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Wave 10

PUBLIC OPINION RESEARCH INTO BIOTECHNOLOGY ISSUES IN CANADA

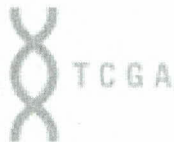
**Presented to the Biotechnology Assistant Deputy Minister Coordinating Committee
(BACC), Government of Canada**

December 2003

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 Earnscliffe 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.

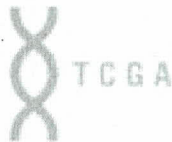
Ontarians are the most likely to believe basic research is one of the most important priorities, while Quebecers are least likely to think so. When it comes to applied research, a west-east divide can be identified, with British Columbians being least likely to say it is one of the most important priorities 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.

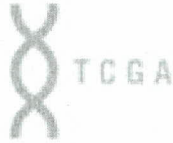
Upon discussion, there was some willingness to allow early results of testing (like Phase 1 trials) in other countries to be submitted and thereby shorten the approval period in Canada, by not forcing Canadian regulations to repeat Phase 1 processes all over again. However,



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 on 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.

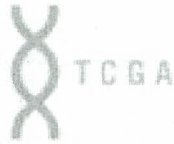
Most (72%) say the federal government should take further steps to ensure the success of the biotechnology industry in the future.

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.

Biotechnology Fall 2003 Survey

Interview Schedule

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1. Some/other people say that while the country has some problems, Canada is generally headed in the right direction at the current time. Other/some people say that there are more things going badly than well in Canada right now and that the country is headed in the wrong direction. Which of those two statements is closer to your own opinion?

Canada is generally headed in the right direction 65
 The country is headed in the wrong direction..... 28
 Don't Know/Refused..... 7

2. When you hear the word biotechnology, do you have a positive, neutral, or negative reaction?

Positive reaction 34
 Neutral reaction 45
 Negative reaction..... 15
 Don't Know/Refused..... 6

3. Would you say you are very familiar, somewhat familiar, not very familiar, or not at all familiar with biotechnology?

Very familiar 16
 Somewhat familiar 54
 Not very familiar..... 22
 Not at all familiar 7
 Don't Know/Refused..... 0

4. In general, would you say you strongly support, somewhat support, somewhat oppose or strongly oppose the use of products and processes that involve biotechnology?

Strongly support..... 14
 Somewhat support..... 54
 Somewhat oppose 17
 Strongly oppose 8
 Don't Know/Refused..... 8

5. Over the past few months, have you seen or heard about any Canadian discoveries in the field of biotechnology?

Yes..... 29
 No 68
 Don't Know/Refused..... 2

6. Which of the following two statements most closely reflects your view: Biotechnology will be one of the most important sources of jobs and economic growth in the 21st century OR Biotechnology might be seen as important now, but probably won't be one of the most important sources of jobs and economic growth in the 21st century.

Biotech will be one of the most important sources of jobs 54
 Biotech might be seen as important now, but probably won't be 41
 Don't Know/Refused..... 5

7. Would you say you are very familiar, somewhat familiar, not very familiar, or not at all familiar with government regulations that apply in the field of biotechnology?

Very familiar.....	3
Somewhat familiar.....	25
Not very familiar.....	40
Not at all familiar.....	31
Don't Know/Refused.....	1

8. Would you say you are very confident, somewhat confident, not very or not at all confident in the government's ability to ensure that biotechnology products that are made available are safe?

Very confident.....	10
Somewhat confident.....	43
Not very confident.....	29
Not at all confident.....	14
Don't Know/Refused.....	3

9. Which of the following two statements most closely reflects your view: The government of Canada probably an effective job of studying and monitoring the impact of biotechnology products OR The government of Canada probably does not do enough to study and monitor the impact of biotechnology products?

Gov effective job study & monitor impact of biotech product.....	28
Gov not do enough study & monitor impact of biotech product.....	65
Don't Know/Refused.....	7

10. In terms of managing the issues associated with biotechnology, do you think it is best that Canada work on its own to develop appropriate standards and regulations or do you think it is best that Canada work with other nations to develop international agreements on standards and regulations?

Canada work on its own development.....	18
Canada work with other nations.....	80
Don't Know/Refused.....	2

The government of Canada is seeking to ensure that Canadians reap the benefits of biotechnology innovations that can be used in healthcare. I would like to read you a list of initiatives that government could pursue to promote development of these innovations, and ask you to react to each of them, by indicating whether you think each is be one of the most important things that government could do, an important thing but not one of the most important, or not an important thing for government to do.

11. Increase funding for basic biotechnology research, such as investigation of the genetic causes of certain diseases.

One of the most important things that government could do.....	59
An important thing but not one of the most important.....	35
Not an important thing for government to do.....	5
Don't Know/Refused.....	1

12. Increase funding for applied biotechnology research, such as developing products like genetic tests for inherited diseases and medicines to treat them.

One of the most important things that government could do.....	58
An important thing but not one of the most important.....	35
Not an important thing for government to do.....	6
Don't Know/Refused.....	2

13. Establish rules that would strengthen existing privacy protection rules as they apply to genetic information used in biotechnology research.

One of the most important things that government could do	49
An important thing but not one of the most important	38
Not an important thing for government to do	10
Don't Know/Refused	3

14. Increase funding for scientific research in aid of government evaluation of the safety of biotechnology products for Canadians.

One of the most important things that government could do	50
An important thing but not one of the most important	42
Not an important thing for government to do	6
Don't Know/Refused	2

15. Collaborate with other countries like those in Europe and the US to evaluate the safety of biotechnology products.

One of the most important things that government could do	62
An important thing but not one of the most important	31
Not an important thing for government to do	5
Don't Know/Refused	1

16. Speeding up the evaluation process for biotechnology products, while maintaining the same standards for product safety.

One of the most important things that government could do	41
An important thing but not one of the most important	45
Not an important thing for government to do	11
Don't Know/Refused	2

17. Support national programs to assess the value that each of these new health technologies/treatments can provide to the healthcare system, as compared to other treatments already available.

One of the most important things that government could do	46
An important thing but not one of the most important	47
Not an important thing for government to do	5
Don't Know/Refused	2

18. Work with provincial governments to establish common practices in the use of new technologies in provincial health care systems.

One of the most important things that government could do	58
An important thing but not one of the most important	36
Not an important thing for government to do	5
Don't Know/Refused	1

Over the past few years, Canadian scientists have made major discoveries in the field of biotechnology. It takes 10 years or more to turn a discovery into an application, such as a genetic test for a disease, and Canadian discoverers often don't have access to the resources to finance that development. In many cases the result is that US and foreign companies are buying the rights to the discovery from the Canadian scientists and are developing products and applications from them.

Common
info

19. Some people say that the government of Canada should take measures to try to ensure that Canadian based discoveries are developed within Canada, because the private sector in Canada is not doing enough. Others say that the government already does enough to support research and development, and may end up wasting taxpayers money if it tried to do more, so it would be best for government not to get involved. Which of those two views is closest to your own?

Gov should ensure Canadian discoveries developed in Canada.....	72
Gov already does enough support research and development	23
Don't Know/Refused	5

There are some measures that the government of Canada could introduce to help ensure that Canadian biotechnology discoveries turn into Canadian products. I would like to read you some of the ideas under consideration, and want you to indicate whether you think each is one of the very best ideas, a good idea but not one of the best, or not a good idea.

20. Extending the period under which firms can get tax breaks for research and development investments, from 10 years to 15 years.

One of the very best ideas.....	27
A good idea but not one of the best	48
Not a good idea	23
Don't Know/Refused	4

21. Allowing shareholders in Canadian biotechnology firms to claim the tax breaks that their firms are unable to use, in order to increase willingness to invest in these firms. This approach is similar to one already used by other sectors that face similar circumstances as the biotechnology sector.

One of the very best ideas.....	24
A good idea but not one of the best	55
Not a good idea	16
Don't Know/Refused	5

22. Allowing companies who partner with Canadian biotechnology firms to use the tax breaks that the biotechnology firms are unable to use, in order to facilitate more partnerships with these firms.

One of the very best ideas.....	22
A good idea but not one of the best	53
Not a good idea	18
Don't Know/Refused	7

23. Contributing more direct financial support to Canadian biotechnology firms, through government programs that provide seed funding to development of high technology products.

One of the very best ideas.....	26
A good idea but not one of the best	55
Not a good idea	15
Don't Know/Refused	4

24. Contributing money to existing Canadian private sector venture capital funds, thereby increasing the pool of money available to Canadian firms. Decisions about how the funds would be allocated would be made by private sector experts who work for the venture capital fund, but the government would share in any possible profits.

One of the very best ideas.....	18
A good idea but not one of the best	51
Not a good idea	26
Don't Know/Refused	5

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25. Creating a new venture capital fund to invest specifically in health applications of biotechnology. This fund would be funded jointly by government and the private sector. Decisions about how the funds would be allocated would be made by experts from the venture capital industry, as well as health care experts such as doctors, health administrators, and health researchers..

One of the very best ideas..... 41
 A good idea but not one of the best 48
 Not a good idea 8
 Don't Know/Refused..... 3

This part of the survey is about the subject of personal genetic information. Genetic information is the information contained in human DNA, which tells us about our genetic characteristics and inherited traits like eye colour or some inherited diseases that have been passed on through generations.

- 26b Would you say you are very familiar, somewhat familiar, not very familiar, or not at all familiar with issues involving genetic information?

Very familiar 17
 Somewhat familiar 51
 Not very familiar..... 24
 Not at all familiar 9

27. Would you say you are very interested, somewhat interested, not very interested, or not at all interested in this issue?

Very interested..... 31
 Somewhat interested 53
 Not very interested 12
 Not at all interested..... 4
 Don't Know/Refused..... 0

28. How interested are you in knowing more about your own genetic characteristics? Very, somewhat, not very, not at all?

Very interested..... 34
 Somewhat interested 39
 Not very interested 17
 Not at all interested..... 10
 Don't Know/Refused..... 0

29. Is it your opinion that the benefits of knowing more about our genetic information outweigh the drawbacks, or do the drawbacks outweigh the benefits?

Knowing more about our genetic info outweigh drawbacks 67
 The drawbacks outweigh the benefits 22
 Don't Know/Refused..... 12

30. Have you ever been asked to undergo a genetic test?

Yes..... 8
 No 92

Increased scientific knowledge about our genetic characteristics has implications for health and medical research. Many health and medical researchers are dedicating themselves to learning more about the ways in which genetic information determines how and why certain people develop disorders and illnesses by studying genetic information from large groups of people.

31. In the future, how important a role do you think genetic information will play in health research in Canada: very, somewhat, not very, not at all?

Very important 67
Somewhat important..... 29
Not very important 2
Not at all important 1
Don't Know/Refused 0

32. If you had a genetic test, would you be very, somewhat, not very or not at all willing to contribute the information to a database that would be used for health research if your identity was stripped from the database?

