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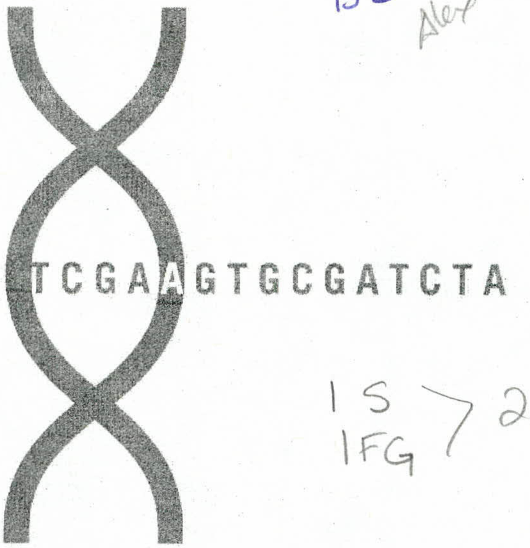

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PUBLIC OPINION RESEARCH INTO GENETIC PRIVACY ISSUES

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

March 2003

FINAL REPORT

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

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

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Introduction

Pollara Research and Earnscliffe Research and Communications are pleased to present this report on a public opinion research program into genetic privacy issues conducted in February and March 2003 for the Assistant Deputy Minister Coordinating Committee (BACC), Government of Canada.

The work comprised two instruments:

- a telephone survey of 1200 Canadians;
- one night of focus groups (a total of 2 groups) designed to support the survey by probing nuanced and underlying opinions.

The research was commissioned to establish a baseline of opinion on a range of genetic privacy issues in order to support the work of a Government of Canada task force that is looking at policy development in the area. Among the areas probed were:

- general familiarity and awareness of genetic information and privacy issues;
- willingness to undergo, and experience with genetic testing;
- perceptions of the current and preferred governance models for privacy in connection with personal genetic information;
- the role of research and potential privacy constraints on its use of genetic information; and
- the degree to which insurance companies should have access to existing genetic information.

The telephone work began on February 10, 2003, and ended on February 20, 2003. The survey reports on the views of a random sample of 1200 Canadians and carries a margin of error for the national sample of +/- 2.8%, nineteen times out of twenty.

One night of focus groups (two groups in all) was conducted in Toronto on March 6, 2003 and drew participants from our proprietary public opinion segment called *Involved Canadians*, a 30% cluster of the Canadian population that is more involved in public affairs and more informed about and interested in emerging public policy issues.

The focus groups followed a set agenda for discussion and probed in more detail opinion underlying the results of the telephone surveys.

This report consists of a number of documents:

- A written summary of findings, which combines the results of the telephone survey and the focus groups. It indicates where the focus group discussions either elaborated on or deviated from the survey results.

- A Moderator's Guide used in the focus groups.
- A survey questionnaire with overall quantitative results and
- A presentation "deck" -- a precis of the main findings illustrated with quantitative data.

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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Summary of Findings

Overall Impressions

Canadians have not yet engaged in any profound way in thinking about the privacy implications in the coming revolution in personal genetic information. Though they are fully aware of the kinds of personal inferences that could be gleaned from genetic information, they haven't been exposed to much discussion about the privacy implications. Nevertheless, they have no trouble thinking those through, understanding potential consequences and trade-offs and reaching conclusions quickly.

Genetic information is generally seen in the same light as health information though many believe it to be more fundamentally personal with more worrying implications for abuse. Most people default to a desire for strong privacy controls over genetic information but their views become quite considered and nuanced as they think about the health and medical research uses for this kind of information. They are much less sanguine about any uses that might potentially disadvantage individuals or allow discrimination on the basis of genetic characteristics.

On the whole, most people believe there are more benefits from knowing more about our genetic information than drawbacks. Most show a strong interest in having access to their own genetic information in the number of instances they believe it could make a substantial difference to their personal health and welfare.

