

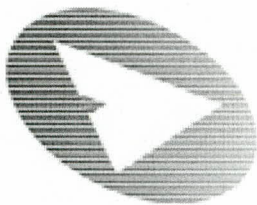
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A Canada - US Public Opinion Research Study on Emerging Technologies

Report of Findings

The Canadian Biotechnology Secretariat
Industry Canada

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Introduction

Decima is pleased to present this report on a public opinion research program conducted in March of 2005 for the Canadian Biotechnology Secretariat and an International team of experts that the secretariat that has come together in order to conduct a multi-national study of attitudes about emerging technologies.

This research involved a total of 24 focus groups, conducted in 10 cities across Canada and the United States, including:

- St Johns, Nfld
- Sherbrooke, Que
- Ottawa, On
- Toronto, On
- Calgary, Alta
- Edmonton, Alta
- Vancouver, BC
- San Francisco, Ca
- St. Louis, Mo
- Boston, Mass

The research was designed to accomplish several major objectives:

- To gather an understanding of familiarity with several emerging technologies, namely biotechnology, nanotechnology, pharmacogenetics, stem cell research, GM trees, gene banks and genetic research, in both Canada and the United States;
- To gather information on interest in and support for these emerging technologies;
- To gather information on concerns and considerations associated with these emerging technologies;
- To gather insights about what lessons from past experience with recent technologies can instruct about how authorities should consider other research;
- To gauge how important Canadians and Americans believe these technologies are for the future and the health of the economy and society;
- To explore Canadians' preferred content, sources, mediums for information on these technologies

Stem Cell Research

Awareness and Familiarity

There is widespread awareness of stem cell research among populations in both Canada and the United States. Familiarity might actually be higher in the US where a number of factors have pushed it in the national spotlight of late. Not only have people heard about stem cell research, in the US particularly, they have discussed it with others. Specifically, the US election campaign, and the efforts of Christopher Reeve and Michael J Fox to promote such research have given the issue a lot of profile. From a public opinion perspective, this makes it a unique and interesting area of emerging technology.

Owing to this profile, in the US, stem cell research has become the “poster child” of biotechnology, whereas in Canada stem cell research tends to be seen as just one of a range of associated areas of research and technological development that fall under the biotechnology umbrella.

Unlike other areas of technology discussed in these focus groups, the general public tend to hold similar levels of knowledge and interest in stem cell research as found among Involved Canadians/Americans. This is an issue that has saturated public opinion as much as any issue of new technology/innovation has that we have tested in recent years.

In general population groups, people reveal a fairly detailed knowledge about this technology and some of its side effects and implications. Overall, what this higher level of understanding appears to have done is bring clarity to peoples’ thoughts about the technology – people provide specific examples of how it might benefit society, and they go straight to the main concern about this technology, that being how stem cells are obtained. Particularly in the US, there is relatively little “waffling” over issues...people have thought about it and come to some conclusions. So when discussing the pros and cons of involvement with this technology, people were quite firm in their views, and quite clear in the rationale that underlaid these views.

This situation is an example that demonstrates how in the right media environment, the general population’s knowledge and understanding of an issue will “catch up” to where involved Canadians/Americans are. In some groups, people will go to great lengths describing minutiae about stem cell research, such as how certain state governments have passed bills allowing for funding of stem cell research, to ensure research continues in spite of the Bush decision.

Benefits of Stem Cell Research

Participants were widely of a view that there could be significant benefits that flow from stem cell research, and many understood why such benefits might be possible – that stem cells’ unique properties offer the potential for many more ways of developing treatments/cures for disease. Again, a very high number of people understood what stem cells are and what makes them unique.

Stem cell research came up on an unaided basis in almost every US focus group (and most Canadian groups) as an example of biotechnology. There is widespread awareness of stem cell research among the population in both Canada and the United States. Indeed, in general public groups (where there is generally less understanding of new technologies) participants knew an incredible amount about the technology and its potential.

In the US, stem cell research can be characterized as the current “poster child” of biotechnology, whereas in Canada stem cell research is seen as just one of a range of associated areas of research and technological development that fall under the biotechnology umbrella. The US election, Christopher Reeve and Michael J Fox issues have given the issue a lot of profile in the United States. However, whether that profile has been a positive or negative from the perspective of public attitudes is less certain. The section on stem cell research will illuminate this discussion.

In Canada, the main aspect of biotechnology that engenders concern is GM food. Overall attitudes toward GM food tend to be more negative than positive. The criticism derives from two areas of concern: the first is about the risks that might be involved in consuming these foods, and second revolves around the motivations and actions of producers of GM food. In almost every group, the Schmeiser case comes up as an example of what is wrong with GM food. In the United States, opinion is more mixed, with risks a definite concern but absent the overlay of “undue corporate influence” that is in evidence in Canada.

Main Findings

Awareness and Familiarity

The focus groups began with a broad discussion that revolved around the current and future impact of new technologies on society. Participants were invited to discuss their perceptions of the new technologies that were most likely to revolutionize our world or their own world, which then led to a discussion of a range of specific emerging technologies and perceptions that surround them.

The emerging technologies that were most consistently raised in open-ended discussions were computers and information technology (IT), Cell phones, Nanotechnology, Monitoring/military applications like retinal scanning and Biotechnology.

Of these, all were met with a high level of interest and enthusiasm, with the exception of cellular telephones. Unlike IT where people almost universally see it as “empowering” technology, cell phones appear to be more well-known for being an irritant than a benefit.

On an unaided basis, nanotechnology was raised as a “revolutionary” technology at least as often as biotechnology was, and people tended to be more favourably disposed to this area than biotechnology. On an unaided basis, most didn’t raise negatives about this type of technology. The main negative that is raised on an unaided basis regards the potential privacy implications of nanotechnology applications. This was of particular concern in the United States, where there were strong fears raised about the powers assigned to government under the US Patriot Act. Nanotechnology was viewed as a field that could be utilized for purposes under the Patriot act that the public had some significant concerns about.

Ultimately, the groups revealed that nanotechnology is positioned as the “next big thing” in terms of technology that is likely to affect our lives. Nanotech applications that were most often recalled were:

- The tiny ingestible camera
- Implantable devices to regulate things like insulin levels
- Implantable monitors that allow people to be tracked anywhere they go

Biotechnology was cited by a significant number of people as a revolutionary technology. Most people know what biotechnology involves, and tend to think of health and food applications, which generate a mix of benefits and risks.

The moderator's guide and methodology were developed through an extensive process of consultation with an international team of experts in the area of emerging technologies and their impact on society.

The work began on February 20 2005, and ended on March 31, 2005.

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However, to some extent, the bloom has to come off the rose on stem cell research, both in Canada and the US. Like many technologies, it was touted by the media as a revolutionary technology that would bring benefits immediately, and because there haven't been many demonstrable examples of applications as yet, people are beginning to raise questions about the extent to which benefits will be reaped from this area of inquiry. While those in the research and scientific community have generally been careful not to promise too much too soon with technologies like this, the media has clearly played a role in heightening public expectations about when benefits from this type of research would begin to flow.

However, this issue of "expectations" is important as a consideration because many feel that they have set aside what they view as significant ethical issues because of the promise that this field of inquiry might yield...in the absence of more tangible near term benefits questions around ethical issues could grow.

Risks of Stem Cell Research

In most groups, risks were not a major area of discussion or concern regarding stem cell research. People talked mostly about risks in the context of the individuals who might take these treatments that those people are taking risks by being treated with new technologies like stem cell research. For the most part, people generally felt this to be part of the natural process of scientific discovery and learning, and that people make the choice to take the risks.

The other aspect of "risk" that was raised regarded the potential for rogue elements of the scientific community taking research "too far", using stem cells for socially unacceptable purposes which they were not intended for. Among the general population groups (in both Canada and the US) this was a significant theme of concern.

Ethical Considerations

What was consistent across the groups was that concerns about stem cell research revolve almost entirely around ethical issues regarding how researchers get stem cells, rather than the research itself.

In particular, ethical concerns were found to be more pronounced in the US than in Canada, owing chiefly to the religious community and strong religious convictions in the US, leading to strong concerns about this kind of technology. The main issue revolved around whether conducting stem cell research amounted to ending a life or not, and whether it was morally acceptable or not to use stem cells from fetuses that were going to be discarded by fertility clinics.

In the US groups, people entered the discussion with clear and well considered views. There were long debates about whether embryos that are under 2 weeks old should be considered fetuses or not, with detailed scientific discussions about whether there is a heartbeat at that point or not. Ultimately, there was a segment of roughly one in four in the US groups, who were adamantly opposed to stem cell research on those grounds, and whose views did not move upon discussion.

While similar concerns were certainly in evidence within Canada, the level of adamant opposition was not nearly as high. Fewer people made specific reference to their religious views when discussing the issue, people were taking a more pragmatic view of the ethics of this kind of research or not. In a few groups, the ethical question was turned on its head, saying it is immoral to not conduct stem cell research because it could save lives

Some direct questions were asked about the decision by George Bush to ban federal funding for stem cell research. Overall, Canadians viewed that decision more cynically than Americans, believing that he did it for political and/or spurious reasons or based on poor information.

In the US, while a clear majority were against the decision, almost all respected Bush's right to make that decision.

Obtaining Stem Cells – Other Methods

In the discussions, two other methods of collecting stem cells for research were tabled with participants. The results were markedly different, and in one case, the implication was a marked difference in overall support for stem cell research.

Reaction to other methods of collecting and conducting research using stem cells:

- **Creating embryos in a lab for the purpose of extracting stem cells.** The creation of embryos in a lab to create stem cells is much **less** acceptable than the use of embryos from fertility clinics – consistent in both Canada and in the US. The primary reason was that in this case, the explicit purpose of the creation of life is to destroy it. In the case of taking stem cells from fertility clinics, the purpose is to “use it for research rather than destroying it”, which is seen to be less ethically problematic for people.
- **Extracting stem cells from umbilical cords post-birth.** The other scenario tested in the groups involved extracting stem cells are drawn from umbilical cords post-birth. This scenario proved to change the entire dynamic of the assessment significantly, particularly in Canadian groups but also in American groups. Most of those who disapproved of stem cell research initially changed to approving of such research in this scenario, as for them there was no longer an ethical concern involved (as long as the mother consented to her umbilical cord being used for research). While there remained a handful of people who remained opposed to the technology on ethical grounds (because stem cell research was too close to “playing god”), this was a very small number (under one in ten participants overall).