Very willing 50
Somewhat willing 32
Not very willing..... 7
Not at all willing..... 9
Don't Know/Refused 2

The following questions are about the privacy rights in relation to genetic information. These rights involve the laws, regulations, and guidelines that govern confidentiality in the collection and use of genetic information. Privacy rights can restrict what people are allowed to know about you, and can also protect the confidentiality of your genetic information once it has been collected.

33. Do you think the rules governing access to genetic information should be more strictly regulated than other health information, or should it be regulated in the same way as health information?

More strictly regulated than other health information 54
Regulated in the same way as health information..... 43
Don't Know/Refused 2

34. The government has many roles. One is to ensure the privacy of personal information. Another is to support research and development to improve health care and create jobs. In your view, should government pursue these roles with equal emphasis, should privacy be pursued with greater emphasis, or should research and development be pursued with greater emphasis?

Equal emphasis 32
Privacy be pursued with greater emphasis 31
Research and development be pursued with greater emphasis 32
Don't Know/Refused 4

35. Some people say that a person who has a genetic test has an obligation to inform family members of the results if there is something that might affect those family members. Other people say that a person who has a genetic test does not have an obligation to inform family members of the results even if there is something that might affect them, that sharing such information is fundamentally a personal decision. Which of those two views is closest to your own?

Person who has a genetic test has an obligation to inform family 60
Person who has a genetic test does not have an obligation to inform family.... 37
Don't Know/Refused 3

When new genetic technologies become more widespread, they sometimes generate new issues that are not explicitly dealt with in existing laws and government policies. There are two points of view about how these potential legal "gaps" should be addressed. I would like to know which is closest to your view.

36. Some people say that there is no need to change laws immediately, and they should only be changed if someone proves there is a gap in the protection current laws provide. Other people say that as soon as a potential gap is recognized the laws should be changed before someone may try to take advantage of it. Which of those two views is closest to your own?

There is no need to change laws immediately	17
Law changed as soon as potential gap is recognized	80
Don't Know/Refused	3

Like many other issues in Canada, genetic information is governed by a mix of federal and provincial laws and policies. The federal government, is considering a series of initiatives in the area of genetic information and privacy.

37. The goal of this effort is to enhance Canadians' privacy protection and freedom from discrimination while enabling them to benefit from genetic research and health innovation. The basic principle is to strike a balance between protecting privacy and promoting health research in biotechnology. Would you say more emphasis be placed on protecting privacy, more emphasis be placed on promoting health research, or you agree with the idea of striking a balance between these two goals?

More emphasis be placed on protecting privacy	12
More emphasis be placed on promoting health research	13
Agree with the idea of striking a balance between these two goals	73
Don't Know/Refused	2

A number of specific initiatives regarding the protection of genetic privacy are being considered by the federal government. I will outline each initiative briefly. For each, please indicate whether you think this is one of the most important steps that should be taken, important but not one of the most important steps, or not an important step.

38. Change Canada's Privacy act to make it clear that genetic samples and information from those samples are protected as types of personal information.

One of the most important steps that should be taken	67
Important but not one of the most important steps	27
Not an important step	5
Don't Know/Refused	1

39. Change the Canadian Human Rights act to clarify that discrimination on the basis of genetic predispositions is covered.

One of the most important steps that should be taken	53
Important but not one of the most important steps	34
Not an important step	9
Don't Know/Refused	5

40. Ensure that the collection and use of genetic information for genetic research meet new criteria for privacy protection above and beyond the current criteria that apply to health research?

One of the most important steps that should be taken	46
Important but not one of the most important steps	41
Not an important step	7
Don't Know/Refused	5

41. Developing a complementary code of ethics to guide the collection and use of genetic information for a range of possible uses.
- | | |
|---|----|
| One of the most important steps that should be taken..... | 54 |
| Important but not one of the most important steps | 38 |
| Not an important step | 5 |
| Don't Know/Refused..... | 2 |
42. Work with the medical research community to establish standards and guidelines for use of genetic information in health research or health care services.
- | | |
|---|----|
| One of the most important steps that should be taken..... | 61 |
| Important but not one of the most important steps | 36 |
| Not an important step | 2 |
| Don't Know/Refused..... | 1 |
43. Work with other countries to establish similar systems to govern how genetic information is used in health research or health care services.
- | | |
|---|----|
| One of the most important steps that should be taken..... | 51 |
| Important but not one of the most important steps | 43 |
| Not an important step | 5 |
| Don't Know/Refused..... | 1 |
44. Engaging provincial governments on genetic information issues, to share information about federal government initiatives, and to share information on aspects that fall within provincial responsibility, like employment and insurance.
- | | |
|---|----|
| One of the most important steps that should be taken..... | 37 |
| Important but not one of the most important steps | 48 |
| Not an important step | 10 |
| Don't Know/Refused..... | 4 |
45. The Biosafety protocol is an international agreement developed by 140 countries, including Canada, to set out procedures for achieving safe trade, commercial handling and use of genetically modified organisms. Have you seen or heard anything about this agreement?
- | | |
|-------------------------|----|
| Yes..... | 13 |
| No | 86 |
| Don't Know/Refused..... | 1 |
46. Some people feel that Canada should ratify this agreement now, given the importance of having a formal international agreement on the safe transfer, handling and use of these organisms. Other people say that the Government of Canada should not ratify the Biosafety Protocol until Canada knows more of the details about the conditions it must meet and how the agreement will be implemented. Which of these two points of view is closer to your own?
- | | |
|---|----|
| Canada should ratify this agreement now | 20 |
| Government should not ratify until plan meets agreement | 68 |
| Don't Know/Refused..... | 12 |

47. In your view, is it more important to invest in science and research to support laws and regulations for biotechnology that help protect the Canadian environment, more important to invest in science and research that will help ensure Canadian industry is a leader in the field of biotechnology, or should government strike a balance between these two goals?

More important to invest Biotech that helps protect environment	20
More important to invest ensure industry is leader in biotech	10
Government should strike a balance between these two goals	68
Don't Know/Refused	2

①

Biotechnology Focus Groups

Moderator's Guide December 2003

Warm-up (5 min)

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 (15 min)

1. Have you heard of the word biotechnology?

2^{ab} What does it mean? ^{2a} What does it encompass? ^{2b}

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

4^a *Definition: Biotechnology is an umbrella term covering a range 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. Biotechnology is sometimes referred to as life sciences, genetic modification, genomics or proteomics. It includes numerous applications, everything from cross-breeding plants to genetic testing to screen for inherited diseases.*

4^b Biotechnology has applications in a number of fields. Can you recall any that you have heard of?

preamble
5^{ab} We would like to hear your reaction to various applications of biotechnology. For each of the following, please tell me if you feel that this type of application is acceptable or not acceptable to you, and why you feel that way. (a) (b)

(DISCUSS 3, ROTATED FOR EACH GROUP, FINISH WITH A HEALTH APPLICATION TO LEAD INTO THE NEXT SECTION)

5^{ab} • DNA testing, to be used in criminal investigations

6^{ab} • The genetic modification of stem cells from bone marrow to develop cells that can treat certain forms of blindness

- 7ab • The development of a test that can detect viruses like SARS in humans
- 8ab • Biofuels, such as ethanol, which are products that utilize genetically modified grains, forest products and other agricultural products to generate energy
- 9ab • GM corn, that resists herbicides
- 10ab • GM wheat, that resists pests

Health Innovation in Biotechnology (30 min)

NOTE: Lead in from previous section with a couple of health applications, like the bone marrow or diabetes applications...

The government of Canada is seeking to ensure that Canadians reap the benefits of biotechnology innovations that can be used in healthcare. I would like to give you a list of initiatives that government might pursue to spur development in this area, and ask you to react to each of them, by indicating whether you think each is be one of the most important things that government could do by putting a (1) beside them, an important thing but not one of the most important (2), or not an important thing for government to do (3).

HANDOUT 1

- 11a. ○ Increase funding for basic biotechnology research, such as investigation of the genetic causes of certain diseases
- 11b. ○ Increase funding for applied biotechnology research, such as developing products like genetic tests for inherited diseases and medicines to treat them
- 11c. ○ Establish rules that would strengthen existing privacy protection rules as they apply to genetic information used in biotechnology research
- 11d. ○ Increase funding for scientific research in aid of government evaluation of the safety of biotechnology products for Canadians
- 11e. ○ Collaborate with other countries like those in Europe and the US to evaluate the safety of biotechnology products
- 11f. ○ Speeding up the evaluation process for biotechnology products, while maintaining the same standards for product safety
- 11g. ○ Support national programs to assess the value that each of these new health technologies/treatments can provide to the healthcare system, as compared to other treatments already available – for example new treatments for diabetes involving insertion of enzymes in the pancreas versus existing processes to treat diabetes (insulin injections)
- 11h. ○ Work with provincial governments to establish common practices in the use of new technologies in provincial health care systems

preamble

ab

UxQ

Government will have to make choices and trade offs between some of these priorities, and I would like to understand the preferences you have regarding some of them. I am going to provide you with two competing priorities and want you to indicate which is most important for government to focus on as part of an initiative to promote biotechnology health benefits, and why.

- 12ab Between investment in basic research and in applied/commercial health research
- 13ab Between investment in research and helping to integrate new products into health care systems
- 14ab Between investing in regulations/safety/stewardship and in promoting research that leads to the development of health products
- 15ab Between increasing the speed of product approval processes and taking more time to assess the safety of product approvals
 - Do you think that the speed of product approval processes can be shortened and the quality of safety standards maintained?
- 16ab Between working on improving Canada's safety system and working to establish international systems to evaluate the safety of products made through biotechnology

17a → c

- Would you accept biotechnology products into Canada (without them having to go through the entire Canadian regulatory approval process) if they had been approved in Europe? Japan? US?

17a

17b

5

18a → e

- What are the major criteria by which you would assess potential new treatments that might be integrated into the health care system against those already available?

- What matters most in your assessment?
- Where does cost fit into the equation?
- If a treatment is deemed unaffordable, how will you react?
- What will you need to know/understand in order to accept that something might be unaffordable within our public system?

Economic Levers (30 min)

19

How important do you think the biotechnology sector in Canada will be in the next decade?

20

Is Canada a world leader in this field now?

21ab

What are the major advantages that Canada has in this field? Disadvantages?

21a

21b

Over the past few years, Canadian scientists have made major discoveries in the field of biotechnology. But the sector faces some problems, chiefly related to the fact that it takes a long time, 10 years or more, to turn a discovery into an application, such as a genetic test for a disease, and Canadian discoverers often don't have access to the resources to finance that development. In a number of cases the result is that US and foreign companies are buying the intellectual property from the Canadian discoverers and are developing products and applications from them.

