme de son mari. Cependant, sans le consentement écrit, la loi stipulait qu'elle ne pouvait pas avoir accès au sperme de son mari. Mme. Blood a présenté sa cause devant les tribunaux et a finalement été entendue par la cour d'appel de la cour supérieure de la Grande-Bretagne (Appeal Court of the High Court of Great Britain).

En fin de compte, la cour décida de maintenir la loi mais décida de lui permettre d'emporter le sperme de son mari à l'étranger pour l'utiliser dans un traitement.

Sondez :

- Dans quelle mesure le consentement est-il important? Devrait-on permettre des exceptions à la règle?
- Le consentement devrait-il être enchâssé dans la loi? Les médecins devraient-ils être punis s'ils ne respectent pas la loi? Et s'ils étaient mis en prison?
- Qu'en est-il des conséquences de l'utilisation du sperme ou des ovules de personnes décédées pour créer un embryon et peut-être même un enfant? Cela devrait-il être permis? Pourquoi? Pourquoi pas? D'après vous, comment réagirait un enfant en apprenant qu'un de ses parents était mort avant qu'il naisse? *(Marie, ne devrait-on pas dire «avant qu'il soit conçu?»)*

3. <u>La recherche sur les cellules souches ou le clonage thérapeutique</u>

Lisez le cas de la recherche sur les cellules souches ou le clonage thérapeutique :

Frank et Déborah suivaient le processus de fécondation in vitro dans une clinique de fertilité. Les scientifiques ont produit un certain nombre d'embryons. En fait, il y en avait tellement qu'ils en ont transféré trois dans l'utérus de Déborah et placé les autres dans un congélateur pour les préserver au cas où Déborah et Frank veuillent les utiliser plus tard.

Neuf mois plus tard, Déborah a donné naissance à des triplets. Décidant que leur famille était complète et qu'ils ne voudraient pas utiliser les embryons pour tenter d'avoir d'autres enfants, ils ont fait don des embryons à un laboratoire de recherche. Les scientifiques ont décidé d'utiliser certains des embryons de Déborah et Frank pour la recherche qu'ils faisaient sur les embryons et les cellules souches.

Les cellules souches embryonnaires sont les cellules maîtresses desquelles le foetus se développe. Elles peuvent produire n'importe quel type de cellule dans le corps, des cellules du cerveau à celles du foie. Ces cellules souches embryonnaires se développent peu après la conception et sont les cellules ancestrales de tous les tissus du corps, comme les muscles, les os, les nerfs et la peau.

Les chercheurs qui ont utilisé ces embryons ont présenté les résultats de leur recherche en novembre dernier. Ces recherches montraient que les cellules pouvaient être une source riche de nouveau tissus permettant de traiter des maladies où les cellules du cerveau sont détruites comme la maladie de Parkinson ou la maladie d'Alzheimer.

Après le prélèvement des cellules souches, les embryons ne peuvent pas être remis au congélateur et ne sont plus viables, c'est-à-dire qu'ils ne peuvent pas devenir humains. Cependant, les cellules peuvent être multipliées et utilisées pour toute une gamme d'utilités.

Sondez : Cela devrait-il être permis? Pourquoi? Pourquoi pas?
Sondez : Croyez-vous que de telles recherches devraient être permises avec ces embryons? Pourquoi? Pourquoi pas?
[Nous désirons savoir si les groupes de discussion amorceront une discussion sur l'éthique centrée sur cet enjeu - si possible, laissez-leur le temps d'étoffer]

IV. Discussion sur l'établissement d'une nouvelle législation pour les TRG (30 minutes)

Objectifs : Identifier ce qui sous-tend les opinions par rapport à l'établissement par le gouvernement du Canada d'une législation définissant un cadre de travail législatif complet et équilibré pour les TRG.

1. Dans quelle mesure est-il important pour vous que le gouvernement du Canada adopte une législation pour réglementer et superviser les techniques de reproduction et de génétique? Pourquoi pensez-vous que c'est important / que ce n'est pas important?

2. Si les autres pays ont des législations ou des directives gouvernementales dans ce domaine, dans quelle mesure croyez-vous qu'il soit important que le en Canada ait aussi?

3. D'après vous, les normes et les règlements devraient-ils toucher surtout la santé et la sécurité ou la législation devrait-elle également englober les questions morales?

Sondez :

- Sur quelles questions morales devrait-on s'attarder? Pourquoi?
- S'il y avait un organisme de conseil moral, qui devrait y participer? Les éthiciens? Les scientifiques? Des Canadiens ayant utilisé des traitements de fertilité? Des bureaucrates? Des praticiens?

V. Conclusion (10 minutes)

Sondez pour savoir quels sont les messages que les participants estiment être les plus importants en ce qui concerne la réglementation de ce domaine :

- Que la santé des Canadiens sera préservée en réglementant certaines pratiques et en en interdisant certaines autres;
- Que le matériel de reproduction humain, comme le sperme, les ovules et les embryons, sera traité avec respect;
- Que le bien-être de toutes les personnes, surtout des femmes utilisant ces techniques et des enfants nés suite à leur utilisation, sera respecté;
- Que certaines normes, morales et pratiques, seront établies et observées pour assurer une pratique sûre et une approche uniforme aux questions éthiques difficiles.

VI. Remerciez et terminez.