Regulatory Systems/Governance

The focus groups in both Canada and the US revealed that on stem cell research, as on other issues involving new technology, particularly those that have potential

implications for health or the environment, there is a growing sense that regulatory and governance systems are not all that stringent in their management of risks. \

The concerns were as follows:

- Confidence has been seriously undermined by the recent problems on pharmaceutical products, such as Celebrex and Vioxx. This growing lack of confidence is related to three issues, all of which were in evidence previously but now have a growing number of people concerned:
- Concerns that corporate interests influence the approval process, both in terms of speed and acceptability;
- Concerns that regulators do not necessarily have the skills or resources to adequately “keep up” with rapid advances in technology in areas like stem cell research (this concern was particularly evident in the Canadian groups);
- A general lack of knowledge about what systems govern these technologies, and how rigorous those systems are.

Combined, these factors led many people (in both Canada and the US) to come to a conclusion that regulatory systems governing technologies like stem cell research ought to be governed by tighter/stricter controls or regulations than are in place now. This is of course absent actual knowledge of what controls are in place now, but perceptions are that the systems aren’t all that stringent now, and given the revolutionary nature of some of these technologies more checks and balances ought to be put into the regulatory/oversight system.

When asked about how much trust they put into the scientists who carry out this research, the general view was that in the main, scientists involved in areas like stem cell research were very bright people whose primary interest is to develop technologies that can help people. The main concern revolved around “rogue elements” of the scientific community who might push technology faster than it should be pushed, and had to be closely monitored.

There was, however, a notable minority view (in both Canada and the US) that scientists are inherently amoral and must have clear ethical parameters placed around them to the greatest extent possible, in order to guard against broaches of the public interest.

That said, the consensus view in virtually every group was that people wanted their country to be a leader in stem cell research. The reasons why people came to this conclusion were as follows:

- People had a higher level of confidence in the scientists involved in doing research and the ethical systems governing research were likely better in their respective country than in other countries;
- That being a leader helps to ensure that each respective country has a “seat at the table” when decisions about what is acceptable and not acceptable are taken at an international level;

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- That there is an inevitability to these technologies that means others will pursue science in these ways, and it is better to have leaders in your own country that can be controlled than leaders in other countries that might be more difficult to control;
 - That there are important benefits to be gained from these technologies (health and economic) that make it worth being at the leading edge;

Ballot Question: Overall Approval/Disapproval

For each of the emerging technologies that were investigated in these groups, respondents were asked to place themselves on a continuum of approval or disapproval with that respective type of technology. People were asked to situate themselves in one of four categories:

- Disapprove of research and development of the technology under any circumstance
- Disapprove of research and development of the technology except under special circumstances
- Approve of research and development of the technology, but with tighter controls and regulations
- Approve of research and development of the technology with current levels of government regulation

In the case of stem cell research, two scenarios were tested, the first assuming that stem cells would be sourced from embryos which were from fertility clinics that were not going to be used in artificial insemination, the other assuming that stem cells would be sourced from umbilical cords.

The results indicate the following:

- Slightly fewer than seven in ten overall indicated that they approve of stem cell research under its current parameters (from fertility clinics) with either current or tighter regulations.
- There were some significant differences between Americans and Canadians on this question. Americans tended to be more likely to disapprove under any circumstance than Canadians, owing directly to religious considerations.
- About nine in ten overall say they approve of stem cell research in the scenario where stem cells are drawn from umbilical cords. The opinion dynamic is clearly altered in this scenario, where most people who disapproved of the technology in its current use move to some type of approval.

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- Most of the resistance to stem cell research dissipates when stem cells are taken from another source that does not require using an embryo to get stem cells.
 - Although the majority suggest they approve of the technology in both of these scenarios, in most cases they do so with the proviso that tighter regulations be placed on the field.
 - Discussion reveals that people default to establishing tighter regulations because they are increasingly concerned about the efficacy of the regulatory process (driven by the recent events involving the FDA, the potential influence of corporate interests, and concerns about the capabilities and resources assigned to regulatory authorities).

Overall, with the exception of a strong minority who voice ethical concerns about stem cell research, most people are supportive of this field of inquiry, even in its current (and more controversial) form. In future if there were ways of obtaining stem cells without involving the destruction of an embryo (such as through umbilical cords or adult stem cells), there would be broader, and deeper support for stem cell research.

However, irrespective how stem cells are obtained, there is a clear and far reaching demand for tighter controls/regulations over these areas of inquiry, and more specifically the products that derive from these areas of research.

Nanotechnology

On an unaided basis in the introduction to the focus group discussions, nanotechnology was frequently raised as a “revolutionary” technology, and people tended to be more favourably disposed to this area than biotechnology.

On an unaided basis, most didn't raise negatives about this type of technology. The main negative that is raised on an unaided basis regards potential privacy implications of nanotechnology applications. This was of particular concern in the United States, where there were strong fears raised about the powers assigned to government under the US Patriot Act. Nanotechnology was viewed as a field that could be utilized for purposes under the Patriot Act that made some respondents very uncomfortable.

Ultimately, the groups suggest that nanotechnology is positioned as the “next big thing” in terms of technology that is likely to affect our lives. Nanotechnology applications that were most often recalled were:

- The ingestible camera
- Implantable devices to regulate things like insulin levels
- Implantable monitors that allow people to be tracked anywhere they go
- Less invasive surgeries

Most understand that the technology involves “tiny machines”. Other than that, people don't necessarily know specifics about how this technology works, such as the fact that molecules at the atomic level have unique properties.

Most see nanotechnology as something that is very much here today, not science fiction, even if some of the applications seem like they were first identified in science fiction years ago. When people discuss applications like the ingestible camera or less invasive surgeries, they see these applications as being in current use, with more new technologies like them not far behind.

While some applications clearly pose more risks and more benefits than others, there wasn't the same variance in acceptability as found in various aspects of biotechnology.

A series of different applications were tested in the focus group discussions. The main focus of the assessment was a calculus of the risks versus the benefits associated with the technology. This approach is consistent with what is found in various areas of biotechnology, with the exception of the fact that ethical issues were rarely raised with regard to nanotechnology applications.

So even the case of nanomolecules in pants was seen as serving a useful purpose and was not seen as providing a significant risk, so most were accepting of the application.

Benefits of Nanotechnology

There were seen to be some fairly significant benefits that might flow from advances in nanotechnology. Like biotechnology, what was notable about these technologies was that people felt that the advances would not just be slightly better than technologies used today, but substantially better, taking a “giant step forward” in key areas that affect our lives, particularly:

- Health
- Environment
- Convenience/make life easier

This idea of significant “marginal benefit” over existing technologies was one of the most important elements of the assessment of nanotechnology. For example, the implantable device to regulate insulin or other key enzymes in the body was seen as so much better than existing technologies that the benefits would outweigh the risks.

Risks/Concerns associated with Nanotechnology

Nanotechnology is a topic where participants were most likely to raise environmental concerns, whether in regard to the nanomolecules in wrinkle resistant pants or to applications in industry.

- The question “where do these nanomolecules go” was the most pervasive question raised in regard to risks. People weren’t clear about what the environmental impacts of such technologies might be, how ecosystems might be affected by the introduction of new nanomolecules.
- Health concerns are obviously important as well but because most health related applications are seen as being driven by individual choice people tend to be less expressive of those concerns. In addition, as is the case with biotechnology, the benefits are seen as being so significant as compared to risks that taking those risks was seen as being acceptable.
- However, these questions about health and the environment often raised issues in discussion about regulatory systems governing nanotechnology. Some wondered whether certain applications are regulated at all, and in the absence of knowledge about how these systems work they tend to assume that there is little to no regulation, which exacerbates concerns.

Moral Issues

Most don't see there being strong moral considerations that are unique to nanotechnology, the moral issues involved tend to be about broader issues regarding access to new technologies.

People want to know whether these new technologies will be accessible to all or only to certain groups in society. But those moral issues are not any different for this area than for any other area of health treatment now, where some can afford certain products and others cannot.

Confidence in regulatory systems

As alluded to above, the most serious concern or issue associated with nanotechnology raised in the focus groups had to do with the stringency of regulatory processes associated with these technologies.

Overall confidence in regulatory systems as applied to nanotechnology was low to moderate in general, and among certain segments of the population, general public and females in particular, there were some significant concerns raised, on questions like:

- Questions about how different nanotechnology applications get regulatory approvals (or do not require regulatory approval).
- Recent problems for regulatory systems governing pharmaceutical products, such as Celebrex and Vioxx.
- Concerns that corporate interests influence the approval process, both in terms of speed and acceptability;
- Concerns that regulators do not necessarily have the skills or resources to adequately "keep up" with rapid advances in technology in areas like nanotechnology
- A general lack of knowledge about what systems govern these technologies, and how rigorous those systems are.

Trust in Scientists

In terms of trust/social distance from scientists, as found in other aspects of this research program, the majority express a high level of trust in scientists and scientific research to pursue goals that are of common cause to society. Those who express less trust and more social distance from those involved in science tended to be three segments of people.

Those who tend to be female, among the general public, who tend not necessarily to fear science or scientists writ large but fear the “rogue elements” of the scientific community who might take research “Too far”.

Those who are extremely fearful of the role of corporate interests influencing society in negative ways, producing products or applications that might not necessarily serve social needs as much as other things might (Viagra is the example often cited).

Those who hold very strong religious or moral convictions, who tend to believe that scientists are amoral and need to be given clear moral guidance by society and society’s leaders. This group was more likely to be found in US groups than Canadian groups.

World Leadership

Almost to a person in these groups, people felt that it is a good thing for Canada or the US to be a world leader in these technologies. Even those who expressed views that lean against the advance of these technologies felt that they wanted their country to be a world leader.