Other circumstances that may be useful to provide context:

- Many Canadian firms can't take advantage of existing research and development tax incentives (that have to be used within 10 years) because their investments don't yield income until it is too late for them to write off the investment against that income.

- o *There isn't the scale of venture capital in Canada to adequately finance more than a few discoveries*

Some people say that the government of Canada should take measures to try and ensure that Canadian based discoveries be developed within Canada, because of the potential importance of this sector to Canada's future. Others say that the government already does enough to support research and development, and may end up wasting taxpayers money if it tried to do more, so it would be best for government not to get involved. What do you think?

In your view, where would support to this sector fit in terms of government economic priorities? Would it be at the level of health care and education? Aid to farmers re: mad cow? Climate change? Aboriginal programs? Cultural programs?

Within the narrower category of economic development priorities, where would this fit? Is it more/less important than supporting to traditional sectors (like forestry, oil and gas, farming, automotive)?

There are some measures that the government of Canada could introduce to help ensure that Canadian biotechnology turn in to Canadian products. I am going to pass you a hand-out of some of these ideas, and I would like for you to react to each, indicating whether you think this is one of the best ideas for government to do, a good idea but not one of the best, or not a very good idea. Again, for simplicity sake, please put a 1 beside the very best ideas, 2 beside the good but not best ideas, and 3 beside the ideas that you don't think are all that strong.

For each, I would like to discuss what reaction you had, and why.

HANDOUT 2

- o Extending the period under which firms can use tax credits for research and development investments, from 10 years to 15 years.
- o Allowing shareholders in Canadian biotechnology firms to claim the tax breaks that their firms are unable to use, in order to increase willingness to invest in these firms. This approach is similar to one already used by other sectors that face similar circumstances as the biotechnology sector.
- o Allowing companies who partner with Canadian biotechnology firms to use the tax breaks that the biotechnology firms are unable to use, in order to facilitate more partnerships with these firms.
- o Contributing more direct financial support to Canadian biotechnology firms, through government programs that provide seed funding to development of high technology products.
- o Contributing money to existing Canadian private sector venture capital funds, thereby increasing the pool of money available to Canadian firms. Decisions about how the funds would be allocated would be made by private sector experts who work for the venture capital fund, but the government would share in any possible profits.
- o Creating a new venture capital fund to invest specifically in health applications, including biotechnology. This fund would be funded jointly by government and the private sector. Decisions about how the funds would be allocated would be made by experts from the venture

capital industry, as well as health care experts such as doctors, health administrators, and health researchers. The government would share in any possible profits.

31ab Which, if any of these alternatives rated a (1) on your list? Why? 31a 31b

32ab Which one raises the most concern to you? Why? 32a 32b

33 Assuming that there will be a relatively small amount of new money available in the federal budget in the coming year, how important would you say it is that part of the new money (10-15%) be allocated to (the best idea out of the group)? This would mean that this would be the top economic development priority for government.

Genetic Information and Privacy (40 min)

34ab This part of the discussion is about the subject of personal genetic information. 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.

34b ○ Is genetic testing something that you might do at sometime or for some reason, or something you would probably not do?

35a The next set of issues we are going to discuss are about privacy rights in relation to genetic information. These rights involve the laws, regulations, and guidelines that govern confidentiality in the collection and use of genetic information. Privacy rights can restrict what people are allowed to know about you, and can also protect the confidentiality of your genetic information once it has been collected. I'd like to make it clear that I am not making reference to DNA in criminal investigations, rather for uses of genetic information in areas like health research.

35b ○ If you were to have a genetic test, would you be willing to contribute the information to a research database from which health researchers could investigate genetic diseases?

36 ○ Is it your opinion that genetic information should be treated differently from other health information (such as a personal medical history or family medical history) or should it be treated the same way the same as other health information? Why is that? 36c 36d

Like many other issues in Canada, genetic information is governed by a mix of federal and provincial laws and policies. The federal government is considering a series of initiatives in the area of genetic information and privacy.

37b ○ The basic goal of this effort is to strike a balance between protecting privacy and promoting health research in biotechnology. Would you say you agree with the overall goal of striking a balance between these two goals, should more emphasis be placed on protecting privacy, or should more emphasis be placed on promoting health research?

38a-79 A number of specific initiatives regarding the protection of genetic privacy are being considered by the federal government. I want to hand out to you a document that outlines some of the ideas under consideration, and gather your reactions, again looking at each initiative and indicating whether you think it is one of the most important things government can do (1), important but not one of the most important things (2), or not a very important thing for government to do (3).

HANDOUT 3

- 37a ○ Change Canada's Privacy act to make it clear that genetic samples and information from those samples are protected as types of personal information.
- 37b ○ Change the Canadian Human Rights act to clarify that discrimination on the basis of genetic predispositions is covered.
- 37c ○ Ensure that the collection and use of genetic information for genetic research meet new criteria for privacy protection above and beyond the current criteria that apply to health research
- 37d ○ Developing a complementary code of ethics to guide the collection and use of genetic information for a range of possible uses.
- 37e ○ Work with the medical research community to establish standards and guidelines for use of genetic information in health research or health care services
- 37f ○ Work with other countries to establish similar systems to govern how genetic information is used in health research or health care services
- 37g ○ Engaging provincial governments on genetic information issues, to share information about federal government initiatives, and to share information on aspects that fall within provincial responsibility, like employment and insurance

38 Are there other things that you might imagine government pursuing in this regard?

39 What might those things include?

When new genetic technologies become more widespread, they sometimes generate new issues that are not explicitly dealt with in existing laws and government policies. There are two points of view about how these potential legal "gaps" should be addressed, and the case of changing the privacy act in the way we discussed is a case in point.

40 Some people say that there is no need to change laws unless a circumstance proves there is a gap in the protection current laws provide. Other people say that as soon as a potential gap is recognized the laws should be changed before someone may try to take advantage of it. Which of those two views is closest to your own?

3

EARNSCLIFFE



Presentation to: BACC

Public Opinion Research on Biotechnology

Research Findings

December 2003

EARNSCLIFFE



Research Overview

- This wave of research was focused in five main subject areas
 - Trend lines on familiarity and overall attitudes
 - Health innovation
 - Economic levers
 - Genetic Information and Privacy initiatives
 - The Biosafety Protocol
- The research involved:
 - A national quantitative survey with a sample of 1000 Canadians
 - 8 focus groups nationwide

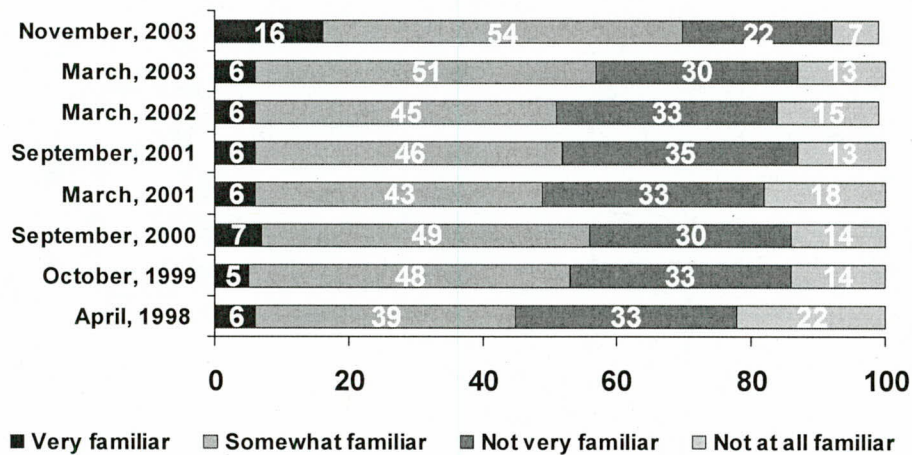
Top of Mind Attitudes

- Familiarity with biotechnology has shown signs of growth, after a long period of low levels of reported familiarity
 - Consistent with focus group results which suggest that knowledge and understanding has grown markedly over the past year
 - The improvements are so sizeable that they require confirmation in the next tracking wave
- Support for biotechnology among Canadians has risen in this wave to 2.5:1
 - Again, levels on this measure have jumped from earlier this year, which is consistent with what focus groups have indicated

3

Familiarity with Biotechnology

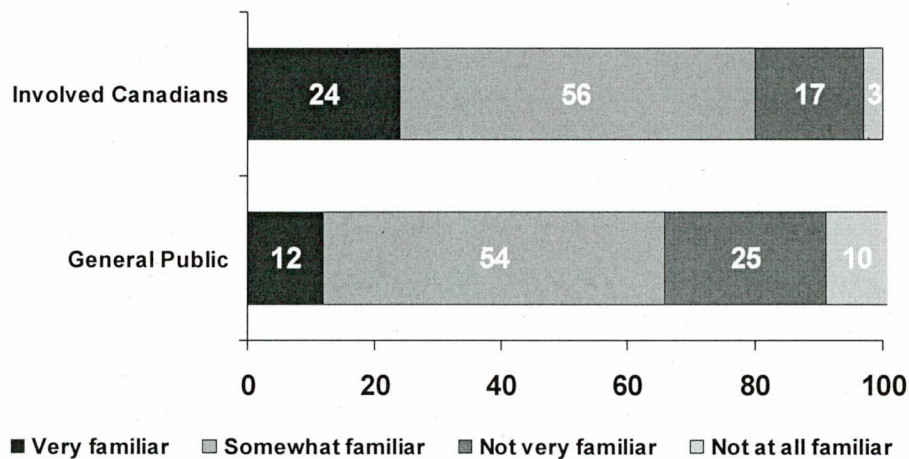
Would you say you are very familiar, somewhat familiar, not very familiar or not at all familiar with biotechnology?



4

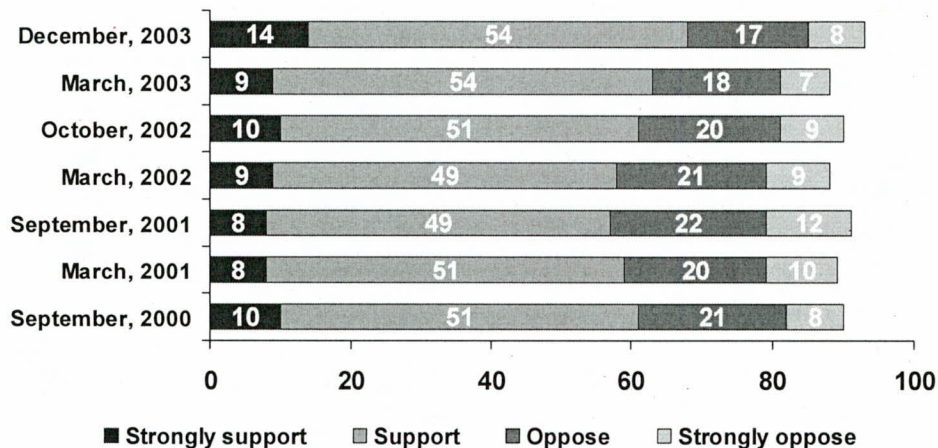
Familiarity – Involved Canadians

Would you say you are very familiar, somewhat familiar, not very familiar or not at all familiar with biotechnology?



