



PUBLIC OPINION RESEARCH INTO BIOTECHNOLOGY ISSUES IN CANADA

Presented to the Biotechnology Assistant Deputy Minister Coordinating Committee
(BACC), Government of Canada

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EXECUTIVE SUMMARY

Prepared for the Biotechnology Assistant Deputy Minister Coordinating Committee, Government of Canada,
by Pollara Research.

The opinions and statements in this publication do not necessarily reflect the policy of the Government of Canada.



Introduction

Pollara is pleased to present this report on a public opinion research program conducted in December of 2003 for the Biotechnology Assistant Deputy Minister Coordinating Committee (BACC).

This wave of research was completed in December 2003 and was comprised of a telephone survey of 1000 Canadians and eight focus groups nationwide.

The research was designed to accomplish the following major objectives:

- To track sentiment on a range of biotechnology issues in Canada, using a baseline of data developed in previous waves of research;
- To evaluate Canadian attitudes toward the advancement of a health innovation agenda that centers on biotechnology health research;
- To evaluate Canadian attitudes toward potential economic measures or “levers” that might spur the advance of Canada’s biotechnology sector;
- To gather Canadian opinions on genetic information and privacy initiatives;
- To gather information from Canadians about their knowledge and beliefs surrounding the biosafety protocol.

The telephone work began on December 4, 2003, and ended on December 16, 2003. The margin of error is +/- 3.1%, 19 times out of 20.

Further information can be obtained from Pollara Research in Toronto, and Earncliffe Research and Communications in Ottawa. Please contact us at our offices, at (416) 921 0090 or (613) 233 8080, or via e-mail:

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Trend Lines

This wave of research focused on investigating a series of emerging issues associated with biotechnology that have arisen for a number of departments within the federal government, as well as tracking several questions that have been followed through previous waves.

In the areas of knowledge and familiarity, trends established in previous waves appeared even more pronounced in this wave. The improvements are so sizeable that they require confirmation in the next tracking wave. The number of Canadians who describe themselves as very familiar with biotechnology has more than doubled, from 6% to 16% while the number who say they are not at all familiar fell from 13% to 7%. Overall, there is a jump in the level of familiarity, from 57% to 70% of Canadians who say they are at least somewhat familiar with this field. Among Involved Canadians, fully 80% say they are at least somewhat familiar with this field.

In addition, this wave revealed an increase in the number of Canadians who express support for biotechnology in general. The ratio of support to opposition has risen from about 2:1 (63% to 25%) in March 2003, to 2.5:1 (68% to 25%). Opposition remains stable, down from around 30% in earlier waves between 2000 and 2002.

In the area of genetic information and privacy, the tracking data reveals some slight differences from results a year ago. While the vast majority believes in genetic research and would contribute their genetic information to such research if they were tested, there is a growing unease among some about access to and the uses of databases of genetic information – specifically the access to such information by insurance companies.

What has not changed in the area of genetic privacy is Canadians' wish to have governments strike a balance between privacy and facilitating research: some 73% want government to strike such a balance when considering laws and guidelines in this area.



Attitudes and Familiarity

Overall attitudes about the technology are very consistent with what previous research has shown. Canadians see enormous promise in the health biotechnology field specifically, believing it will provide significant benefits to individual Canadians. Potential health benefits remain the most important driver of attitudes toward biotechnology among Canadians.

In the areas of knowledge and familiarity, trends revealed in previous waves appeared even more pronounced in this wave. The improvements are so sizeable, that they require confirmation in the next tracking wave. The number of Canadians who describe themselves as very familiar with biotechnology has more than doubled, from 6% to 16%, and the number who say they are not at all familiar fell from 13% to 7%. Overall, there is a jump in the level of familiarity, from 57% to 70% of Canadians who say they are at least somewhat familiar with this field. Among Involved Canadians, fully 80% say they are at least somewhat familiar with this field.

This data confirms focus group findings, evident over the past couple of waves of research, which also suggest that there has been an increase in familiarity with biotechnology. Respondents can often cite several examples of applications they have heard of, as well as Canadian discoveries. Furthermore, once the conversation gets moving in focus groups, people reveal a more comprehensive knowledge of the field than they initially express.

In addition, this wave revealed an increase in the number of Canadians who express support for biotechnology in general. Now the ratio of those who support to those who oppose the technology has risen from about 2:1 (63% to 25%) in March 2003, to 2.5:1 (68% to 25%). Opposition remains stable at a quarter of the population, down from around 30% in earlier waves between 2000 and 2002.