Among those who were broadly supportive of the technologies advancing, the benefits were seen to be personal (new applications and products they could use), as well as economic (providing new, highly paid jobs)

Among those who tended to express some resistance to the advance of nanotechnology, there was an equally strong sense that their respective country should be a world leader. While this might seem like a contradiction the technologies were going to advance, better for them to advance within the boundaries of their respective countries (Canada or the US), where they can be controlled.

Ballot Question: Overall Approval/Disapproval

For each of the emerging technologies that were investigated in these groups, respondents were asked to place themselves on a continuum of approval or disapproval with that respective type of technology. People were asked to situate themselves in one of four categories:

- Disapprove of research and development of the technology under any circumstance
- Disapprove of research and development of the technology except under special circumstances
- Approve of research and development of the technology, but with tighter controls and regulations

-
- Approve of research and development of the technology with current levels of government regulation

In the case of nanotechnology, the results indicate that:

- More than nine in ten overall indicated that they approve of nanotechnology, with a slight majority indicating the proviso that it be done under tighter controls and regulations. This level of approval is a reflection of a very strong, very widely held belief in the benefits of the technology, and the highest level of strong support among all of the emerging technologies investigated in this research.
- The main area of concern regarding nanotechnology regards the long-term environmental risks involved, and the ability of governance mechanisms to adequately assess and manage the risks. While many indicated that they would rather say they approve under current regulations, because they believe they want to gain the benefits earlier, ultimately people leaned toward tighter controls because of concerns that existing controls are not all that stringent.

Gene Banks

In both countries, and between both Involved Canadians/Americans and the general public, awareness of genetic health research and "Gene banks" specifically is relatively low.

Only a few individuals, mostly involved Canadians/Americans, have any awareness at all of this field of inquiry, and only a handful have been asked to contribute genetic information to a research database. In all of the (few) cases where people have been asked, it has been because they have been identified as having a predisposition to a particular disease or disorder.

Participants were asked to discuss whether they would be willing to contribute their genetic information to a research study in two different scenarios, one "prospective" in that the data would be collected at random and was not for one specific type of research (could be used for a range of research studies), and one "retrospective" in that the genetic information would be drawn from a tumour that had been removed previously.

In both cases people were told that they would be provided absolute anonymity and that a health research organization would be the organization that would approach them for their genetic information. The specifics of the two scenarios can be found in the attached moderator's guide.

In the first scenario, when asked whether they might contribute their genetic information to such a study, between seven and eight in ten said they would contribute, although there was some variation across cities (in San Francisco all said they would contribute, in St. Louis more than half said they would not). Overall, Involved Canadians/Americans tended to be more resistant than the general population to contribute.

Those who were willing to contribute indicated so for one main reason: that they believed genetic research would yield important breakthroughs in health treatment, and they understood that the only way that such breakthroughs could occur was if people were willing to contribute. It should be noted that people were absolutely adamant that the anonymity provisions would be airtight.

Those who were resistant to contribute:

- Were concerned about privacy implications of allowing their genetic information to be collected – specifically they were concerned about the potential of insurance companies to access this information.
- Were concerned that people might use the database to conduct research that they personally would not be supportive of.
- Did not like the idea of their genetic information creating negative implications (in areas like insurance) for their family and others with similar genetic composition in future, as organizations like insurance companies learn about genetic commonalities and implications, and begin to use that knowledge against people in future.

People who are close to research in some way (used to work in a lab, currently work at a university, etc.) tend to believe strongly in this kind of work, owing in significant part to awareness of specific work and breakthroughs that are occurring now, and the level of stringency that they believe ethics boards, etc. place on those who are involved in research.

There were usually only one of these people in each group, so this is not necessarily representative of a wide segment of the population. However, it does provide some important insight to the issues of social distance and trust raised in other parts of these groups. Specifically, those who are closest to the people and systems involved in these technologies have the highest level of trust in them.

In scenario 2 (the “retrospective” case), roughly nine in ten were willing to contribute their genetic information, a slightly greater willingness to contribute than in the first scenario. This was the case for a few reasons:

- If they had had a disease, they felt that they had to do more to help research on that disease;
- Because the database would only be for “one” type of research there was seen as being a greater sense of what the purpose of the genetic information might be utilized for.

The final set of questions in this segment of the focus groups took this case study of the “retrospective” example and asked about perceptions of consent. At issue is whether consent for this kind of research is implied when someone agrees to have surgery or whether people should have to be asked each time a DNA sample might be taken from a tumour for a genetic database.

The results were quite conclusive on this question.

First, although they did not know for sure most people felt that consent was probably implied when they agreed to surgery, assuming that language involving “research” was included under the consent agreement with the hospital/surgeon.

In future, the consensus preference was for consent to be made once, as part of the original consent form – people did not want to have researchers coming back to them over and over again to get approval. While it had not been made explicit in the past that this kind of genetic research might be done using their sample, there was enough broad support for this kind of research that people were prepared to accept that it be used, even if specific consent was not offered.

However, there was a strongly held view that going forward, there should be an explicit agreement about genetic research built into the consent form, that it is unreasonable to assume consent for genetic research based on the “catch-all” words that connote research in general that is currently in many of these forms.

Pharmacogenetics

Pharmacogenetics, or personalized medicine, was another of the emerging technologies that was investigated in focus groups.

As a point of departure, there was little to no awareness of the term pharmacogenetics, and only vague recollection of the term “personal medicine” among participants. When provided with a definition of the field, people indicated that in fact they did have a sense of what the topic might involve, or had heard about one or another type of treatment that was specially targeted to certain groups.

So for most people, pharmacogenetics was seen as a natural evolution of drug treatment, seen as an advance from the “blunt instrument” that is used now in having one drug (with one formula) for everyone. The main difference that people recognized was that there might be a genetic element to the research, with at first blush did not raise any concerns for people.

In current context where certain drugs have been pulled off the shelf because certain individuals were adversely affected this was seen as a technology that might alleviate these kinds of problems.

When asked about the “personalizing” of drug treatment, people were not necessarily opposed to the use of technology for these purposes, but they had difficulty seeing how the personalizing would work from a practical perspective, because they perceived that the personalization would be extremely expensive.

The main concern about this area regards funding, whether some areas of pharmacogenetics will get more funding than others, and some of that might have ethnic or racial implications. However, it was clear from the discussion that people didn’t see that there was a fundamental difference on this question of directing funding toward some and away from others that is unique to pharmacogenetics. In other words, the issue is something that is intrinsic to research in general and not specific to this area.

- HIV/AIDS was mentioned by a few people as an example of a disease that mobilized support and received (what some felt was) disproportionate levels of funding compared to diseases like cancer in the 80s and 90s.

Moreover, it was assumed that individuals involved in contributing their genetic information to studies like this would have to consent to their information being used in this way, so if people had concerns about such issues they could opt not to allow their genetic information to be used. So overall there was no significant concern (moral or otherwise) that pharmacogenetics raised in the groups.

Indeed, for the most part, people were quite supportive of technologies associated with pharmacogenetics, for the reason that technologies like this are seen as advances, taking current treatments and making them better for those who need them.

GM Trees

GM trees were another emerging technology that was raised for discussion in the focus groups (in Canada only). In fact there were two related areas of tree or forest technology discussed in these groups:

- Genetic modification of trees
- Genetic identification and selection of trees

Like a number of other emerging technologies discussed in the groups, very few had heard of GM trees. Is not one of the areas of biotechnology that has generated much if any awareness among the population.

Even among involved Canadians, awareness levels on GM trees were low, although they were quickly able to make reference to other things they know about forestry and biotechnology to offer thoughtful views on the issues.

First off, a majority of people believe genetic modification of trees is fundamentally different from genetic selection and identification of trees. While some see them as being just two different ways of getting to the same result, most don't think so. This mix of views is true among involved Canadians as well as the general public.

The two areas are seen as being different because:

- Genetic modification is a much more precise process;
- Genetic modification is a much faster process, and that speed doesn't allow for appropriate levels of evaluation to occur;
- Genetic selection and identification is more "natural" in that what occurs "could happen in nature", whereas genetic modification involves applications that would never happen in nature, particularly the introduction of non-species genes;
- People have greater concerns about risks, specifically long term environmental risks, associated with genetic modification – people use Australia example of invasive/non-native species being introduced to an ecosystem that is not prepared to deal with it, the result being very significant for the environment;
- Genetic identification and selection is seen as being consistent with historical practice in agriculture, so it isn't seen as being so far from what is already done in other related areas.

As a result, most express less trepidation about genetic identification and selection than genetic modification, see it as a natural extension of what we have done with crops for centuries...the words people use to describe the differences are "natural, more passive". That isn't to say that there is no risk assigned to genetic identification and selection, but that risk is seen as lower in this area than in the area of genetic modification.

However, there is one major area of concern that is common to both genetic modification and genetic identification and selection.

- Monoculture. To some this is the most important and most disconcerting potential aspect of these technologies. Specifically, a number of people, particularly involved Canadians, asked whether considerations associated with ensuring forests are not monoculturally reforested have to be taken into account by those involved in conducting and regulating such research in future.

Benefits

Most of the benefits from this type of research were seen as economic benefits, ie. accruing to companies rather than to individuals. While important to the Canadian economy, these benefits were not seen as being as significant as benefits that might flow from an area like stem cell research.

Some see very important benefits in remedying things that are causing problems in forestry, like dutch elm which is an invasive disease, or the pine beetle which is ravaging forests in BC.

Risks

The major risks associated with this field of inquiry are unknown, long-term risks to the environment, and the ecosystem, from creating new species that people do not know how it will impact the environment.

Moreover, risks were seen as being very significant if technologies like these lead to a monoculture in forestry, which was seen as a significant problem

Ethical Issues

The focus groups did not reveal significant moral issues associated with GM trees. One or two respondents indicated that there was an ethical issue involved in taking unnecessary risks in an area where the benefits might not outweigh the risks, but there was not a clear ethical question raised about research and development in this area per se.