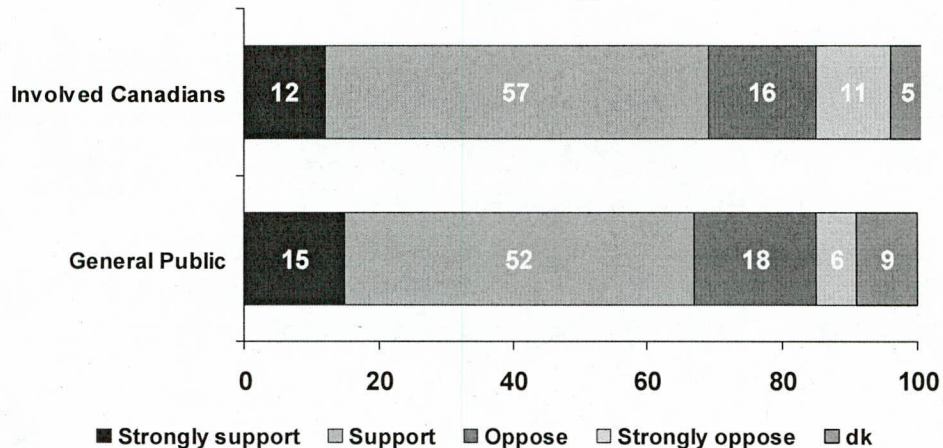
Support or Oppose Biotechnology

In general, would you say you strongly support, somewhat support, somewhat oppose or strongly oppose the use of products and processes that involve biotechnology?



Support or Oppose - Involved

In general, would you say you strongly support, somewhat support, somewhat oppose or strongly oppose the use of products and processes that involve biotechnology?

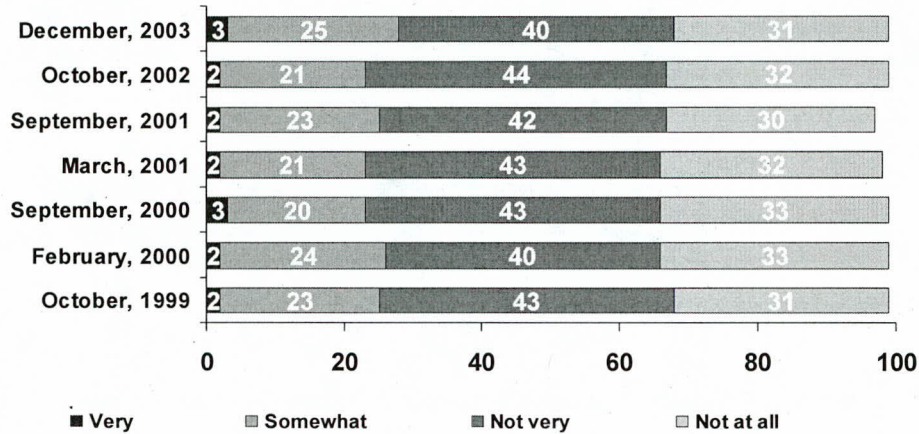


Stewardship Issues

- Canadians know little about Canada's biotechnology stewardship and regulatory regime
 - Unchanged from previous waves of research
- Their confidence in the regime is moderate
 - Half say they are very or somewhat confident
 - Fewer than one in five say they are "not at all confident"
- There is a broad consensus that more can be done, and that government probably hasn't done enough
 - "Speeding up" evaluations runs contrary to this view, erodes the already moderate level of confidence in the system
- And there is a similarly broad consensus that work should be done at the international level
 - Focus groups reinforce this finding
 - People prefer a Canadian regime but one that collaborates actively with the international community to establish standards, best practices

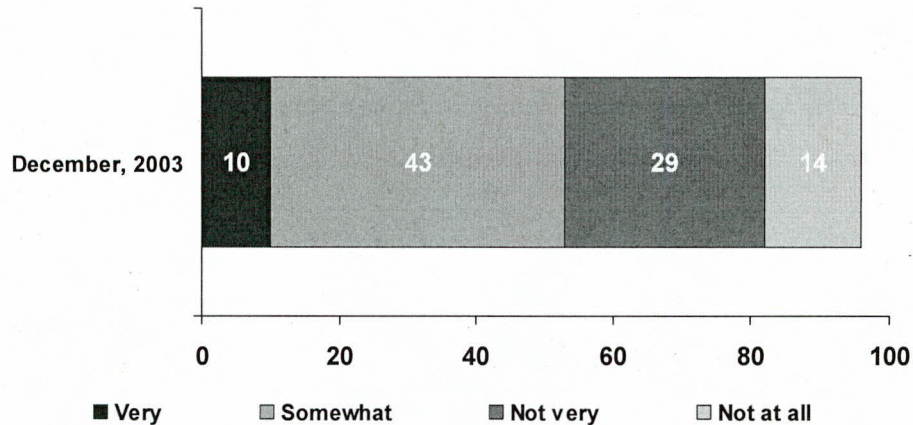
Familiarity - Regulatory System

How familiar would you say you are with the ways in which the federal government regulates biotechnology?



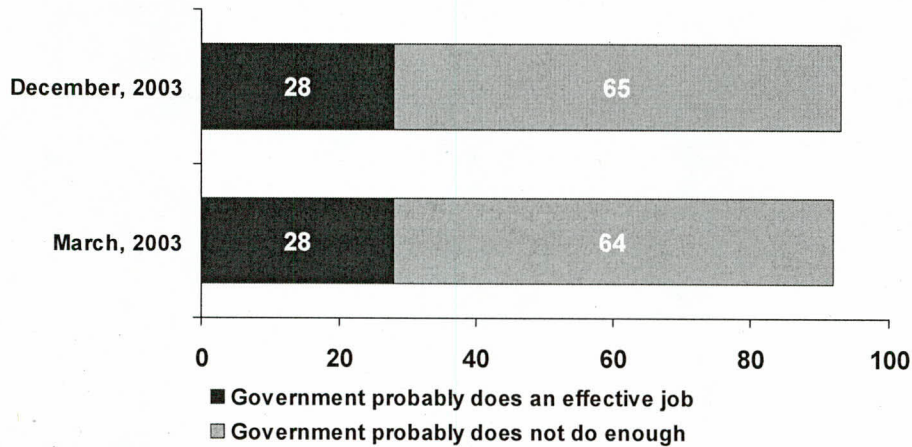
Confidence in Stewardship Regime

Would you say you are very confident, somewhat confident, not very or not at all confident in the government's ability to ensure that biotechnology products that are made available are safe?



Government Stewardship

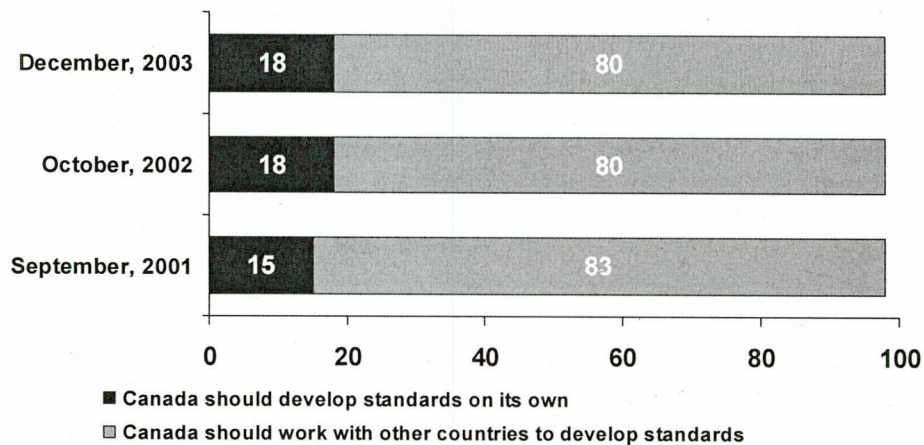
Which of the following two statements most closely reflects your view: The government of Canada probably does an effective job of studying and monitoring the impact of biotechnology products OR The government of Canada probably does not do enough to study and monitor the impact of biotechnology products



11

Regulation – Work Alone or With Others

In terms of managing the issues associated with biotechnology, do you think it is better for Canada to develop its own standards and regulations or do you think it is better for Canada to work with other nations to develop standards and regulations?



12

Health Innovation (1)

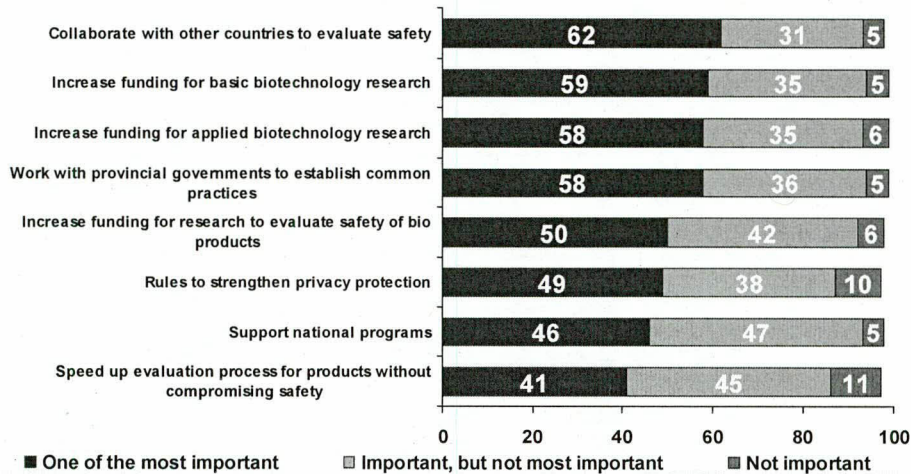
- Health is the strongest driver on the biotechnology file
 - Canadians believe that biotechnology will be a core contributor to future improvements in health care
 - And many believe they personally will benefit from innovation in this field
- Priorities lie in two areas:
 - Investing in basic and applied research
 - Participating in a more comprehensive, international evaluation regime
 - But not one that supercedes or substitutes for Canadian authority or capacity
- Little to no appetite for “speeding up” evaluation processes, even with assurance that safety will not be compromised
 - Speeding up the process undermines already tenuous belief that system is sound

Health Innovation (2)