That said, there remains continued and widespread wariness about GM food, reconfirmed in this wave in focus groups. If anything, people express stronger dissatisfaction than they have in the past about the lack of labeling and labeling standards for GM foods.

Canadians tend to know little about the federal government's biotechnology regulations. Only 3% say they are very familiar with it and a quarter say they are only somewhat familiar. This is unchanged from previous waves.

Confidence is moderate in the government's ability to ensure that biotechnology products that are made available are safe. Half say they are very or somewhat confident, while fewer than one in five say they are not at all confident. Opposition to biotechnology as a whole correlates strongly to the lack of confidence: of those who oppose the technology, a third say they are not at all confident and another four in ten say they are not very confident. This compares to only 7% and 26% respectively for those who support it.

There is a broad consensus that the Government of Canada probably does not do enough to study and monitor the impact of biotechnology products. Here, again, those who already oppose biotechnology are more likely to believe that the government does not do enough.

Priorities and Health Innovation in Biotechnology

Health and medicine are the strongest drivers of support for biotechnology. Canadians generally believe that it will be a core contributor to future improvements in health care. Most importantly, and most crucially in terms of public support, many believe that they will personally benefit from health innovations in the biotechnology field.

The top priorities for the federal government identified in the survey tend to lie in two areas: investing in research -basic as well as applied- and collaboration with the provinces in order to establish common practices, as well as internationally in order to evaluate safety. In each of these cases, nearly two thirds of respondents suggested that these activities were “one of the most important” things that government should do.

Ontarians are the most likely to believe basic research is one of the most important priorities, while Quebecers are least likely to think so. When it comes to applied research, a west-east divide can be identified, with British Columbians being least likely to say it is one of the most important priorities and residents of Atlantic Canada to be most likely to think so. Quebecers and Albertans are more likely to see strengthening of the existing privacy protection measures as one of the most important government priorities, as well as older Canadians over the age of 55. Atlantic Canadians are least likely to see this as an important priority. They also give a lower than average priority rating for collaboration with other countries, as do Albertans. British Columbians tend to rate this priority highest.

Focus groups help to illustrate the findings. They revealed four key findings:

- Canadians do not have a sense that the federal government has made a significant recent investment in the biotechnology field;
- They also tend to be of the opinion that health research continues to be underfunded and not given the attention it probably deserves;
- They are generally unaware of efforts undertaken to regulate the technology; and
- They believe that the technology (and economies in general) are global in nature and as a result, national regulatory regimes are only going to be of limited utility in ensuring that these applications are rigorously tested.

When forced to prioritize, focus group participants tended to choose those priorities that centred on funding for both basic and applied research, followed by funding for government research into safety and regulations governing products. The most capable and influential people in the groups tended to place equal or almost equal emphasis on the stewardship element as they did on fostering the discoveries and applications.

Speeding up evaluations, however, is not seen as something to be valued. This was the lowest rated of the list of potential priorities in the realm of health innovation. Besides rating lowest of the priorities, in focus groups this notion of “speeding up” appears to erode the already moderate levels of confidence in the system.

The “speeding up” issue sparked significant debate in the focus group discussions. The majority, particularly those who are the most thoughtful opinion leaders, does not believe that speeding up the approval process can be done without compromising safety to one extent or another. Most participants show no appetite for any compromise of safety in order to get products onto market faster. The major reason these people cite is that seeing potential side effects over “generations” in an organism or in the organisms that interact with it is essential to the question of safety, and there is “no way to speed up that generational evaluation process” without compromising safety. Moreover, people believe that individuals in dire straits have ways of accessing treatments that are still being tested and for most, that should suffice as a way to deal with concerns about speed.

A minority, about one in four, believes the processes might be able to be sped up without compromising safety but even in those cases, they do not believe that it can be sped up by much: cutting some red tape is seen as the only possible step that could be taken. This is expected to be able to only reduce the time by 20% or so without compromising safety.

In the groups, a series of forced choices or “trade-offs” between these potential priorities was put to the participants. The first of these was between basic and applied or commercial research. The groups suggested that people do not want to choose between investment in basic research and in applied or commercial health research. They were both seen as equally important and participants wanted to ensure both get adequately supported.