Applications

A series of applications in the area of GM trees were tested in the groups. Participants offered consistent perspectives on GM forestry applications. In a nutshell, the purpose of the application is as important as the process itself, and that has a notable influence on the extent to which each application is seen as acceptable or unacceptable.

Trees modified to take on greater amounts of Carbon

- Split opinion on this application, as much opposition as support overall

-
- Some felt that this would be a useful way of helping to address a serious problem that faces Canada (climate change).
 - But many don't feel this is an appropriate use of science, because it represents a band-aid to a problem that was created by humans.
 - Others wondered what happens in terms of long term impacts - if the tree does take on the carbon whether the composition of gases in the atmosphere is affected in a negative way, and whether that would be appropriate.

Development of fast-growth trees

- More support than opposition to this application, by a small margin
- When clearly and explicitly geared toward an economic benefit like this, there was surprisingly high levels of support – there was seen as a clear and natural rationale to investigate the possibilities in this area
- People appeared to be picturing forest plantations when discussing this application, seemed more accepting of the idea
- A number of people felt that if such technologies were developed, it might help take the pressure off natural forests
- If private money involved, and controls in place, the application was seen as being acceptable

Development of trees to resist certain types of diseases/pests

- Applications developed to address these kinds of applications were seen as being more acceptable than unacceptable, also by a narrow margin.
- Support for these technologies rested on the idea that the diseases and pests that are infesting these trees are often times invasive themselves, and there is therefore a rationale for science to take steps to address that imbalance in nature
- Concerns are similar to those associated with other applications that making such a change might make the ecosystem more unbalanced.

Regulatory System

Attitudes about the regulatory system and the scientists involved in the regulatory system are generally mixed, and not all that favourable among a fairly significant number of respondents. Most did not know what bodies might be involved in oversight, which had a significant influence over perceptions.

- Consistent with what has been heard in other areas of new technology, in the absence of information more people are defaulting to a greater sense of laxity than stringency in regulatory systems. Most

don't know who would play this role in forestry, they don't think of forestry in the same way as they think of health products for example.

Indeed the subtext to the discussion of specific applications above, there was a broadly held sense that regulatory and oversight mechanisms will have to be appropriately thorough, much more thorough than they are perceived to be now in order to inspire enough confidence to engender broad public support.

Scientists

As was the case in other areas of emerging technology, generally there was a fair degree of trust in scientists in this area. Consistent with other areas most scientists are trusted but the real concern is about "rogue" elements, the <5% who may "take things too far" or be influenced by money to do things contrary to the public interest.

There was definitely more trust placed in scientists that are doing the research and developing the products than those that are involved in the regulatory system, mostly because they perceive that the capacity of those involved in research is much greater.

World leadership

In spite of evident concerns about key aspects of this technology, most want Canada to be a world leader in this area, because:

- Canada is hugely dependent on forestry, Canada needs to be at the leading edge because others will be there and can't afford to fall behind other countries in this area.
- As in other areas, there is a belief that if a country is in a leadership position, being in that position allows for greater influence on the ways in which regulatory, governance, and oversight processes are established (internationally). While most would want systems in Canada to be better than they are they generally believe that Canada's systems (or systems they would create) would be built in consideration of safety and other considerations to a greater extent than most other countries

Ballot Question: Approve or Disapprove

On our ballot questions, a majority (roughly three in five) were of the view that the technologies are acceptable, but want there to be tighter controls on their development than they believe are in place now. About one in four would say they are unacceptable except under special circumstances, and a handful would say they are acceptable under current controls and regulations.

For genetic identification and selection, people tend to be more accepting and supportive of this type of research and application of technology. In this case, a majority (roughly three in four) are of the view that the technologies are acceptable, but again want tighter controls on their development than they believe are in place now. About one in four would say they are acceptable with

tighter controls, and only a handful would say they are unacceptable except under special circumstances.

Those who say unacceptable except under certain circumstances say so:

- Because they don't see that there is a clear enough purpose or benefit to warrant taking the risk in this area

Those who say acceptable but with tighter controls say so:

- Because they can see that there could be some potential benefits in this area, that we should be a world leader in this research (because forestry is important to our economy), but they fear that there aren't enough stringent regulations in place for a field like this in order to have appropriate comfort.

Those who say acceptable under current controls say so:

- Because they believe that these applications could provide benefits, and don't want to place too many controls on those doing research.

Overall there is fairly broad but not very deep support for forestry applications of biotechnology. People who are supportive in general are so mostly because they believe in scientific endeavour and believe that such endeavour will lead to benefits.

However, most don't see the benefits of these technologies accruing to themselves personally. This, coupled with concerns about the environmental risks of developing these kinds of applications, and a perceived laxity in the governance/regulation of such technologies, particularly those that involve genetic modification, there tends to be a fair number of people who suggest that these technologies be limited, and among those who are supportive, only a relatively mild level of support, unlike other areas of biotechnology where the pockets of support are much stronger in their beliefs.

If applications in forestry that involved genetic identification and selection were the main focus of research and commercial activity, overall public comfort would likely be much higher than with GM applications. This fact owes in significant part to the notion that this kind of research is seen as an extension of what has been done with crops for centuries and that the process would not move quite as fast as with GM, giving people more comfort that environmental safety would be carefully managed.

Bioethics

Most participants were revealed to possess little to no knowledge of ethical systems in place to govern research and applications in biotechnology in Canada. Involved Canadians were more likely to offer some knowledge of ethical systems than the general public, but even among this segment of the population, no more than about one in four could offer a view about ethical systems and frameworks in place in Canada.

Those who were able to offer a view generally believe there are some systems in place at the level of hospitals and university research institutions, and probably some laws in place nationally, but their instinct is that systems in place aren't all that comprehensive overall.

As unaided discussion ensued, people tended to offer a view that publicly funded research is probably relatively well governed from an ethical perspective. However, people raised strong questions about the extent to which private sector research is governed (or not) by ethical systems. In this sphere, the expectation is that some companies may have some systems in place but most probably not, and even those that do probably have made them so broad that virtually anything could be interpreted as fitting under those guidelines.

Confidence in Ethical Systems

Participants were asked to comment on the level of confidence they assign to the three main tiers of ethical governance – ethics boards, government, and international institutions. The results were as follows:

- Research institutions were assigned the highest level of confidence among the three “tiers”. Most felt that the closer that such bodies were to the actual research, the more able they would be to play an effective oversight role. Moreover, in a number of the groups, there were individuals present who had firsthand knowledge of research ethics boards, and to a person these people offered very strong views that these bodies were very stringent and their role was able to closely govern research that fell under their mandate.
- Participants expressed modest levels of confidence in the federal government. Some don't believe governments can appropriately play a role in ethics, for a number of reasons.
 - First and foremost, governments could only realistically govern ethics at the most general level, on issues where there was extremely broad public consensus, such as banning cloning, but that it could not (and many said should not) impose its view of ethics on society.
 - Second, people were concerned that politics may enter the arena of ethical governance, which would be inappropriate at best, and dangerous for society at worst. Overall, the discussions revealed a deep-seated cynicism about

government, and this strongly skewed people's belief that governments could play a constructive role in this field.

- At the international level, there was little to no confidence at all in the ability of institutions like the UN or WHO playing a constructive role in the ethical arena. While many wished or hoped that these bodies could play a stronger role, most did not believe it was realistic, or even possible, for a number of reasons:
 - That cultural differences between countries would make it difficult, if not impossible, even to establish broad principles in this area
 - Most don't think it could have any teeth, and could not have any elements that would be enforceable on signatory countries
 - That whatever might be agreed to would have to be watered down to such an extent to get buy in that it would be meaningless in practice.

When the current system of ethical governance was outlined, generally people tended to have slightly higher levels of confidence that systems are in place than they had previously.

- While there was a sense that systems were obviously not aligned under one institution and not perfect, that there were enough different mechanisms in place that most issues should be addressed.
- The most prevalent concern raised in the groups about the system as it currently stands regarded privately funded research, the idea that those initiatives don't involve ethics boards was seen as revealing a gap in the system – this was exacerbated by concerns that private interests could do things that might bend (or even break) the laws involved but it would be difficult if not impossible to monitor these activities to ensure ethical norms were being followed.
- Many were concerned about enforcement of the rules, believed that people could probably fairly easily get around the rules and laws in place now – that was the area where people felt that more stringency could be added

Roles and Responsibilities in Future

By and large people felt that the right players are taking on the right roles now, and that if there were mechanisms to cover the private sector research (in guidelines as well as enforcement mechanisms) there would be more comfort with the system as it currently stands.

Two documents that outline ethical guidelines and systems were tested in the groups, both of which met with lukewarm reactions.

- The UNESCO agreement and principles were seen as being very general, very “motherhood”, not all that helpful because they are seen

as being at too high a level to be meaningful, and because signatories had no effective accountability to such guidelines.

- The tri-council statement was similar, most felt principles were filled with “motherhood” statements, which were likely not all that useful in practice. Indeed, after reading the tri-council statement, some began to lose faith in the effectiveness of ethics boards, fearing that using those guidelines they would end up “rubber stamping” virtually all of the proposals that were put forth.

Discussions then pursued the idea of an enhanced federal role in the area of bioethics, and what some of the elements of such a role might be.

On an unaided basis, there was not a clear demand for a greater federal role in this area. When probed further, a clear majority were reluctant to assign more responsibility to government, again owing to deep-seated cynicism about government as well as questions about what kinds of specific rules might be put into practice, and whether they would be done in the public interest. Upon discussion, there was not outright aversion to certain kinds of roles, but people didn't embrace those roles, rather they indicated that they might be willing to consider them if designed in an appropriate fashion.