- In groups, a series of forced choices were put to respondents
 - Balance sought between basic and applied
 - More lean toward dedicating resources to health application research than regulatory research
 - Groups suggest this is not because regulatory research is a lower priority, but because it is not seen to be as costly
 - Canadians want comfort that the stewardship regime is capable of dealing with this new technology
- On the issue of evaluating how products will integrate into health care systems, people generally want to leave that to experts
 - Seen as extremely complex, too many considerations for them to take into account
 - Would need specifics of each case to assess properly

Health Innovation

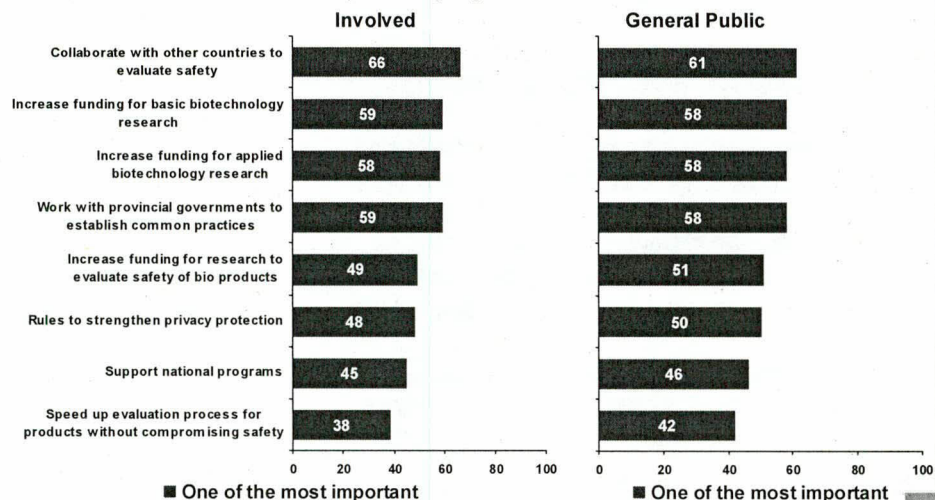
The government of Canada is seeking to ensure that Canadians reap the benefits of biotechnology innovations that can be used in healthcare. I would like to read you a list of initiatives that government could pursue to promote development of these innovations, and ask you to react to each of them, by indicating whether you think each is one of the most important things that government could do, an important thing but not one of the most important, or not an important thing for government to do.



15

Involved vs General Public

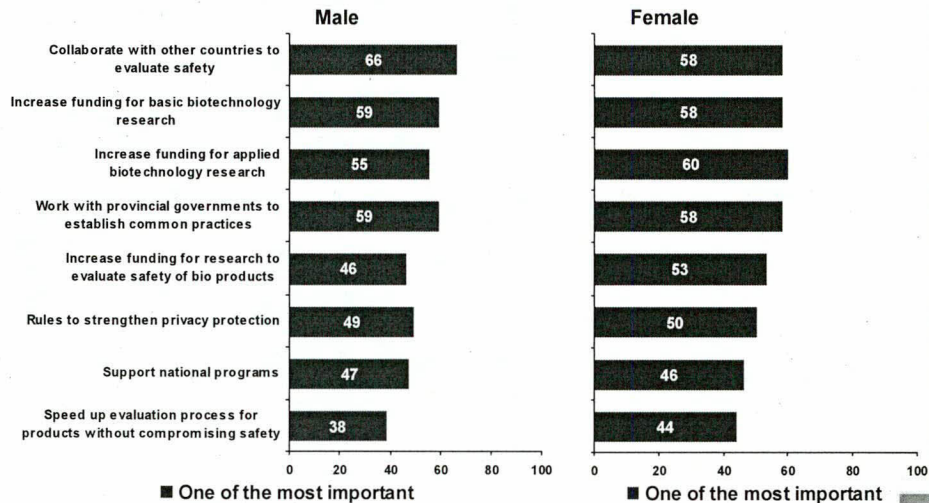
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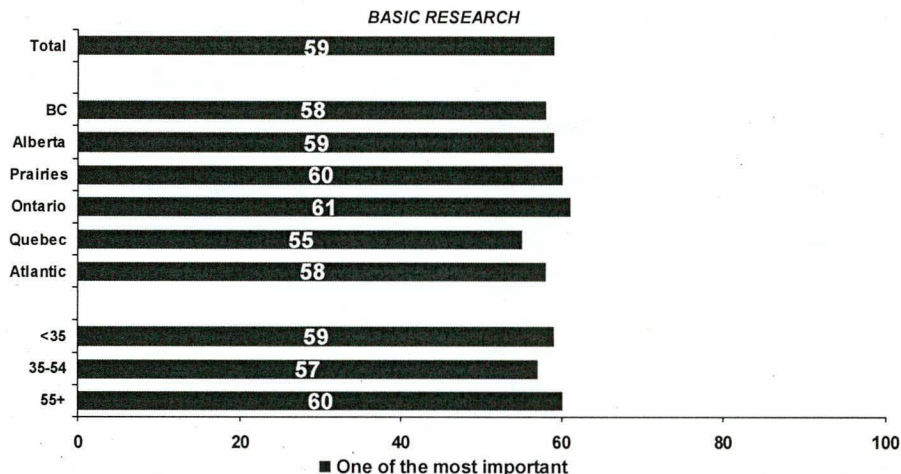
Male vs Female

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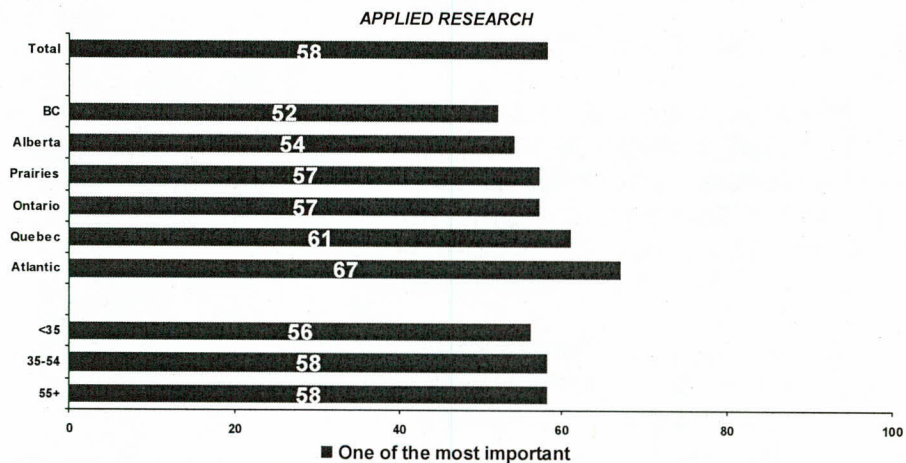
Priority: Basic Research

The government of Canada is seeking to ensure that Canadians reap the benefits of biotechnology innovations that can be used in healthcare. I would like to read you a list of initiatives that government could pursue to promote development of these innovations, and ask you to react to each of them, by indicating whether you think each is be one of the most important things that government could do, an important thing but not one of the most important, or not an important thing for government to do.



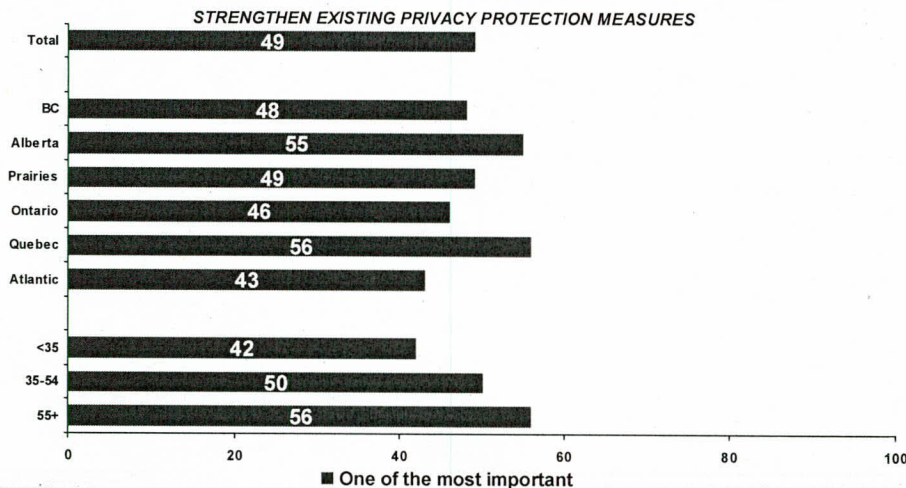
Priority: Applied Research

The government of Canada is seeking to ensure that Canadians reap the benefits of biotechnology innovations that can be used in healthcare. I would like to read you a list of initiatives that government could pursue to promote development of these innovations, and ask you to react to each of them, by indicating whether you think each is be one of the most important things that government could do, an important thing but not one of the most important, or not an important thing for government to do.



Priority: Privacy Protection

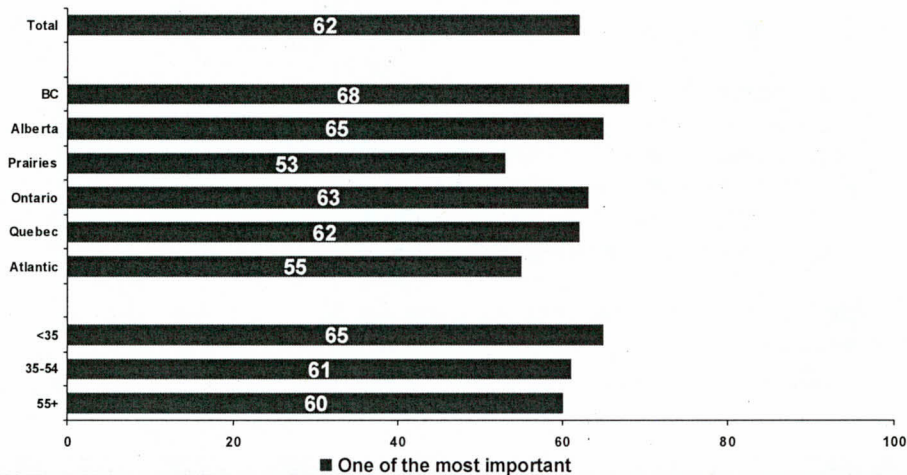
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Priority: Collaborate with Others

The government of Canada is seeking to ensure that Canadians reap the benefits of biotechnology innovations that can be used in healthcare. I would like to read you a list of initiatives that government could pursue to promote development of these innovations, and ask you to react to each of them, by indicating whether you think each is be one of the most important things that government could do, an important thing but not one of the most important, or not an important thing for government to do.