The second of these “trade-offs” probed the desired balance between dedicating resources to health application research or to regulatory research. In this case, the general consensus in the groups was to lean towards the former. This is not because regulatory research is or should be a lower priority, but because most do not believe that this priority has to be a particularly costly exercise, at least not as costly as investments in basic and applied research. It was therefore not clear to some that there would have to be a trade-off between these priorities. However, they would not want nothing done in the area of regulatory improvements, but they do not see that doing so has to crowd out investment in research. All want resources dedicated to regulations, safety and stewardship. The real question is how much, and that tends to depend on perceptions of how expensive it would be.

Looking at the issue regarding regulatory cooperation between countries in the biotechnology field, the survey reveals that only one in five Canadians think it best for Canada to develop its own standards and regulations, while an overwhelming majority prefers cooperation with other countries in this area. This preference is especially pronounced among those who support of biotechnology in general. There is however little appetite for collaboration in the execution of evaluations. People want Canadian experts to work with those in other countries to develop the most effective means of evaluating these technologies, but they believe Canada should have its own system of approvals that every product should have to go through, regardless of whether it was approved in another country with similar approval processes.

Upon discussion, there was some willingness to allow early results of testing (like Phase 1 trials) in other countries to be submitted and thereby shorten the approval period in Canada, by not forcing Canadian regulations to repeat Phase 1 processes all over again. However,



people do want the major components of the evaluations to take place in Canada, even after they are carried out in other countries, regardless of which country it is. Note that the U.S. was universally rejected as a country from which Canada could take results in order to shorten the Canadian approval process. There is a widespread sense, gleaned in this wave as well as in previous biotechnology research, that the U.S. approval system is too fast, fuelled in part by the fact that it “takes longer” in Canada to approve products, as well as a broadly held suspicion that the pharmaceutical industry in the U.S. has undue influence over those approval processes.

The final area of trade-offs in focus groups had to do with cost versus access to some of these technologies in health care systems. Ultimately, on the issue of evaluating how products will integrate into health care systems, people generally see these questions as more appropriate for health experts to assess than ordinary Canadians. There are too many variables and considerations for them to assess and they feel they would need the specifics of each case to understand this issue properly.

That said, access is undeniably an underlying concern with regard to these technologies but few have any way of wrestling with the choices inherent in the access questions: they do not want to pay more taxes to get products cheaper but they also do not want to cap prices if it means companies would not make products. By and large, people want the applications and they want them at an affordable cost. They like the idea of a PMPRB or a similar federal agency acting as a check on pricing.

Economic Levers

The survey revealed that Canadians not necessarily agreed on whether biotechnology is one of the most important sources of jobs and growth in the future. About half believe it will be, and slightly fewer than half don't think it will be. Most people in the focus groups thought the biotechnology sector is a sector in its infancy, and therefore does not yet make a big contribution to the economy or jobs.

That is not to say that people do not believe the sector is important. As has been pointed out earlier in this report, they believe in its importance first and foremost because of the health benefits it promises, and secondly because of the economic benefits it might provide.

Canadians are increasingly of the view that Canada is one of the world's leaders in biotechnology. What is notable about this view is that in focus groups, people see Canada and Canadian researchers as "underdogs" in this field, who have worked extremely hard to become leaders in a few niche areas, but may not be big enough to lead in more than a few key areas of biotechnology.

The advantages that Canada is seen to have revolve around the brainpower of highly educated scientists at universities, and the fact that Canadians have a natural expertise in areas related to biotechnology, such as agriculture.

The disadvantages center our relatively small "size", and the lack of money available to develop these technologies in Canada, compared to what is seen to be available in other places, particularly the U.S. This idea of being at a competitive disadvantage due to Canada's size was a thread that was very consistent throughout the groups.

One other crucial aspect of the prevailing attitudinal set is a distinction that many respondents make about companies in general, and in particular those in this field. As is the case in a number of areas, Canadians tend to have a strong affinity for small biotechnology companies and entrepreneurs, while harbouring negative attitudes about larger companies. This attitude is particularly prevalent in regard to multinationals, but also when it comes to large Canadian companies. It translates directly into their views about how much should be done to foster the sector's development – if the discussion focuses on small groups of researchers, there is broad agreement for the need for government support. If the discussion focuses on larger firms, support is dampened.

The problems affecting the sector in terms of financing limitations resonate quite deeply in focus groups. Involved Canadians specifically grasp the nature of the problem that faces these firms. This is in large part because the reasons go to the heart of what they generally believe about Canadian researchers and Canadian companies: they are small, have many very highly skilled and educated people working for them, and have no money. They also tend to understand the tax write-off problem. Some get it right away while others need analogies to be drawn between it and the old RRSP contribution model, where if a person did

not use the available contribution amount, it lapsed after seven years. It is very important to recognize that because Canadians have become so much more involved in financial affairs of their own over the past decade, they are much more adept at understanding issues involving financial affairs affecting firms than they are generally given credit for.