Some of the concerns raised about an enhanced federal role were:

- That politicians will influence decisions, and are not appropriate to
- That public servants are not appropriate to trust with topics like this
- That it will likely be very costly to taxpayers with little benefit
- There was a very deeply resounding sense of cynicism about politics and the role of government in general
- There were fears that creating another level of bureaucracy in the realm of ethics, particularly one that involved government, could easily get bogged down and inhibit progress in some promising areas of research

A number of specific operational and organizational elements of an enhanced government role were tabled for discussion. Reactions to these ideas were as follows:

- *Create a law that indicates that public servants must always integrate ethical considerations into any public policy decision about biotechnology*
 - This proposal garnered little to no interest. The position was seen as too strong, too “big brother” in character, and people were reluctant to having public servants playing such a “gatekeeper” role.
- *Have a body as an advisory mechanism (like a watchdog) to raise any ethical issues about public policy to political leaders*

-
- This idea was found to have some merit, but people were more comfortable with the idea of a body reporting to the public than to political leaders
 - *Have an advisory body it as a mechanism to take issues on board and provide guidance to political leaders about how to address issues*
 - Like the last proposal, people expressed resistance to the idea of such a body reporting to government

In terms of representation:

- *Have public servants play this role, as a group or individually*
- *Have experts along with public servants who are involved in policy making about biotechnology play this role*
- *Have lay people as well as experts and public servants involved*

While there was no absolute consensus on the “representation” questions, most were of a view that there should be a majority of experts involved in a body like this, with minority representation from lay people and public servants.

Finally, respondents were given a hand-out that outlined some of the efforts made in other countries to establish ethical systems at a national level, and were asked to react to the idea of Canada having a similar type of mechanism, and if so, what elements were seen as having the most appeal. No single model was seen as having all of the ideal aspects, but elements that were most appealing included:

- The idea of the body reporting to the public, not to politicians
- The idea of the body not being appointed by political leaders, or at least not having any political dimension involved in the appointment process
- The idea that such a body would have fewer than 20 representatives
- The body playing a watchdog role, particularly for practices in the private sector

Overall, participants expressed a strong belief that ethical considerations need to be taken into greater account as genetic technologies and applications advance. While most have a moderate to high level of confidence that the combination of ethics boards and national laws should appropriately address the issues for research that is publicly funded, the real area of concern going forward is private sector research. Although this is an area of some concern, people remain cautious and uncertain about appropriate remedial action. While some would like to see an arms length body of government play a stronger role, others express a fairly high degree of reluctance to consent to the establishment of such a mechanism. If a body were proposed that had a number the preferred features outlined above, it is possible that people might have a favourable reaction, but the mechanism would have to be designed in a set of very specific ways in order to be widely viewed as a useful step.

Information Consumption

Most Canadians, both those in the general population as well as Involved Canadians, are interested but not all that actively engaged in seeking information on emerging technologies.

Certainly people do come across information on these topics in their daily lives, and many will take the time to read something they come across (particularly involved Canadians), but for the most part people don't actively seek out information on these technologies.

The internet is by far the main source of information, websites are the preferred means of collecting information.

The groups of people that tend to seek out information on their own on these technologies are:

- People that have a very strong scientific bent, people who subscribe to magazines like popular science (probably 1-2 out of 10 participants)
- Those who have a personal interest in a particular technology, usually regarding a health treatment for themselves or someone they know
- Those who express the strongest concerns about new technologies, and to seek out information in future.

Among those who have not sought out information, a lack of a reason to do so and time as reasons for not seeking information.

Importantly, those who express the strongest concerns about biotechnology are more likely than average to seek out information going forward.

Canadians also strongly expressed an interest in getting balanced information on the subject. They very strongly expressed an interest in hearing about both the risks and benefits of biotechnology. This is especially true of the group that expressed concern about the technology - it is clear from the data overall that this segment is very focused on finding and using balanced information on the topic.

Trust and Credibility

This part of the focus groups tested the trust and credibility of various players or institutions that might express opinions about emerging technologies, including, but not exclusive to:

- Political leaders
- Religious leaders
- Environmental groups
- Scientists (who work at universities)
- Health Canada/Environment Canada
- The world health organization
- Scientific journals
- Scientific magazines

While some of these organizations/individuals/outlets are more trusted than others, there is a broadly held belief that no single source of information can be trusted on these technologies.

- Because none has a monopoly of knowledge/information in an area like this
- Because financial interests can play a role in influencing what people might say, and that raises questions about even the most seemingly credible source
- Because some who can have authority may not have all that much knowledge

In Canada, the most trusted sources of information are:

- Scientific magazines and journals
- Scientists (university scientists)
- Media, public servants, environmental groups all seen as having very modest levels of credibility
- Companies, politicians were seen as having little to no credibility

In the US, the results were very consistent, with one notable exception:

- PBS was placed above all other media outlets as a trusted source of information on issues and technologies like these. Of note, CBC was not differentiated from the private networks in Canada in the same way as PBS was in the United States

Bioportal

In four of the focus groups, respondents were shown a new website established to provide a single “portal” of information about biotechnology and other emerging technologies for the government of Canada, combining the materials produced by the 12 different federal departments and agencies with a stake in biotechnology.

Overall reaction was broadly positive, with a few individual exceptions. The site was seen as being demonstrably better than other government websites that most participants recalled visiting in the past. Most would characterize it as “a step in the right direction” as it currently stands, probably a “B+” in letter grade terms.

- Involved Canadians were the most favourable toward the website. Those with the most interest in these issues and greatest likelihood to visit the bioportal were found among the involved Canadians.
- Some, particularly those who most cynical toward government in general, were not all that favourable toward the website.
- The site was seen by most as being usefully informative about general information regarding biotechnology, and being reasonably balanced in nature, although there were some who strongly felt that there was “bias” on the site toward support for the technology.
- People were quite impressed by the overall look of the site. While it still fit within the bounds of “government”, it was seen as having a more modern, clean look to it than most other government sites that respondents had visited.

Parts of the website that were most appealing:

- The section on “biobasics”, where some of the issues and definitions are outlined;
- The section on “bioregulations”, where people can explore the kinds of regulatory systems that govern this field of endeavour;
- The section on health applications, where people can see how biotechnology research might aid in treatment of a wide range of diseases and disorders, and the state of play of research in each disease area.

Areas which were felt needed additions or improvement:

- More information about the regulatory processes governing different technologies. People felt that they were not told enough about what these processes involve, who is involved in conducting the research, how it gets reported and how long the process takes from time of initial submission to final approval.

-
- What kinds of efforts are being made to study long-term impacts of these technologies. While the site does mention concerns raised about applications of biotechnology, in some key areas, like novel foods, nothing is mentioned about what efforts are being taken to monitor these issues over the long term. This ends up exacerbating concerns about the technologies, both because some hadn't thought about all of the concerns raised, but also because nothing is written to answer the obvious questions raised by those concerns. From these groups, the question that was left unanswered in the novel food section was "so what is being done to deal with these potential concerns?"
 - The actual studies and research data utilized to determine whether a specific product or application is truly safe. Some people, particularly those most predisposed to seeking out further information, were looking for these actual studies, so they could do their own assessment of the validity of the research and the findings. Ultimately few if any will actually wish to review results of some of these studies, but there is an expectation of transparency for a site like this, which requires those involved in creating it to go as far as possible.
 - More "hyperlinks" between keywords and further information. Some words had hyperlinks, while others did not, and it was felt that a lot more could be linked to further information.
 - More access to websites of organizations with an interest in biotechnology. The bibliographies that were on the site were useful, but respondents noticed that most of them were sites of other governments or international organizations, not stakeholder groups which people would like to be able to go to gather various points of view.

The group of people who indicated that they would be most likely to seek out information on emerging technologies going forward tend to hold a common set of views and sentiments, which has important implications for the design of a website like this.

- They tend to be involved Canadians
- They tend to be more skeptical than average about the technologies involved
- They tend to have an interest in scientific issues, and higher than average capacity of understanding detailed scientific information

Therefore ultimately, with a site like this, it is this core group of interested people that the site has to satisfy, and that means the inclusion of a lot more information than would necessarily be demanded by the average person. So practically speaking, the site needs to:

- Be very focused on providing a sense of balance in its language and tone
- Go as far as possible to make detailed information available, specifically the actual studies submitted/and approvals done to prove the safety of biotechnology applications

-
- Allow people to link to a wide range of information within and without the site

Based on the needs of the average person, with a few improvements in terms of additional information or better internal links, the site as it currently stands likely serves the necessary purposes.

However, based on the needs of the average person who might visit this site, more elements would be ideally added to the site, in each of the three areas listed above.

APPENDIX

International Biotechnology Research Focus Group Moderator's Guide

Warm-up

The moderator will take a few minutes to go around the table and ask respondents to introduce themselves, and outline a few ground rules: want to ensure that people share their views openly, let everyone participate, want people to talk about their views, not "other people's views", ensure that we don't want people to "debate" each other – everyone's views are valid, there are no right or wrong answers.

The moderator will also point out that there is a one-way mirror, observers in the back, and audio and video taping, but ensure that all discussion is confidential.

Introduction

1. Tonight we are going to talk about new technologies. What are some of the newest technologies that are changing our world, the things we do, the treatments for our health, the products we use?

2. Have you heard of the word biotechnology? *3b*

3. What does it mean? What does it encompass? *3a*

4. Is it a subject you know a lot about, a little about, or not much about?

Definition: Biotechnology is a term that encompasses a broad spectrum of scientific applications used in many sectors, such as health, natural resources, and agriculture. It involves the use of living organisms, or parts of living organisms, to provide new methods of production and make new products. Related to biotechnology are the areas of life sciences, genetic modification and genomics.

5. Biotechnology has applications in a number of fields. Can you recall any that you have heard of? *5a*

6. Have you heard of the word nanotechnology? What does it mean? What does it encompass? *6b*

7. Is it a subject you know a lot about, a little about, or not much about? *6c*

Tonight we are going to discuss a number of specific aspects of these emerging technologies.

For Final 2 nights of groups only:

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- 7b. Have you sought out information on biotech issues in the past?
- 7c. Where did you seek it from?
- 7d. (If yes) What did you seek it out for? Did you find what you need?
- 7e. (If no) Why not? (Probe: never occurred to them/nowhere to go/barriers/nobody credible)

GM Trees

I'd like to talk about an area of biotechnology you may or may not have heard of, genetically modified trees.