COLLABORATE WITH OTHER COUNTRIES



Economic Levers

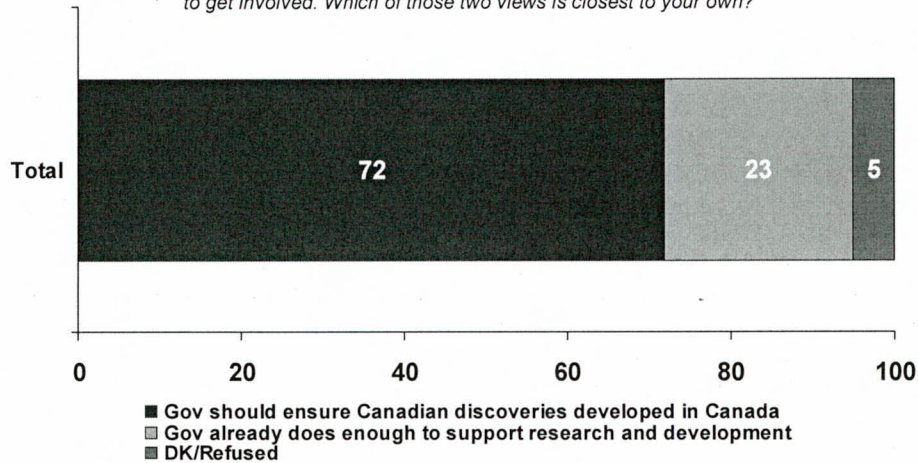
- Respondents were given a brief on the characteristics of the biotechnology sector, and were asked two core questions:
 - Whether government should do more to foster this sector
 - Appropriateness of 6 possible economic levers

- When provided with a brief overview of the Canadian sector and its current circumstances, most say government should take further steps to ensure its success going forward
- While the subject was complex for some, involved Canadians were able to weigh in on the issue thoughtfully
 - They know more about tax credits and venture capital than some may realize, largely because of the number that are invested in mutual funds and the stock market
- Support for a greater government role is relatively broad, but not deep
 - A small majority see this sector as being very important in terms of jobs and growth in the future, while the rest are unsure
 - The main reason why people say they think government should take steps is because of the potential health benefits involved

- Among the alternatives, one stood out in the survey, three in the groups
 - In the survey, establishing a venture capital fund that would be run by private sector experts but include health care experts in decision making roles was the most appealing option
 - People like the idea, specifically because people believed that decisions made by such a fund would not only take bottom line considerations into account, but other "public interest" considerations as well
 - i.e. disease treatments that may not involve a high number of cases may warrant venture capital support even if it might not make more money than other potential investments
 - And that Canada is a small country with a small pool of venture capital, compared to the US
- In groups, the venture capital fund was also found appealing, as well as two other options:
 - Extending the R&D tax benefit from 10 to 15 years
 - Many feel that the current problem with unused R&D tax credits is one of fairness rather than handouts, given the fact that these companies have earned the R&D credits, but just can't use them
 - Establishing a flow through share model where shareholders could write off the tax breaks allotted to firms
 - People saw that they personally (and any Canadian) might be able to benefit from the situation
 - These tax credit options are also well grasped by respondents -- there is an analogy between RRSP deductions and R&D deductions that makes the subject relatively simple to explain

Economic Levers

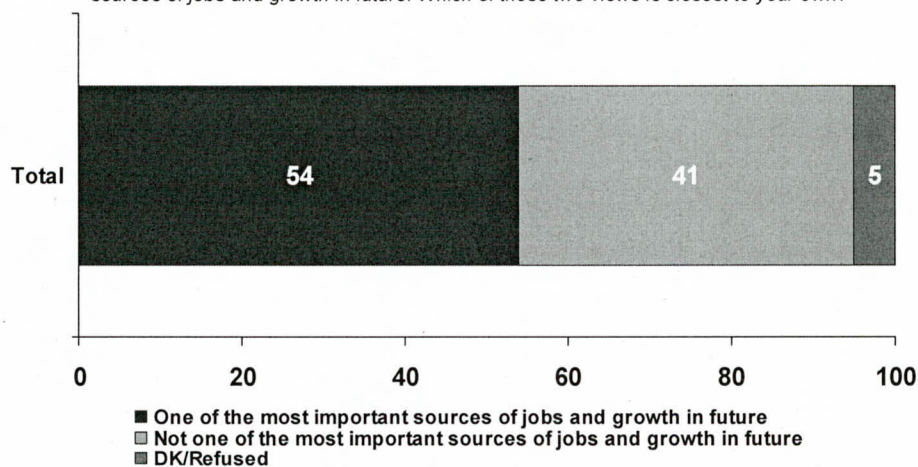
Some people say that the government of Canada should take measures to try to ensure that Canadian based discoveries are developed within Canada, because the private sector in Canada is not doing enough. Others say that the government already does enough to support research and development, and may end up wasting taxpayers money if it tried to do more, so it would be best for government not to get involved. Which of those two views is closest to your own?



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Biotechnology: Source of Jobs/Growth?

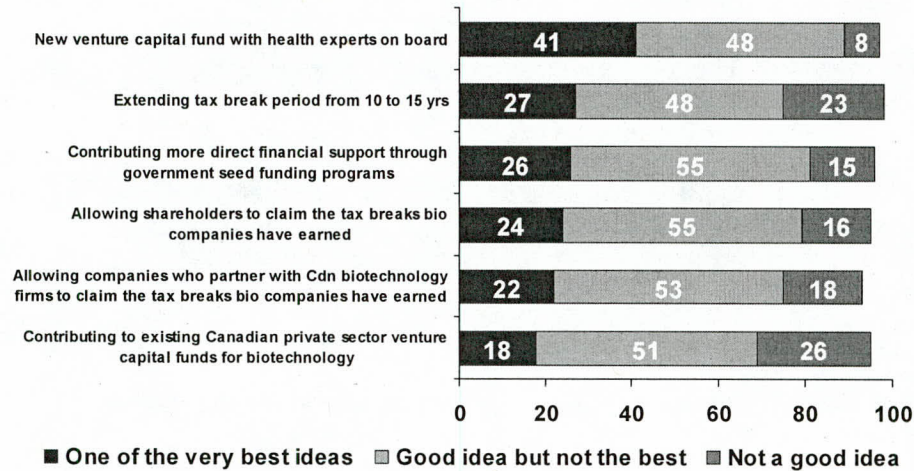
Some people say that biotechnology will be one of the most important sources of jobs and growth in future. Others say that this sector might be important now, but might not be one of the most important sources of jobs and growth in future. Which of those two views is closest to your own?



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Economic Levers

There are some measures that the government of Canada could introduce to help ensure that Canadian biotechnology discoveries turn into Canadian products. I would like to read you some of the ideas under consideration, and want you to indicate whether you think each is one of the very best ideas, a good idea but not one of the best, or not a good idea.



27

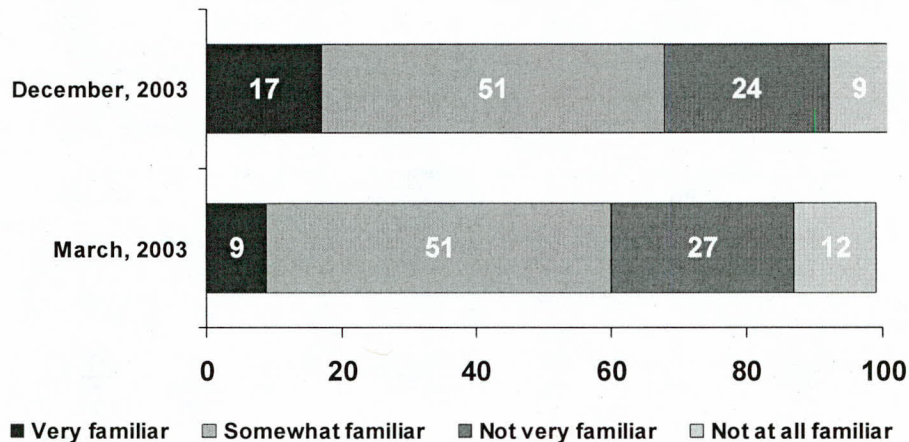
Genetic Privacy -
Familiarity and Interest

- Trends identified last spring have been confirmed this wave
 - Low initial engagement, high engagement upon discussion, strong but considered views offered
 - Which suggests there will be public profile once debate begins, at least among Involved Canadians

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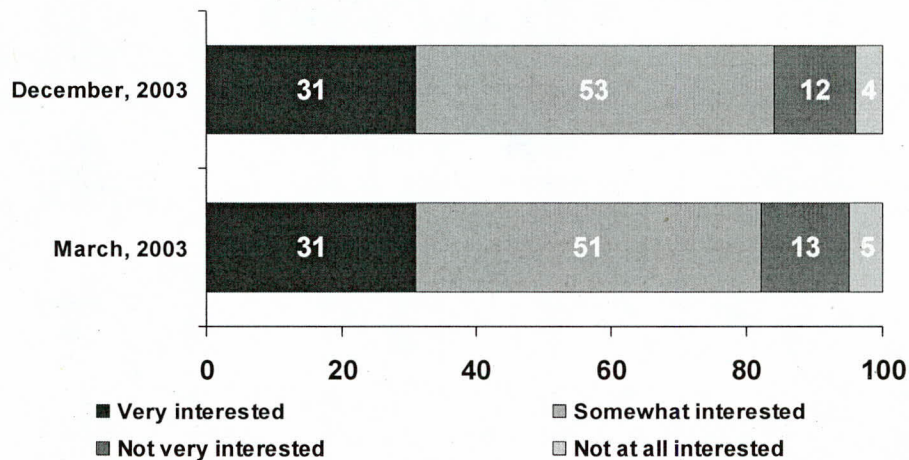
Familiarity with Genetic Information Issue

Would you say you are very familiar, somewhat familiar, not very familiar, or not at all familiar with issues involving genetic information?



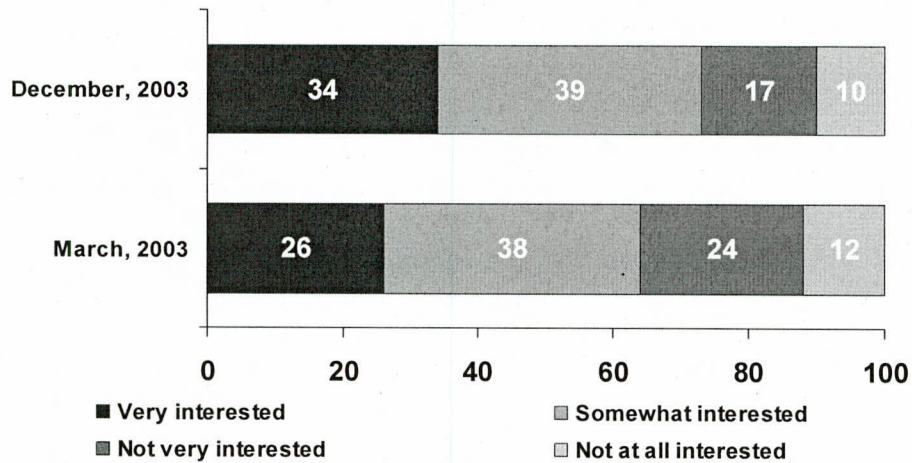
Interest in Genetic Information Issue

Would you say you are very interested, somewhat interested, not very interested, or not at all interested in issues involving genetic information?