Genetic Information – Familiarity and Interest

There appears to be good basic understanding about what genetic information might indicate about inherited traits. Most people (over 90%) have no trouble identifying what conclusions might be drawn from genetic information – for instance, the risk of contracting inherited diseases like Huntington's – and what could not – for instance, the risk of getting into a car accident.

Discussion reveals that while some over-estimate the extent to which current technology can pinpoint the genetic roots of particular characteristics, most know some of the diseases that are genetically transmitted and the reality that there is much less information about the vast majority of potentially inherited characteristics.

The genetic diseases that people tend to be most aware of are breast cancer (BRCA), Huntington's Disease and Alzheimer's. In addition, a sizeable number of people understand the fact that most genetic tests can only identify pre-dispositions, or levels of risk for diseases, and that only a few can provide certainty about the likelihood of a disease manifesting itself in a person.

While most *Involved Canadians* are in fact quite familiar with the subject, people generally underestimate their own familiarity. Self-assessed knowledge about the field is relatively low with fewer than one in ten saying they were "very familiar" with the subject matter. As we have seen on other issues associated with biotechnology, many people have a sense that there is "more going on than anyone could possibly keep up on" in this area. While in terms of specific research studies that may be true, *Involved Canadians*, and to a lesser extent the general public, have good basic understanding of the subject matter and the processes by which research and testing are done. This is one of those rare subjects in public opinion research where people truly underestimate their level of familiarity with an issue.

Interest levels are somewhat higher than familiarity – about one in three say they are "very interested" in the issues involving genetic information. However, other than those who have friends or family members with medical problems where genetic research holds some promise, most say they don't follow the subject that closely. Most say they will read a newspaper story or watch a news program about this subject if they come across it but do not search out information in the subject area.

Genetic Testing

Most Canadians believe that genetic testing is not common and do not know anyone who has been tested. Only about 10% say they or a family member has been asked to undergo a genetic test -- almost always by a doctor. Of survey participants who reported undergoing testing, most said that the results had been provided to them by a doctor, professional counsellor or both.

Most focus group participants felt that genetic testing was a relatively new area that was not widespread but probably growing. Generally, people sensed that those with high risk of contracting specific disease may have undergone testing but overall, it probably involves a fairly small proportion of the population. The survey results indicated that only 5% of Canadians thought testing was very widespread.

However, Canadians express a fairly high level of interest in learning more about their own genetic information – more than 60% showed some interest while only one in ten said they were not at all interested. Virtually everyone (up to 95% in one circumstance) would be willing to undergo genetic testing in specific circumstances.

- 95% said they would undergo genetic testing if it would determine the best medical approach to dealing with a disease or condition they had.

- Only slightly fewer (89%) said they would agree to testing to determine if there was an inherited disease they might pass on to their children.

There were comparatively lower levels of willingness to test for general purposes of "being more informed" about their genetic make-up, but nevertheless, 58% said they would undergo testing simply to obtain more information about their own genetic characteristics.

Focus group discussions showed that people who were lukewarm to the idea of taking a genetic test for purposes of information-seeking did not see how that information would benefit them. In fact, some suggested that having such a test -- particularly when the result might only provide an indication of possible risk -- might cause undue fear in people about "something they don't have any control over." These people believed that genetic testing for information's sake alone might do more harm than good.

Focus group discussion revealed that there are three main considerations at play when people try to decide whether to undergo genetic testing. They are:

- **The purpose of the test** -- in particular whether there is evident danger to their health or the health or their children from a genetic disorder. In many cases, people said the main reason they might end up having a test is because of some information in their family history that suggests they may be at higher risk.

- **Whether the test would yield an unequivocal (or almost unequivocal) answer as to whether a disease will manifest itself in a person**, or whether the test would only be able to place a person's risk somewhere on a broad continuum. If it would not yield a relatively clear answer, people were not sure that having such a test would benefit them (or their children) and were less prepared to undergo a test.