Biotechnology applications are being explored in forestry:

- To improve forest regeneration and protection
- Create value added forest products

Some of these applications involve the genetic modification of trees, where single genes are inserted or modified to obtain desired traits such as improved growth or disease tolerance.

Other applications involve genetic selection, where trees that have certain traits are identified, selected and reproduced using conventional breeding techniques.

Work in this area remains at the early research stage, no such applications have been approved for use in Canada at this time. Do you have any familiarity with this area of work?

9. In your view, what are the differences between these?

Would you say you are very, somewhat, not very or not at all familiar with genetic modification of trees? Would you say you are very, somewhat, not very or not at all familiar with genetic identification and selection?

There are numerous ways in which genetic modification of trees or genetic identification and selection of trees with certain traits can be used. Please tell me if you strongly agree, agree, disagree or strongly disagree with the following potential applications of these technologies. (Test both the gm and the genetic identification and selection of these applications)

- 11. The development of trees to take on larger than normal amounts of carbon, which may help to reduce greenhouse gases

Decima Research Inc.

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8ab

10ab

Q
stem
for
11-14

5ab

6a→c

7a→h

marginal

different
groups

- 12 • The development of trees to grow faster than other trees, so they can be harvested more quickly
- 13 • The development of trees to resist certain types of diseases, such as Dutch elm disease
- 14 • The development of trees to resist certain types of insects, such as the spruce budworm or the mountain pine beetle

(Test the GM as well as the Genetic Identification and selection applications for each of these questions)

I would like to understand the extent to which you think GM trees might benefit our society. What are the benefits of this kind of research?

And what do you see as the major risks involved?

In terms of the moral or ethical aspect of this research, what are your views? Do your moral concerns lead you to believe we should not go forward in this area of technology?

How confident would you say you are in the safety and regulatory approval systems governing these technologies in Canada? Why do you say that?

And what about in terms of the scientists who are involved in research of these technologies? How confident would you say you are that these applications are in safe hands? Why do you say that?

Would you say it is a good thing or a bad thing for (Canada/the US) to be a world leader in research in this area?

And would you say it is a good thing or a bad thing for the government of (Canada/the US) to be involved in supporting this type of research?

Overall, which of the following best captures your views about GM trees? (Hand-out)

- I approve the use of GM trees, as long as the usual levels of government regulation and control are in place
- I approve of GM trees if it is more tightly controlled and regulated
- I do not approve of GM trees except under very special circumstances
- I do not approve of GM trees under any circumstances

Each respondent will be asked to provide their answer to the above question, and to engage in a discussion about why they feel as they do.

Overall, which of the following best captures your views about genetic identification and selection of trees?

- I approve of this practice, as long as the usual levels of government regulation and control are in place
- I approve of this practice, if it is more tightly controlled and regulated
- I do not approve of this practice, except under very special circumstances
- I do not approve of this practice under any circumstances

Overall, what are the main differences/similarities that you see between these areas? Are you more/less likely to be comfortable with research and applications developed in one of these but not the other?

Stem Cell Research

I would like to talk to you for a few minutes about stem cell research.

Have you heard of stem cell research? What do you know about it?

Can you think of any specific applications of stem cell research you have heard of?

Have you heard much lately?

Before this interview, had you ever discussed stem cell research with anyone? What was the specific topic of that/those discussions?

Stem cell research involves the use of special human cells to study diseases and their cures. Stem cells have the unique ability to grow into any type of cell in the human body. Stem cell research has led to breakthroughs in our understanding of diabetes, MS, and Parkinson's disease that offer the potential for new treatments and cures. However, to conduct this research, scientists have to get stem cells. The most common method of getting stem cells is to obtain them from human embryos that are less than 2 weeks old and have been frozen and stored in fertility clinics. The process of getting stem cells destroys the embryos. However, these embryos are only be used for research if they are not going to be used for fertility treatments. I would like to understand the extent to which you think stem cell research might benefit our society. What are the benefits of this kind of research?

And what do you see as the major risks involved?

31 In terms of the moral or ethical aspect of this research, what are your views?

32a → C Have your read or heard anything about the decision of the current US president about stem cell research? What did you hear? How do you feel about that? 32c

33a → Some people say that President Bush made the right decision when he banned federal funding for "new" stem cell research, that is beyond those stem cell lines that had already been identified and in use. Others say that he didn't make the right decision. What do you think? Why do you feel this way? 33a 33b

34 In terms of obtaining stem cells, there are actually two different ways to get them right now.. I would like to get your reaction to these two approaches, in order to understand which one is of greater or lesser (or equal) concern to you.

- Using embryos frozen in fertility clinics that will not be used in fertilization
- Creating embryos in a lab, which are used only for stem cells, with no intent of creating life.

35 How confident would you say you are in the safety and regulatory approval systems governing stem cell research in Canada?

36a → And what about in terms of the scientists who are involved in research of these technologies? How confident would you say you are that stem cell research is in safe hands? 36b

37 How do you compare the confidence you have in these two groups of organizations/scientists?

38 Would you say it is a good thing or a bad thing for (Canada/the US) to be a world leader in research into stem cell research applications?

39 And would you say it is a good thing or a bad thing for the government of (Canada/the US) to be involved in supporting this type of research?

40a Overall, which of the following best captures your views about stem cell research? (Hand-out)

- I approve the use of stem cell research, as long as the usual levels of government regulation and control are in place
- I approve of stem cell research if it is more tightly controlled and regulated
- I do not approve of stem cell research except under very special circumstances
- I do not approve of stem cell research under any circumstances

Discuss probe
for 40a

Each respondent will be asked to provide their answer to the above question, and to engage in a detailed discussion about why they feel as they do.

Now I would like to ask you the same question under a different scenario. Suppose scientists were able to get all the stem cells they need for research from umbilical cords and no longer had to get them from embryos that were not going to be used in fertility treatments. While not available now, research is evolving that may make it possible to use blood cells from umbilical cords for what is referred to as "cellular therapy". Which of the following would best capture your view about this type of stem cell research?

41a

41a → 41b

Overall, which of the following best captures your views about stem cell research?

- I approve the use of stem cell research, as long as the usual levels of government regulation and control are in place
- I approve of stem cell research if it is more tightly controlled and regulated
- I do not approve of stem cell research except under very special circumstances
- I do not approve of stem cell research under any circumstances

Each respondent will be asked to provide their answer to the above question, and to engage in a detailed discussion about why they feel as they do.

41c (discuss probe)

Pharmacogenetics/Personalized Medicine

42a → I would like to talk to you for a few minutes about a topic called pharmacogenetics, which is often referred to as personalized medicine.

42ab

42b → Have you heard of personalized medicine as it relates to biotechnology? What do you know about it? 42a

This kind of technology is evolving in a couple of different ways,

Personalized medicine, or pharmacogenetics, involves the study of how the genetic make-up of a group of people who are similar such as an ethnic group affects responses to drug treatments. It involves the development of drugs based on a group's genetic profile. Understanding the genetic profile of groups of people is thought by many scientific researchers to be a key to creating more tailored drugs with greater effectiveness.

Common info.

43a

43ab

43a
confirmed

Common info

The next "wave" of this technology involves the study of how an individual's genetic makeup affects the body's response to drug treatments. It involves the development of drugs based on an individual's genetic profile. Understanding an individual's genetic makeup is thought by many scientific researchers to be the key to creating personalized drugs with greater effectiveness.

43b Would you say you are very, somewhat, not very or not at all familiar with personalized medicine involving genetics?

44ab Before this discussion, had you ever discussed personalized medicine with anyone? What was the specific topic of that/those discussions?

45 I would like to understand the extent to which you think personalized medicine might benefit our society. What are the benefits of this kind of research?

46 And what do you see as the major risks involved?

47ab In terms of the moral or ethical aspect of this research, what are your views? Do your moral concerns lead you to believe we should not go forward in this area of technology?

48ab How confident would you say you are in the safety and regulatory approval systems governing personalized medicine in Canada? Why do you say that?

49abc And what about in terms of the scientists who are involved in research of these technologies? How confident would you say you are that personalized medicine is in safe hands? Why do you say that?

50 Would you say it is a good thing or a bad thing for (Canada/the US) to be a world leader in research into personalized medicine applications?

51 And would you say it is a good thing or a bad thing for the government of (Canada/the US) to be involved in supporting this type of research?

52 Overall, which of the following best captures your views about personalized medicine?

- a. I approve the use of this kind of personalized medicine, as long as the usual levels of government regulation and control are in place
- b. I approve of personalized medicine if it is more tightly controlled and regulated
- c. I do not approve of personalized medicine except under very special circumstances.
- d. I do not approve of personalized medicine under any circumstances

Gene Banks

This part of the discussion is about the subject of genetic information in health research. Genetic information is the information contained in human DNA, which tells us about our genetic characteristics and inherited traits like eye colour or having a gene for an inherited disease that has been passed on through generations. In addition to genetics, other factors like environmental factors are believed to play a role in various health problems in combination with genetic factors.

As you may know, one of the areas of health research that is advancing fairly quickly in Canada and internationally involves studying genetic information across large populations, using large databases known as gene banks.

53b Have you heard of "gene banks" or this kind of genetic health research?

- 54
- o Have you or anyone you know been asked to participate in a study like this, which would involve the use of your genetic information?
 - o Let's assume for the moment that you were asked by a health research organization to contribute your genetic information (taken using a blood sample) to a research study. You would be asked not because you have a particular disease or even have a family history of it, rather the information would go into a large, likely national or regional research database from which health researchers could carry out what they refer to as prospective research, investigating genetic commonalities among people, that might lead toward identification of genetic markers or environmental factors associated with diseases. Your identity would be made anonymous in this database, although it would be noted within the health care facility which asked you to participate that you had contributed this information to this database. In this situation, would you be likely to contribute, or not?

- o Why would you make this decision?