Interest in Learning More About Your Genetic Information

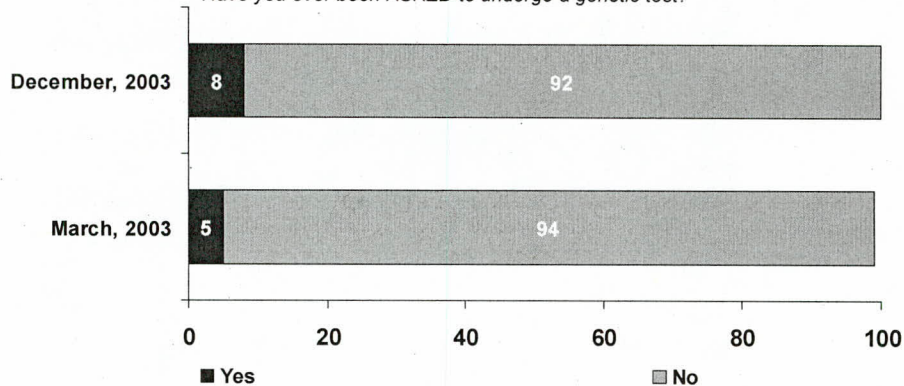
Would you say you are very interested, somewhat interested, not very interested, or not at all interested in knowing more about your own genetic information?



Genetic Test

Genetic testing is a scientific process where genetic information is determined about a person, by testing biological material like blood or saliva samples to reveal genetic characteristics. The information is used to help determine how much risk people have of developing some inherited diseases, like huntington's disease or cystic fibrosis.

Have you ever been ASKED to undergo a genetic test?



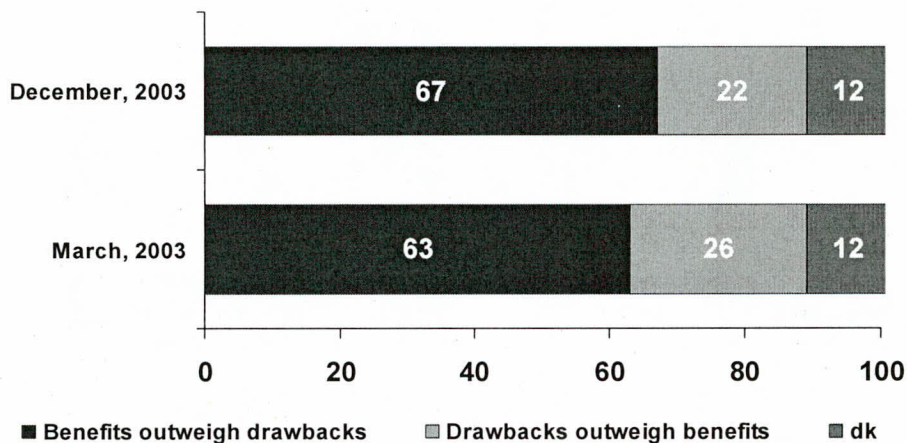
Benefits and Drawbacks

- A large majority believes 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 the importance that this kind of research will have on the future of health care and health treatment

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Overall: Benefits vs. Drawbacks

Is it your opinion that the benefits of knowing more about our genetic information outweigh the drawbacks, or do the drawbacks outweigh the benefits?



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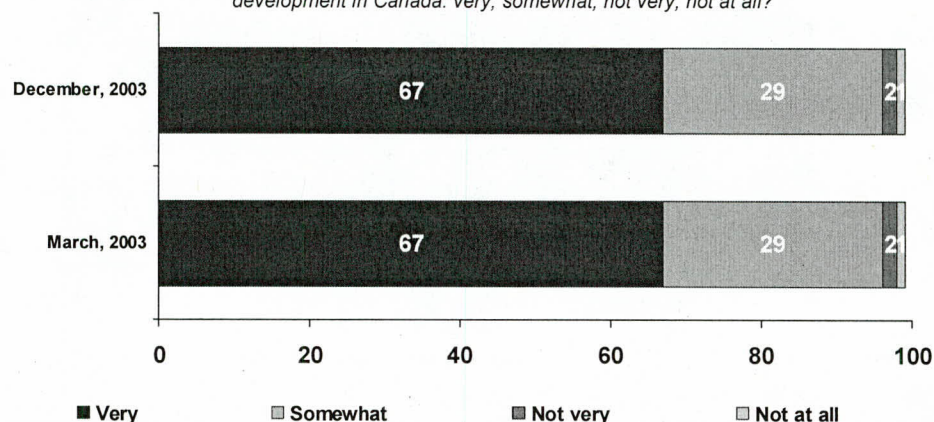
- An overwhelming number of Canadians sees genetic research as central to the future of medical research
 - Willingness to allow personal genetic information to be used in medical research is quite high
 - It gets higher as benefits are introduced
 - But has fallen slightly since the spring, and focus groups suggest that this is chiefly attributable to privacy concerns
 - Groups suggest a chill effect on genetic testing is already occurring, where people have declined tests because of uncertainty about what insurance companies will demand from them at some point in future
- Willingness to contribute genetic information to research reaches its highest point when privacy provisions are introduced, like stripping identity from the database

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Importance of Genetic Info to Health Research

Increased scientific knowledge about our genetic characteristics has implications for health and medical research. Many health and medical researchers are dedicating themselves to learning more about the ways in which genetic information determines how and why certain people develop disorders and illnesses by studying genetic information from large groups of people.

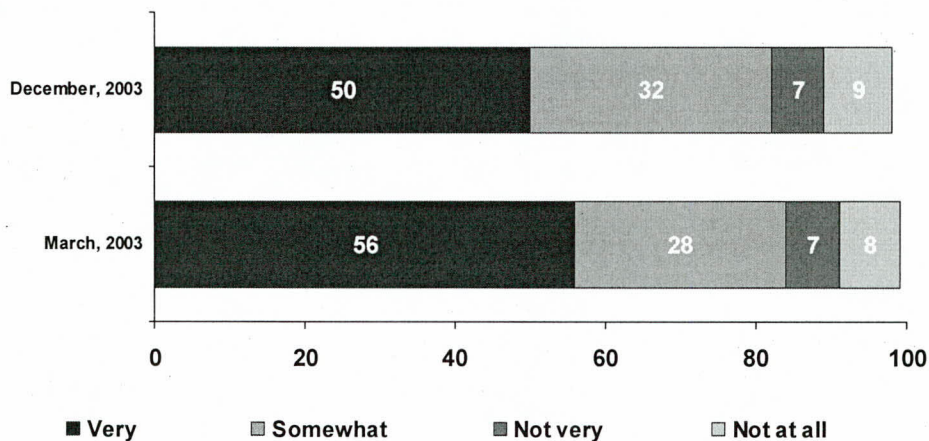
In the future, how important a role do you think genetic information will play in health research and development in Canada: very, somewhat, not very, not at all?



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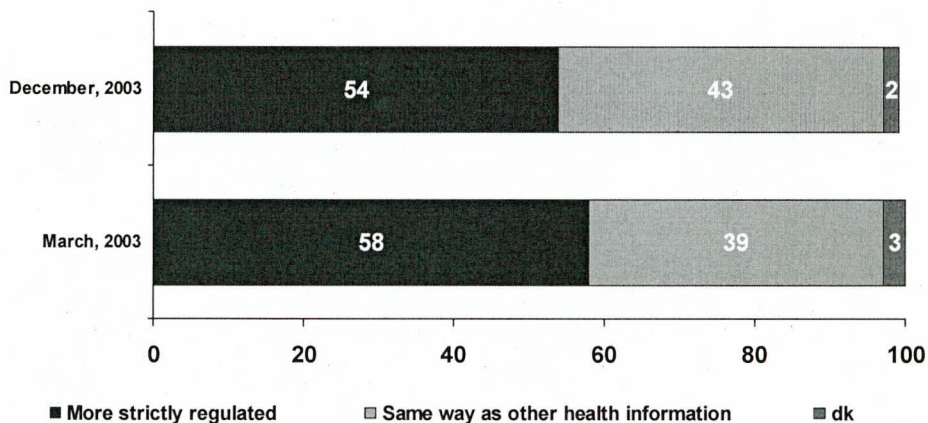
Willingness to contribute to research

*If you had a genetic test, would you be very, somewhat, not very or not at all willing to contribute the information to a database that would be used for health research if **your identity was stripped from the database?***



Rules More Strict on Access to Genetic Information?

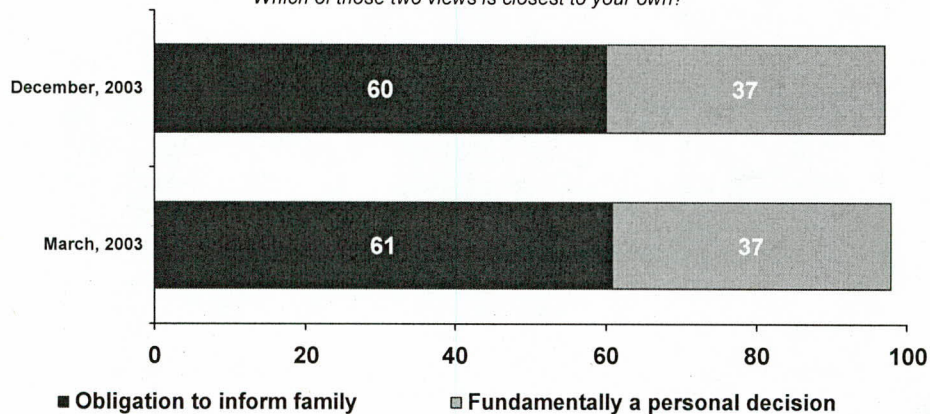
Do you think the rules governing access to genetic information should be more strictly regulated than other health information, or should it be regulated in the same way as other health information?



Forced Choice: Individual vs. Family Rights

Some people say that a person who has a genetic test has an obligation to inform family members of the results if there is something that might affect those family members. Other people say that a person who has a genetic test does not have an obligation to inform family members of the results even if there is something that might affect them, that sharing such information is fundamentally a personal decision.

Which of those two views is closest to your own?