- **Whether there is a cure, treatment, or preventive measure that can be taken to address the disease or condition**. If not, willingness to have a genetic test is much lower – many said that there wasn't much point in knowing about something that you were powerless to address.

It is evident that like in most areas of biotechnology (other than human cloning), people generally come at the issue of genetic testing from the perspective of risk and benefit to themselves, not from a moral or ethical stance.

- Almost 90% disagree with the proposition that they might not test themselves or their children because there is something "morally wrong" with genetic testing.

- Similar numbers of people (82%) say the benefits that will come from genetic testing outweigh the moral objections that some people have to this type of testing.

- In focus groups, there was a handful of people that did come at the issue with moral objections, suggesting that it was wrong to "play God" in this way in any circumstance.

However, even these people did not believe there was a moral dimension to testing *itself*; rather the moral dimension involved the *purpose* to which the results of testing might be put. Unethical use of test results concerns many more people than those who have intrinsic moral objections. Almost 80% believe government should have the right to prevent the use of genetic testing if it deems the tests' purpose to be unethical.

Most people see genetic testing technology as a form of progress in health and medical treatment that properly regulated, could provide important benefits to Canadians.

Most people do draw the line, however, at the concept of home genetic testing kits. At a minimum, those who would allow them would only do so under strict medical referral and supervision. But fully 37% would ban them altogether. In discussions, people expressed two major reservations:

- The first was concern about people taking tests on their own, assessing the information improperly and taking steps based on improper information, particularly when the information that the tests will likely yield will be in risk probabilities, not unequivocal yes/no answers.
- The second was concern about people testing others without their knowledge or consent. Again, if tests were widely available "over the counter", people imagined all sorts of ethical and legal problems with people testing others, a proposition that was of fairly grave concern to some.

Rights Issues

The belief that everyone has the right to choose to be tested is deeply entrenched. As an abstract principle, its appeal is virtually universal.

- Fully 92% of Canadians agree with the proposition that it should be each person's right to determine whether or not they have a genetic test.
- Even if difficult social consequences to testing are posited, fully 75% believe it is still an individual right.
- Only 20% agreed that government should ban testing if it was leading to a variety of pressures on people to take tests they didn't want to take.

However, where rights start to conflict, people feel cross-pressured and the absolute insistence on the primacy of personal rights begins to weaken.

- For instance, some people begin to drop off from the 92% majority when their absolute right is posed against the potential consequence to family members – like their risk of inheriting disease.
- In a forced choice (one people do not want to make), 61% believe that there is an obligation to inform family if there is something that might affect them. Only 37% believe that sharing such information is a fundamentally personal decision.
- When informing family is laid out simply as a value (i.e. there is no mention of fundamental personal rights), 82% concur. Interestingly, 86% believe that family members have a right *not* to know, even if there is a possible problem for them in the future.

In the focus groups, the difficult "rights" trade-offs that genetic privacy issues raise were tabled for discussion. While troubling to some, most were able to make their way through them and come to firm views.

Confidentiality/Access -- Personal Genetic Information

Concern about the confidentiality of personal information is high – particularly when it comes to financial (75% express some level concern) and medical (60%) information. Concern is far less prevalent about personal genetic information (47%), largely because most people haven't seen evidence that it is being widely gathered.

People tend to believe that procedures governing the confidentiality of their personal health information are stringent -- though they are far less certain that is true for their personal financial, communications or genetic information. In fact virtually no one expresses any familiarity at all with regulations and guidelines governing the collection and use of genetic information.

At first glance, Canadians appear to be divided about whether genetic information is fundamentally different than health information -- some regarding genetic information as a subset of health information. However, when asked whether access to genetic information should be more strictly regulated than other health information, 58% said it should be, revealing more of the underlying opinion than the simple initial question does.