All that said, while the issue of supporting the biotechnology sector is clearly seen as important for the federal government to deal with, it is not necessarily seen as urgent. This may be because there are no forward oriented economic development measures in the biotechnology sector that meet the urgency test, so it could be an unreasonable expectation that the government make it a priority.

Survey respondents, as well as those in focus groups, were given a brief on the characteristics of the biotechnology sector, and were asked two core questions: whether government should do more to foster this sector and the appropriateness of six possible economic levers.

Most (72%) say the federal government should take further steps to ensure the success of the biotechnology industry in the future.

Of the six economic levers tested, one stood out most in the survey. Establishing a venture capital fund funded in part by government, run by private sector experts but that would include health care experts that possess real-world experience in hospitals and health administration in decision-making roles was seen as the most appealing option. This option was also appealing to focus group participants. They liked this idea, particularly because they believed that decisions made by such a fund would not only take bottom line considerations into account but would also be sensitive to public interest considerations.

An example was often tabled spontaneously that disease treatments that may not involve a high number of cases may warrant venture capital support even if they might not make more money than other potential investments. Another reason for liking this approach is that since Canada is a small country with a small pool of venture capital as compared to the U.S., this seems to be an effective way of assembling it. The third reason why this venture capital model was appealing was the idea that government might be able to make money from some of the products it invested in; money which in turn, could be utilized to help Canadians to get products at affordable prices.

People tended to reject another venture capital model (contributing to existing Canadian private sector venture capital funds for biotechnology) because it was felt that even though some causes would be worthy, decisions would be made purely on economic considerations to the exclusion of applications that were potentially beneficial to health but not as economically viable.

Focus group respondents tended to lean toward the approaches that are simplest to understand and implement, specifically extending the period for use of tax credits from 10 to 15 years. Some even said they should get up to 20 years. It is a common sense proposition that people think is more like fixing a gap in the tax system than actually providing a new benefit to the sector.



Another economic lever was quite appealing to a number of people. This was the idea of allowing shareholders to use the tax credits available to the biotechnology companies. This concept was deemed appealing because participants could see how any individual might be able to benefit from the measure, not just “companies”. In that sense, the measure was seen as potentially offering benefits to Canadians, not just to the sector. Some drew parallels between that and the “labour sponsored funds” that carry enhanced tax write-offs with them.

The option of direct seed funding support through existing channels was met with mixed reaction in the groups. Some found the idea very appealing, but more people suggested that the other approaches would be simpler, in the case of changing tax credit rules, or have a more effective decision-making model, such as the venture capital experts as operators of a good “check mechanism” in the mixed venture capital model. There were concerns expressed in some groups that the monies might be allocated based more on political considerations than on health or economic considerations.

What the groups were not able to do to the extent that we might have liked (due to limited time and resources), is to test how an investment in this area stacks up against other priorities for government. In general, it was seen as a top economic development priority, worthy of some dedication of resources, but up against other priorities like health care it did not merit the same level of attention. More work will have to be done in order to determine exactly what level of relative priority this area has among Canadians.

Genetic Information and Privacy

People remain generally uninformed about and unengaged in genetic privacy issues. However, those who have been engaged in discussion and who therefore have thought about it, have strong opinions. This suggests that there will be a public profile once the debate begins, at least among Involved Canadians.

There is more perceived urgency around what the governance rules are currently, than in research done earlier in 2003. Since then, there is evidence that people have been exposed to more and have done more thinking about where they stand on the issue.

The survey shows that 17% of Canadians consider themselves very familiar with issues involving genetic information, up from 9% in March 2003. The percentage that says they are somewhat familiar has stayed level at 51%. Three in 10 Canadians are very interested in these issues and half are somewhat interested.

A slightly larger group says it would be interested in learning more about personal genetic information and 8% say they have been asked to undergo a genetic test. A large majority (two thirds of Canadians) believes that the benefits of knowing more about genetic information outweigh the potential drawbacks. This majority has grown by 4% in the past year. This is largely attributable to the perception of importance that this kind of research will have on the future of health care and health treatment: an overwhelming number of Canadians, 97%, sees genetic research as having a very or somewhat central role in the future of medical research.