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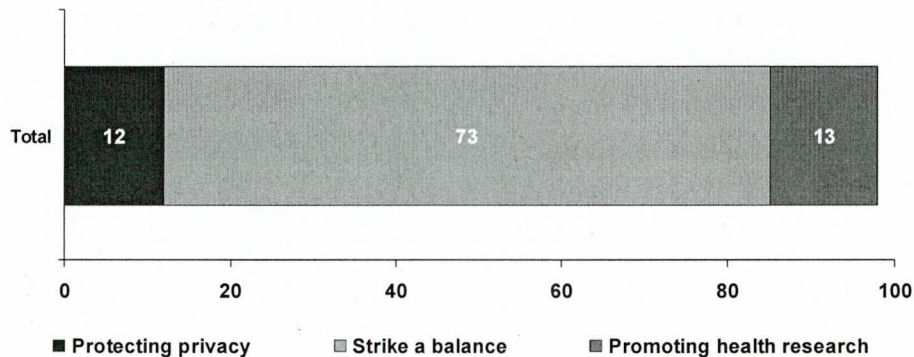
Privacy Governance Priorities

- Most do not want to choose between protection of privacy and health R&D
 - Most say striking a balance between the two is the best approach
- The GI&P working group positioning was widely accepted by survey and focus group respondents
 - Striking a balance seen as the most appropriate way forward
- But groups suggest that concern about privacy will grow if some of the measures proposed are not pursued
 - Will lead people to focus more attention on the privacy issues, fostering worry that government is not taking care of these issues
 - The resultant increase in urgency about privacy may undermine the R&D considerations at play, and with it undermine the consensus around striking a balance

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The federal government is considering a series of initiatives in the area of genetic information and privacy.

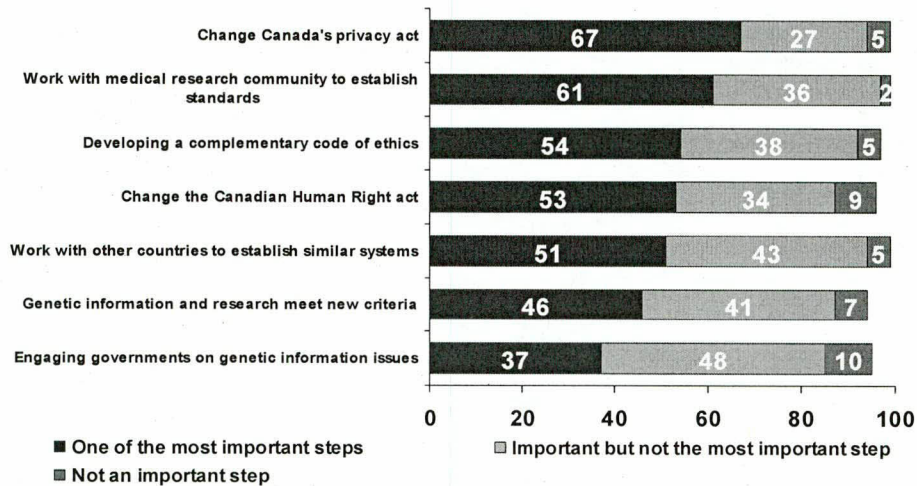
The goal of this effort is to enhance Canadians' privacy protection and freedom from discrimination while enabling them to benefit from genetic research and health innovation. The basic principle is to strike a balance between protecting privacy and promoting health research in biotechnology. Would you say more emphasis be placed on protecting privacy, more emphasis be placed on promoting health research, or you agree with the idea of striking a balance between these two goals?



- A series of potential measures to address genetic privacy issues were tested in the survey and groups
 - Clear, consistent priorities emerged, although most of the measures were accepted
- The top priority was the revision of the privacy act to specifically protect genetic information
 - In the survey, the second priority was to work with the medical community to establish ethical standards in health research
 - In groups, the second priority was to include genetic privacy protection in the Canadian Human Rights legislation
- People believe that changes like the ones tabled in this research should be integrated into legislation before a legal challenge occurs
 - People invoke the concept of preventive action
 - No real affinity for the way in which laws are traditionally changed through court challenges, particularly in this area where people perceive the stakes to be high

Justice Potential Measures

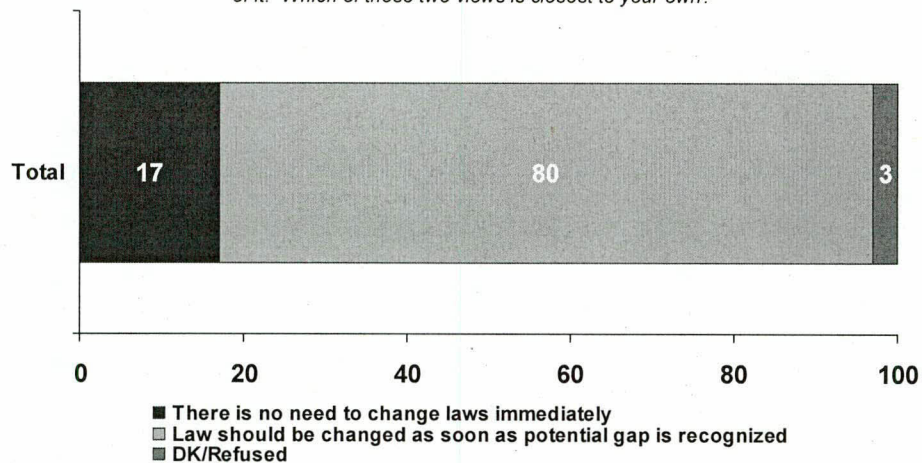
A number of specific initiatives regarding the protection of genetic privacy are being considered by the federal government. I will outline each initiative briefly. For each, please indicate whether you think this is one of the most important steps that should be taken, important but not one of the most important steps, or not an important step.



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When to Change Laws?

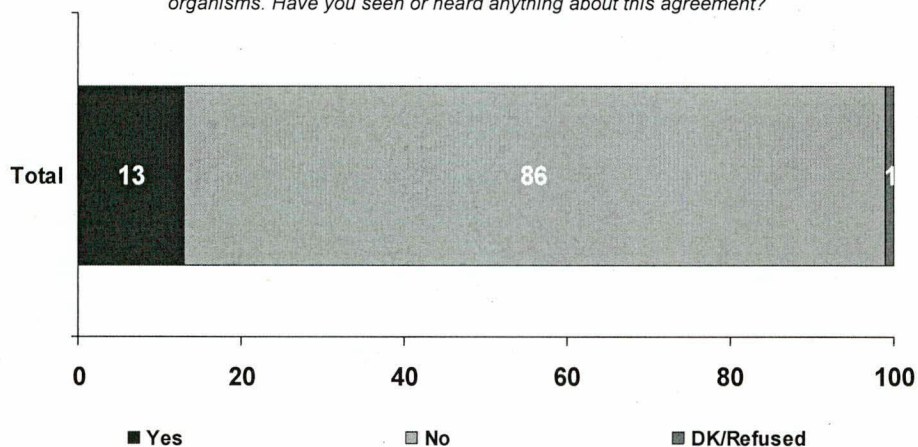
Some people say that there is no need to change laws immediately, and they should only be changed if someone proves there is a gap in the protection current laws provide. Other people say that as soon as a potential gap is recognized the laws should be changed before someone may try to take advantage of it. Which of those two views is closest to your own?



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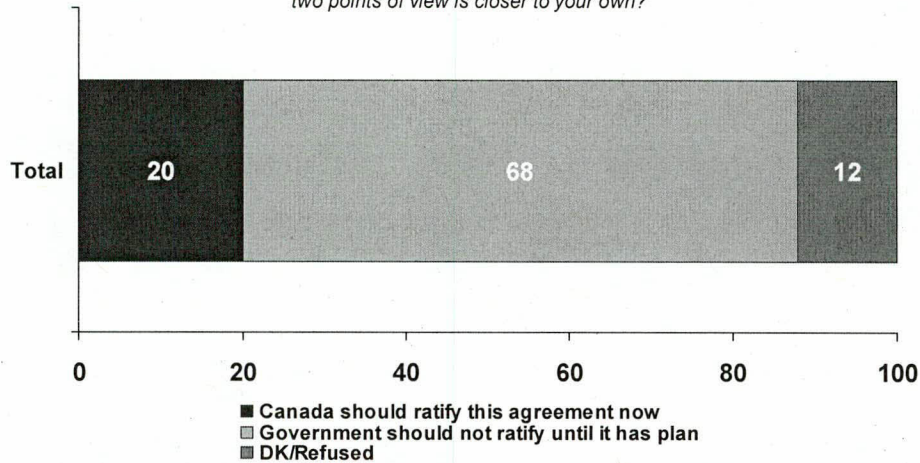
- Awareness of Biosafety Protocol is not very high
- Most say ratification should be preceded by a plan and objective setting process
 - Rather than followed by such a process
- The vast majority says government should strike a balance between developing the stewardship regime for the environment and fostering the economic development of the environmental biotech sector
 - With a very slight tilt toward the stewardship function

The Biosafety protocol is an international agreement developed by 140 countries, including Canada, to set out procedures for achieving safe trade, commercial handling and use of genetically modified organisms. Have you seen or heard anything about this agreement?



Ratify Biosafety Protocol?

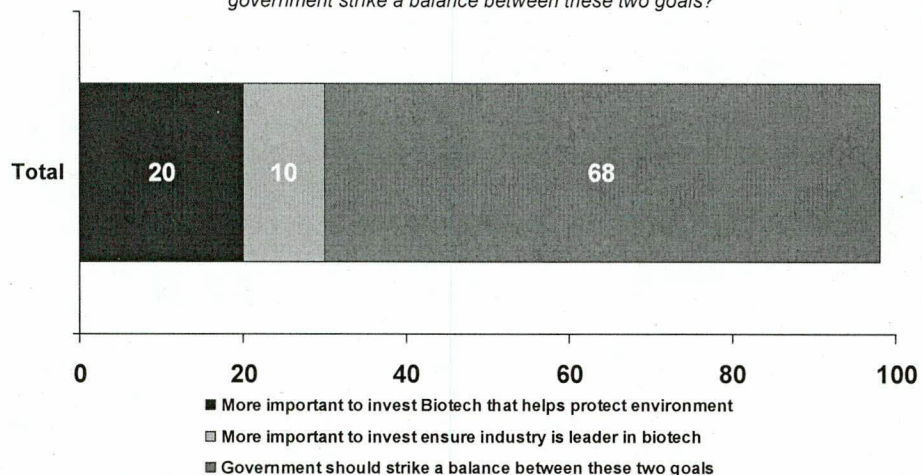
Some people feel that Canada should ratify this agreement now, given the importance of having a formal international agreement on the safe transfer, handling and use of these organisms. Other people say that the Government of Canada should not ratify the Biosafety Protocol until Canada knows more details about the conditions it must meet and how the agreement will be implemented. Which of these two points of view is closer to your own?



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How Should Government Invest?

In your view, is it more important to invest in science and research to support laws and regulations for biotechnology that help protect the Canadian environment, more important to invest in science and research that will help ensure Canadian industry is a leader in the field of biotechnology, or should government strike a balance between these two goals?



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