I'd like to ask you about this issue of consent in a different scenario. I'll use a real world example to inform the discussion, so please imagine you are in the following situation:

- o Imagine that you had had a cancerous tumour identified and removed 3 years ago. As you may know, samples from extracted tumours are often kept for research purposes, in order to study how cancers work, etc. Now imagine that a health researcher discovers that there might be a genetic linkage between people with certain DNA/genetic makeup and certain forms of cancer, and wishes to conduct genetic research to study this linkage. This research would involve taking DNA from a large sample of these extracted tumours, including yours (it would also be made anonymous in the database, although it would be stored at the health care facility as well). In this situation, would you likely be willing to allow your genetic information to be used, or not?

56b In this situation, would you expect that consent would be implied when you provided the sample originally, or would you expect to be approached for consent to use the sample?

57a Right now, the way it works is that researchers are compelled to work through university or hospital ethics boards in order to get approval to conduct research on samples like these, and if that board approves of the research, they may go forward. In that scenario, consent for further research is considered to be implied by the original approval of the sample to be researched.

57ab Some people say that "blanket" consent like this in order for scientists to conduct research is not enough, that you should have to be asked for consent if someone wishes to conduct research using a sample you provided each time someone wishes to use it. Others say that doing this would be impractical and potentially act as a significant drag on research, because it would involve going back to thousands of people potentially dozens of times in order to get consent. They also say that given there are ethics boards involved in approving all research for which samples are used, and that the samples will be anonymous in the research databases, it is unnecessary to get consent from each person each time their sample is used. Which of those two views is closest to your own?

Bioethics

Discussions like that we have had tonight have touched upon a number of important topics regarding ethics. What I would like to do now is have a specific discussion about ethical frameworks and systems to govern research activities that involve genetics.

58 (6) First off, I'd like to understand the extent to which you believe there are ethical frameworks in place to govern research in the area of biotechnology and genetics. Before coming here tonight, what were your perceptions of the ethical guidelines/frameworks in place and to what extent do you believe they apply?

58ab At the level of research (universities, hospitals, firms, research associations)

58b At the federal government level, through legal or independent adjudication bodies

58ab At the international level, like the UN/World Health Organization

59a-d Which of these agents/levels would give you the most confidence that ethical guidelines were going to be put into place and followed in genetic research? Why is that? Let's talk about the other two. What level of confidence do you have in those other bodies to put in place and make effective ethical guidelines to govern genetic research? Again, why do you feel that way?

Common Info

Genetics, biotechnology and other emerging technologies such as nanotechnology deal with humans and living organisms. As such they raise ethical and social issues such as respect for human dignity, consent, privacy, diversity, stigmatization and discrimination etc.

• At the national level, currently in Canada there is no on unique piece of legislation devoted to research involving human subjects or focusing on emerging technology (except for the Human Assisted Reproduction Act). However, different Acts at the Federal level do apply to research involving human subjects (Charter, Federal Privacy Act, PIPEDA, Food and Drug Act, CEPA, regulations on clinical trials, etc.)

60a

• There is no one unique ethical framework that applies to all research (private or public) involving human research. There is however a 'national' ethical framework that applies to research publicly funded. It is called the *Tri-Council Policy Statement on the Ethical Conduct of research involving humans*. This document has a series of broad principles that apply to all research involving human subjects and requires research project to be approved by a Research Ethics Board.

- focus only on research
- has some principles specific to genetic research
- is currently under review
- is mandatory for all publicly funded research undertaken by university, hospital
- is mandatory for private research companies undertaking research with public funds
- does not apply to research privately funded

• At the Provincial level, there are different Acts, regulations and policy that apply directly or indirectly to research involving humans but none of the P/T have specific laws or regulations. Some like Quebec have specific policies for human genetic research and some provisions on research in the Civil Code.

• At the international level, various international organisations (World Health Organisation, World Medical Association, Unesco) have developed numerous 'activities targeted' policies (human cloning, research with vulnerable populations, genetic data protection, human genome, etc.). However, there is currently no 'generic' ethical guidelines encompassing all research involving humans but the Unesco is currently trying to develop such a document. Canada is a member of Unesco and participate actively in the drafting of these principles. The Unesco document will not be mandatory (it is not a binding document for the signatories). It is only a declaratory document with a moral power.

Overall, now that I have described the existing system of ethical guidelines that govern this field for you, how do you react? Does it increase or decrease your confidence that appropriate guidelines and rules are being followed? Are you surprised at any of these (in a negative or positive way)?

When you look at these elements altogether, would you say that this system as a whole has appropriate comprehensiveness, or are there elements that you feel should be added/deleted from this system? Which ones?

62a 62b
Are the roles and responsibilities appropriately divided? Are the right players taking on the right roles, or would you want to see some other roles taken on by these or other bodies to ensure that ethical considerations are appropriately addressed?

62a 62b
Let's look at some of these elements individually.

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62a 62b
And at the level of the federal government, what do you think of the role it plays? Again, do you think it plays an appropriate role, or should more be done by the federal government in this area? If so, what should be done?

62a 62b
Some people say that the federal government should play the current role it plays, where it puts laws in place that prohibit certain kinds of practices but essentially leaves the practical day to day implementation of ethical guidelines to the research and international community. That government doesn't really need to do more, above and beyond what it already does in law, and what ethics boards and the UNESCO guidelines establish. Other people say that the federal government should play a stronger role in this area, because it has much stronger ability to act in an authority role within Canada, and that it has to do more to take ethical issues into account (above and beyond the law) as it makes policy about topics like biotechnology. What do you think is the most appropriate role for the federal government?

62a 62b
If there is a role for the federal government in this area, what would be the best way to set it up? Here are some potential ideas of how it might broaden its role in this area:

- 62a 62b
68c
Common info possible roles of government
In terms of operation:
- 62a 62b
68c
Create a law that indicates that public servants must always integrate ethical considerations into any public policy decision about biotechnology
 - 62a 62b
68c
Have a body as an advisory mechanism (like a watchdog) to raise any ethical issues about public policy to political leaders
 - 62a 62b
68c
Have it as a mechanism to take issues on board and provide guidance to political leaders about how to address issues
 - 62a 62b
68c
Have any body report to the public about its role, activities, etc.
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68c
Other operational elements
- 62a 62b
68c
In terms of representation:

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Nanotechnology involves the application of science and engineering at the atomic scale. It involves the construction of tiny structures and devices by manipulating individual molecules and atoms, which have unique properties at that scale. These structures can be used in medicine and biotechnology, in energy and the environment, and in telecommunications. Some of them have genetic elements, others are not. I'd like to get your reaction to some examples of nanotechnology, and get your sense as to whether you support or oppose the development of such technologies. Start with wrinkle free fabric and cosmetics

Common definition information

78a

- The use of special nano-molecules in fabrics like wrinkle/stain resistant pants
- The use of molecules that enable the production of drinking water by extracting salt from seawater
- The use of implantable /ingestible devices that can measure things like blood pressure or blood sugar on a continuous basis
- The use of molecules that have magnetic properties to extract heavy metals in water treatment facilities.
- The use of light-sensitive molecules that have the ability to detect pollutants in water and air, by the amount of light they emit
- The use of "nanocatalysts" in oil sands development, which are molecules that separate the sand from the oil, that substitute for the energy intensive separation processes that are currently used

78ab

I would like to understand the extent to which you think nanotechnology might benefit our society. What are the benefits of this kind of research? - 78b

79

And what do you see as the major risks involved?

80a-7d

***In terms of the moral or ethical aspect of this research, what are your views? Do your moral concerns differ at all depending on the application involved? Which ones? Why?

81ab

What is your understanding about how regulatory systems for nanotechnology applications work? - 81a
Would you expect that these systems are similar to the ones that govern things like biotechnology, or pharmaceuticals, for example?

82ab

****How confident would you say you are in the safety and regulatory approval systems governing nanotechnology in Canada? Why is that? - 82a
- 82b

83ab

And what about in terms of the scientists who are involved in research of these technologies? How confident would you say you are that nanotechnology is in safe hands? - 83a
- 83b

84

How do you compare the confidence you have in these two groups of organizations/scientists?

85

Would you say it is a good thing or a bad thing for (Canada/the US) to be a world leader in research into nanotechnology?

86

And would you say it is a good thing or a bad thing for the government of (Canada/the US) to be involved in supporting this type of research?

87

Were you aware there is a national institute of nanotechnology in Alberta, at the U of A?

88a

Overall, which of the following best captures your views about nanotechnology? (Hand-out)

88ab

- I approve the use of nanotechnology, as long as the usual levels of government regulation and control are in place
- I approve of nanotechnology if it is more tightly controlled and regulated
- I do not approve of nanotechnology except under very special circumstances
- I do not approve of nanotechnology under any circumstances

Disagree Probe 88b

Each respondent will be asked to provide their answer to the above question, and to engage in a detailed discussion about why they feel as they do.

Trust/Confidence

As we have walked through this discussion, issues surrounding the information you gather about these topics, and the trust and confidence in various stakeholders associated with these topics have been touched upon several times.

89

First off, how often have you actively sought out information about biotechnology or nanotechnology research, applications, ethical guidelines, or studies that have been carried out to evaluate safety?

90

What sources would you go to, which ones come to your minds as being credible, and why?

91ab

What level of trust or confidence do you have in regulatory authorities over these technologies? Why is that? 91a

92

How often have you actively sought out ways to voice your opinions or values about biotechnology or nanotechnology research or implications of such research? 91b

93ab

To what extent do you feel that these kinds of technologies have been developed in consideration of your values and beliefs, ethics? Do you feel that those involved in developing these technologies do think about those things? 93a

If you were to read or hear information these technologies from some of the following, how credible would you deem that information? Why do you feel that way? Are there certain areas (like GM food, nanotechnology, stem cells, pharmacogenetics, etc.) where you might have more/less confidence in what each of these organizations/individuals say? Why is that? (List to be expanded when testing biportal/information needs issues, kept to only key categories when not) 93b

- Political leaders
- Religious leaders
- Environmental groups
- Scientists
- Health Canada/Environment Canada

• Does it matter whether the scientists work for industry or for universities? 94a

Others to probe, only if raised or opportunity presents itself: 94f

- The world health organization, which is part of the United Nations
- Greenpeace
- The Nature Conservancy of Canada /environmental groups
- David Suzuki / Prince Charles
- Government scientists
- Scientists that work for biotechnology companies
- Senior executives of biotechnology companies
- University scientists whose work is funded by government grants
- University scientists whose work is funded by biotechnology companies
- Scientific journals
- Private Television networks like CTV/CBS
- Public television networks like CBC/PBS
- Print media (newspapers and magazines)

Biportal

95 • In future do you think you would go to seek out information on biotechnology/emerging technologies?