- **Following the point up in focus groups, it became clear that for many, genetic information is more personal and more fundamental to identity.** In discussion, most people indicated they would be more disturbed if their personal genetic information was inadvertently made public than if their health records had been.
- **Most people regard their health information as relatively routine, based on medical reality and non-embarrassing** – though that appears to differ for mental health information. However, they believe genetic information is more likely to centre on predisposition than medical reality and might lead to misconception and abuse.

Given the degree to which they regard genetic information as deeply personal, it is not surprising that they have widely diverging levels of comfort with different groups or individuals having access to genetic information. There is a high level of comfort with doctors and medical researchers having access and startlingly low levels of comfort with governments, insurance companies or employers having such access.

Genetic Research

The high comfort levels with medical researchers having access to personal genetic information stems from the nearly universal conviction in Canada that genetic research is central to the future of medical research.

- The vast majority of people (78%) are willing to contribute the information from their genetic test results to a data base that would be used for medical research.

- That number gets higher, nearing 90% as the potential benefits of research are introduced into the discussion. Willingness reaches its high point when privacy protections are part of the equation, for instance stripping identities from the data base.

There are far higher levels of comfort in contributing information to medical researchers than to health care companies. Medical researchers are far more trusted to do what is right and are given more latitude in their ability to access information. Consistent with other research in the health field, Canadians express more resistance to the idea of enabling profit in the field of health care than they do to what they perceive to be "altruistic" activities. Only 22% would deny medical researchers access to Canadians' genetic information while 49% would do so for health care companies.

Much of that resistance seems to rest on top-of-mind attitudes towards health care and pharmaceutical companies (most presume they are one and the same.) As arguments were advanced that linked restricted access by health care companies to the possibility of fewer new treatments, two-thirds of those who originally favoured restricting access changed their minds. However, they still stipulate that the information given to health care companies be provided with consent and be stripped of identifiers.

Bio-banks and Samples

The concept of bio-banks is not yet fully formed in the public mind. Most people don't really understand population health or genetic studies and how they are conducted, though increasingly people are becoming aware of research attempts to trace genetic histories through families and to gather data from related people. They tend to think only in terms of information, not physical samples and have a hard time thinking through the collection and storage of large volumes of genetic information.

- Most people (76%) presume that the genetic information produced in any test is preserved – though they tend to think more of the lab's premises than a data bank. Almost 60% think that is true of the actual sample of blood or saliva as well.

- Fully half of respondents said there was joint ownership of the information between themselves and the organization that administered the test though 43% thought the samples were their property alone.

- Most have no idea whether bio-banks are prevalent or who might be administering them and they presume the regulations governing them would tend to be relatively lax, largely because it is such a new phenomenon.

However, after discussion it seemed quite clear that most people are comfortable with researchers accessing bio-banks for a variety of studies, including those that were not contemplated at the time of contribution. The consistent provisos are that people provide informed consent (though only at the first instance, not at each different research use) and that their identity be masked or stripped away (although large numbers of people would accept researchers having access to their identity if it furthered the cause of medical research and wasn't shared inappropriately).

Consistently however, there is deep resistance to the idea of bio-banks "selling" genetic data bases to others doing research, even with consent. Again, this appears to be more a view of the role of profit in health care than it is a considered decision about these particular circumstances. For instance, few have factored in the cost of gathering and storing the data when they consider the issues.

Genetic Information and Insurance

This research instrument probed extensively into the issue of the insurance industry and its potential access to and use of existing personal genetic information.

Though most people haven't fully thought through a variety of genetic privacy questions, insurance company use of genetic information is one of the few issues that is raised spontaneously in discussion and the issue on which there is the largest consensus. The vast majority (91%) do not believe that insurance companies should have the right to access existing personal genetic information. The level of opposition has increased since the question was first asked three years ago (86%.)