Most people believe that knowing more about their personal genetic information is a good thing, and most people are willing to allow personal genetic information to be used for medical research. Some say, however, that they have been wary about getting tested. This is sometimes because there is no treatment available for many potential diseases, so they do not see the point in knowing they might be predisposed to contracting them. But a number said that they were wary because others (i.e. insurance companies) might want access to the information and they do not want it revealed, so they would not want to get tests done. They understand the realities around federal-provincial jurisdictions, but as it is on other issues, they do not care, as long as somebody ensures that insurance companies and employers cannot access this information. If it doesn't get accomplished, all government(s) will be blamed.

The survey showed that most Canadians, 82%, would be willing to contribute their genetic information to a database if they were guaranteed their identity was stripped from the database. A slight majority, 54%, said they would like the rules governing access to genetic information to be more strictly regulated than other health information, while 43% said that the same kind of regulations would be fine.

On the core question about what considerations should be most important for government to take into account in the context of governance in the area of genetic privacy, the vast majority of Canadians (73%) want to strike a balance between protection of privacy and health research in the biotechnology sector. Only small, but equal, minorities of 12% and 13% chose one over the other.

In spite of this overall preference to “strike a balance,” the research suggests that there is initial evidence of a chill effect on getting tested in the absence of what people perceive as firm rules about what information is protected and from whom. Most believe, for example, that insurance companies have a right to ask people for this information. When the question is raised in groups about who owns or can access genetic information, it immediately catalyzes interest and generates uncertainty about who, in fact, owns genetic information and whether insurance companies can access it. That uncertainty leads to a demand for more certainty, which helps explain the priorities that the research revealed.

In this context, they often begin asking hard questions about protections for privacy, anonymity and the security of databases in genetic research. People in focus groups also raised concerns about those in other countries testing Canadians for genetic information, without privacy rules.

What the focus groups suggested overall is that the importance of taking specific legal steps to protect genetic privacy could over time erode support for facilitating R&D (or striking a balance between privacy and R&D). Without clarity, it may be the case that people will begin leaning toward asking government to err on the side of protecting privacy, instead of striking a balance between privacy and R&D.

A series of potential governance measures to address genetic privacy issues were tested in both the survey and the focus groups. Clear, consistent priorities emerged, although most of the measures were seen as important. The top priority was the revision of the privacy act to specifically protect genetic information: two thirds of Canadians found this to be one of the most important steps and another quarter found it important. In focus groups, this was also seen as the top priority.

In the survey, working with the medical research community to establish standards emerged as the second most important potential measure, with 61% saying it was one of the most important steps and 36% counting it to the second grade of importance.

The idea of making changes to legislation is seen as the most important, because that entrenches specific measures in law that cannot be contravened later, as well as because most people see it as signaling government’s attention to the file.

With regard to the changes to the privacy and human rights acts, most people want specific language identifying specific types of protection – even if experts say something is implicit in the existing legal framework -- because it provides both personal comfort and confidence in the government’s attention to the file.



Indeed, when asked when changes like the ones tabled in this research should be integrated into legislation, an overwhelming majority (80%) said the laws should be changed as soon as a potential gap is recognized, and should not wait until a legal challenge actually occurs. When it comes to this, people invoke the concept of preventative action, fuelled in part by concerns about whether the ordinary Canadians who will end up involved in that legal challenge will be able to properly fight that battle in court. There is no real affinity among Canadians for the way in which laws are traditionally changed through court challenges, particularly in areas like biotechnology where the stakes are perceived to be high.



Environmental Issues

The final area that was investigated in this research involved the biosafety protocol and priority setting for environmental aspects of biotechnology.

Awareness of the biosafety protocol is generally not very high: only 13% of those interviewed say they have heard of the international agreement to set out procedures for achieving safe trade, commercial handling and use of genetically modified organisms. Most, 68%, say the Government of Canada should not ratify the protocol until Canada knows more details about the conditions it must meet and how the agreement will be implemented. About a quarter say the agreement should be ratified now.

The vast majority, 68%, says the federal government should strike a balance between developing the stewardship regime for the environment and fostering the economic development of the environmental biotechnology sector, consistent with what other waves of research have demonstrated about how Canadians think government should deal with the technology in general. Twice as many (20% versus 10%) think it is more important to invest in biotechnology that helps protect the environment, as supposed to more investment to ensure that the Canadian industry is a leader in the biotechnology field.