96 • What information would you likely want to seek out?

97 • Where would you go to find that information?

98ab

• If you were going to get on the internet to find out this information, what organization's site(s) would you likely go to? Why do you identify those organizations/sites specifically? 98a

• What do you know about the roles and responsibilities of the government of Canada with regard to biotechnology? What roles come to mind? 98b

99a → c

• Brief respondents on federal role:

• 12 departments involved, regulatory authority, basic research funding, (promotion) like tax credits for r&d, grants for scientific research into new products 99c

100 • Have you ever been to government of Canada site to gather information before?

101 • What about a government of Canada site on biotechnology?

102 • What would you want from a government of Canada site in terms of specific information?

103 • What about in terms of organization? tone?

104 • What would you expect from a government of Canada site on biotechnology in terms of specific information?

• Let me show you a web site that has been created, id like to get your reactions to it.

• Open Biportal

• I will show you a bit about how it is organized and the kinds of information that is on it, and you let me know how useful it is, how credible it is, what might be missing (in terms of content, organization, tone) 105a 105b 105c

• Put up site, organization

• Explain the four main components, take them through the biobasics and bioregulations sections (show them what they might want to see, ask them to tell moderator what they are interested in and go there on the site to review, discuss) 105d

105a → d

Website visit + discussion

Docs shown to participants

Foreign models for addressing ethical issues:

DENMARK:

The Danish Council of Ethics, created by law in 1987, is a standing body under the supervision of Parliament and Ministry of Health to advise the authorities of the health service on the ethical problems raised by the development of new methods of treatment and techniques in the health field and to inform the public and to promote public debate. Members are appointed by the Ministry of Health and the Parliament committee. Parliament, Ministry of Health, entities in the health field, and population can referred query to Danish Council of Ethics. It is a multidisciplinary committee of 17 members.

FRANCE: The National Consultative Ethics Committee for the Life Science and Health, created by law in 1983 is a standing body under the supervision of the Council of Ministers in order to advise on the ethical issues raised by the knowledge's developments in the field of biology, medicine and health and to inform the public. It is a multidisciplinary committee of 40 members appointed by the President of the Republic based on recommendations of chairperson of both chambers; government; different bodies enumerated in a decree. Chairperson of the chambers, government and different kind of institutions can send query to Committee.

UNITED KINGDOM: In the United Kingdom there are different bodies involved in the ethical debate surrounding development in medicine and medical research. Usually the commission are set up with a specific mandate such as the Human Genetics Advisory Commission, The Human Gene Therapy Advisory commission. The only body that seems to have a general mandate is the Nuffield Council on Bioethics, a private body recognized by the British Medical Research Council. The Nuffield Council on Bioethics is a private multidisciplinary organization supervised by the Nuffield Foundation (a non profit organization). The Nuffield Council on Bioethics analyzes ethical issues raised by the development in Medicine and Biology on its own initiative and publishes its reports for public. It does not report to government.

USA: The President's Council on Bioethics, created by Executive order in 2001 (renewed in 2003) is an ad hoc body (2 years mandate renewal) to advise the President on bioethical issues that may emerge as a consequence of advances in biomedical science and technology. It is a body of no more than 18 members with multidisciplinary background appointed by the President. Its current membership is made up of experts from renowned US universities. The Council makes all of its reports public and its meeting agendas and minutes are available on its web site. Although it reports directly to the President, they are open and transparent in making this information available.

TRI-COUNCIL POLICY STATEMENT ON ETHICS

Context of an Ethics Framework

Norms for the ethics of research involving human subjects are developed and refined within an ever-evolving societal context, elements of which include the need for research and the research community, moral imperatives and ethical principles, and the law.

A. The Need for Research

Research involving human subjects is premised on a fundamental moral commitment to advancing human welfare, knowledge and understanding, and to examining cultural dynamics. Researchers, universities, governments and private institutions undertake or fund research involving human subjects for many reasons, for example: to alleviate human suffering, to validate social or scientific theories, to dispel ignorance, to analyze policy, and to understand human behaviour and the evolving human condition. Research involving human subjects imparts at least three general categories of benefits:

- The basic desire for new knowledge and understanding is the driving force for research.
- The quest to advance knowledge sometimes benefits research subjects. Subjects may benefit from improved treatments for illnesses; the discovery of information concerning one's welfare; the identification of historical, written, oral or cultural traditions; or the satisfaction of contributing to society through research.
- As well, research benefits particular groups and society as a whole. Thus, insights into political behaviour may produce better policy; information about the incidence of disease may improve public health; sociological data about lifestyles may yield social reform; and disciplines based on, for example, texts, dance, theatre or oral history, continue to illuminate past and present realities.

B. A Moral Imperative: Respect for Human Dignity

An ethic of research involving human subjects should include two essential components: (1) the selection and achievement of morally acceptable ends, and (2) the morally acceptable means to those ends.

The first component is directed at defining acceptable ends in terms of the benefits of research for subjects, for associated groups, and for the advancement of knowledge. The second component is directed at ethically appropriate means of conducting research. For example, even in the most promising of research initiatives, the Tri-Council Policy Statement objects to tricking a person into participating by promising false benefits. Part of our core moral objection would concern using another human solely as a means toward even legitimate ends.

The objection provides moral insight that proves pertinent to human research in several ways: First, it translates into the familiar moral imperative of respect for human dignity. It is unacceptable to treat persons solely as means (mere objects or things), because doing so fails to respect their intrinsic human dignity and thus impoverishes all of humanity.

Second, it translates into the requirement that the welfare and integrity of the individual remain paramount in human research.¹ Thus, the moral imperative of respect for human dignity translates into a number of important correlative ethical principles in research ethics. These are elaborated in C. below.

C. Guiding Ethical Principles

The approach taken in this framework is to guide and evoke thoughtful actions based on principles. The principles that follow are based on the guidelines of the Councils over the last decades,² on more recent statements by other Canadian agencies,³ and on statements from the international community.⁴ The principles have been widely adopted by diverse research disciplines. As such, they express common standards, values and aspirations of the research community.

Respect for Human Dignity: The cardinal principle of modern research ethics, as discussed above, is respect for human dignity. This principle aspires to protecting the multiple and interdependent interests of the person -- from bodily to psychological to cultural integrity. This principle forms the basis of the ethical obligations in research that are listed below.

In certain situations, conflicts may arise from application of these principles in isolation from one other. Researchers and REBs must carefully weigh all the principles and circumstances involved to reach a reasoned and defensible conclusion.

Respect for Free and Informed Consent:⁵ Individuals are generally presumed to have the capacity and right to make free and informed decisions. Respect for persons thus means respecting the exercise of individual consent. In practical terms within the ethics review process, the principle of respect for persons translates into the dialogue, process, rights, duties and requirements for free and informed consent by the research subject.

Respect for Vulnerable Persons: Respect for human dignity entails high ethical obligations towards vulnerable persons -- to those whose diminished competence and/or decision-making capacity make them vulnerable. Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination. Ethical obligations to vulnerable individuals in the research enterprise will often translate into special procedures to protect their interests.

Respect for Privacy and Confidentiality: Respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered fundamental to human dignity. Thus, standards of privacy and confidentiality protect the access, control and dissemination of personal information. In doing so, such standards help to protect mental or psychological integrity. They are thus consonant with values underlying privacy, confidentiality and anonymity respected.

Respect for Justice and Inclusiveness: Justice connotes fairness and equity. Procedural justice requires that the ethics review process have fair methods, standards and procedures for reviewing research protocols, and that the process be effectively independent. Justice also concerns the distribution of benefits and burdens of research. On the one hand, distributive justice means that no segment of the population should be unfairly burdened with the harms of research. It thus imposes particular obligations toward individuals who are vulnerable and unable to protect their own interests in order to

ensure that they are not exploited for the advancement of knowledge. History has many chapters of such exploitation. On the other hand, distributive justice also imposes duties neither to neglect nor discriminate against individuals and groups who may benefit from advances in research.

Balancing Harms and Benefits: The analysis, balance and distribution of harms and benefits are critical to the ethics of human research. Modern research ethics, for instance, require a favourable harms-benefit balance -- that is, that the foreseeable harms should not outweigh anticipated benefits. Harms-benefits analysis thus affects the welfare and rights of research subjects, the informed assumption of harms and benefits, and the ethical justifications for competing research paths. Because research involves advancing the frontiers of knowledge, its undertaking often involves uncertainty about the precise magnitude and kind of benefits or harms that attend proposed research. These realities and the principle of respect for human dignity impose ethical obligations on the prerequisites, scientific validity, design and conduct of research. These concerns are particularly evident in biomedical and health research; in research they need to be tempered in areas such as political science, economics or modern history (including biographies), areas in which research may ethically result in the harming of the reputations of organizations or individuals in public life.

Minimizing Harm: A principle directly related to harms-benefits analysis is non-maleficence, or the duty to avoid, prevent or minimize harms to others. Research subjects must not be subjected to unnecessary risks of harm, and their participation in research must be essential to achieving scientifically and societally important aims that cannot be realized without the participation of human subjects. In addition, it should be kept in mind that the principle of minimizing harm requires that the research involve the smallest number of human subjects and the smallest number of tests on these subjects that will ensure scientifically valid data.

Maximizing Benefit: Another principle related to the harms and benefits of research is beneficence. The principle of beneficence imposes a duty to benefit others and, in research ethics, a duty to maximize net benefits. The principle has particular relevance for researchers in professions such as social work, education, health care and applied psychology. As noted earlier, human research is intended to produce benefits for subjects themselves, for other individuals or society as a whole, or for the advancement of knowledge. In most research, the primary benefits produced are for society and for the advancement of knowledge.