Most people do not have any trouble understanding the current rights and practices of insurance companies. They understand that under law, insurance companies:

- generally operate as private sector companies organized to produce profits;
- pool risk and use actuarial projections to calculate risk;
- currently have the right to demand health information and medical tests;
- can refuse to pay benefits if pertinent information was withheld or false information was provided; and
- can charge higher premiums to or refuse to insure higher risk applicants.

Further, most people believe genetic information is similar to health information and cannot easily articulate why it should be treated differently.

Nevertheless, virtually everyone insists that insurance companies should not have access to genetic data. Many cling to the notion that genetic information deals primarily in predispositions not medical certainties and they argue that no one should be penalized for something they may not contract.

They hold to that and reject arguments that this might be quite similar to the impact of gathering family medical histories.

- Argumentation about potential moral hazards or financial risk to the stability of the companies sway about one in five people but those who change their minds, do so grudgingly and without deep conviction.

- Most people are willing to consider the argument that companies can be affected financially if they do not have as much information as applicants about their genetic predispositions, but few believe the impacts would be severe. There is a widespread belief that the companies make sizeable profits and have huge asset bases that render them virtually invulnerable to difficulty.

- As to the moral hazard – most people have not really considered the issue or thought through the degree to which actuarial projections tables cannot compensate for the possibility of higher risk applicants loading up on insurance coverage without paying risk premiums. And though many are quite startled when confronted with the possibility, they nevertheless tend to hold their position. For some, the fraud does not seem very serious; to others it is morally justified because people must be able to protect the futures of their families; to still others it is something insurance companies can afford to deal with.

Most people seem to believe that they have a moral right to insurance even though they know that to be incorrect under law. At the very least, most believe that to be deprived of access to insurance creates so large a vulnerability that they will not willingly ease the way for that to happen. Most believe that pooling risk is as much a social concept as a financial one – that everyone pays premiums not only to be entitled to benefits but also to help underwrite access to insurance for those who are much more vulnerable. Most say they are willing to pay higher premiums to broaden access for higher risk individuals.

Interestingly, when the argument is reversed – that individuals should have the right to voluntarily provide personal genetic information in order to lower their own premiums – about a third (34%) – fewer than the 45% three years ago -- agree that in this case companies should be allowed to use the information. However, in focus group discussions, it didn't take very long for most to recant their support. Others are quick to point out two possible consequences – that pressure would build on everyone to supply their own data or that premiums would go up for all those who refused to supply the information.

The focus group discussions tested a variety of counter arguments to the entrenched resistance. Among the arguments put forward were:

- The insurance industry is a business and insurance coverage is a commercial transaction, not a social right.

- Discrimination, if that is an appropriate word, is central to the principle of insurance and this right has been upheld by Canadian courts.

- Insurance companies have to be able to make business decisions based on the same information that the people it deals with possess and genetic information is now one of those pieces of information that people can obtain.

- If not allowed to have access to this information, insurance companies could be exposed to major financial risks, because people who know they are likely to contract a disease or disability might buy extra insurance but the company would not be able to increase the price of the policy to reflect the higher risk and to cover additional claims.

- The insurance industry wants to insure more people, not fewer. Currently 96% of applicants get covered, 92% with standard ratings. The insurance industry says that the number of people who would be granted coverage is not likely to significantly change if genetic information were to be accessible by them.

- To some extent, submission of genetic information to insurance companies is already allowed by law now, because it falls into the same category that non-disclosure of a family history would be placed.

- In order to cover losses due to fraudulent use by applicants of genetic information, insurance companies would have to increase premiums for all customers, regardless of the risk they pose.

No argument was seen to be particularly powerful or significantly altered the outcome of the discussions even though each seemed straight-forward and plausible. The underlying opinions were so deeply entrenched that they were generally impervious to change.

There was an attempt to find middle ground in the discussion, which met with more, if not majority support. Rather than granting insurance companies a positive right to demand existing genetic information, a scenario was developed in which applicants would be obligated to submit only relevant genetic testing results and payments could be withheld if it was found later that they had not submitted the relevant information. This proposal was met with mixed responses – it fared much better than the alternatives, but there were many who resisted this proposition as well, seeing it as a thin edge of a wedge that would eventually compel most people to reveal their genetic information to insurance companies.

Finally, though there was only very limited discussion, it was clear that employers fare no better than insurance companies in this context. Virtually the same number (90%) said employers should not have access to genetic information of applicants or employees.

Governance Priorities

Absent arguments about the benefits that might be derived from use of personal genetic information, most Canadians default towards the strict protection of genetic privacy.

But the data suggests strongly that this is far from the only priority they would set. They assign high positive values to health and medical uses – particularly developing cures for genetically-based diseases. That leads them to being quite open to research uses of genetic information.

In fact, most people do not want to choose between protecting privacy and facilitating health research and believe there is a balance to be found between the two. Of those who make the choice, perhaps surprisingly, slightly more choose to emphasize research than choose to emphasize privacy protection.

When it comes to regulatory and ethical governance systems, more Canadians (56%) believe the medical and research community should play the main role in determining priorities and procedures than believe the government should (41%.) Focus groups indicate that Canadians views are actually quite considered and nuanced – they believe it is government that should set legislation but think the research and medical community more expert and closer to the situation on the ground. In truth, they would want a strongly collaborative effort.

Conclusions

The results suggest that there is broad comfort with and support for a regime that balances the strict protection of personal genetic information with facilitating access to such information to gain important corollary benefits. However, that support requires consistent linkage between the substance of initiatives and the benefits to be derived or else the default position comes into play, i.e. the insistence on stringent privacy protection.

There is strong evidence from the research that an increase in knowledge about the area and discussion about it increase the conviction that the benefits of facilitating access to genetic information outweigh the drawbacks. At the end of the survey instrument – after almost 30 minutes of questioning about the issues – the question of benefits versus drawbacks was posed once again. The assessment that benefits of knowing more about our genetic information outdrew drawbacks grew from 63% to 77%.

Perhaps even more striking, *Involved Canadians* – those who are most likely to hear about these issues first and engage most strongly – become even more favourable than the general population. Focus group work suggests that once they are given a sense that those responsible for governing these issues are thinking about them and working to improve their governance, concerns about potential abuse or misuse abate and interest in gaining the benefits increases.

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Public Opinion Research on
Genetic Information and Privacy
March 2003

Appendix 1

Genetic Information and Privacy Moderator's Guide

Introduction (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

Genetic Information – Familiarity and Interest (15 min)

This 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 that have been passed on through generations. Genetic information can be studied using saliva, hair, blood, or any biological material that contains cells. Over the past few years, there have been some significant scientific breakthroughs in understanding the genetic characteristics of people, one of the most notable being the human genome project.

1 - What can genetic information tell us? (Open-ended)
2a→c - If not mentioned, can it tell us:
    - 2a A person's risk of getting certain inherited diseases, like cystic fibrosis or Huntington's Disease?
    - 2b Whether a person has a gene that may cause disease in his or her child, but won't develop in them personally?
    - 2c Whether a person's spouse is at risk of developing their partner's inherited disease?
3ab - How familiar are you with issues involving genetic information? 3a Have you seen, read, heard anything about this subject lately? 3b

4 • How interested in this issue are you?

5 • How interested are you in knowing more about your own genetic characteristics?

6ab • Is it your opinion that knowing more about our genetic information is a good thing, or a bad thing? 6a Why is that? 6b

Genetic Testing (15 min)

7a→c 7a The next set of questions is about genetic testing. 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.

7b • Is genetic testing something that you might do at sometime or for some reason, or something you would probably not do on yourself for any reason?

7c • Why/why not?

8a→f Would you have a genetic test:

- 8a • To obtain more information about your genetic characteristics
- 8b • To determine your risk of developing a genetic disease or condition
- 8c • If it would help determine the best medical approach to dealing with a particular disease or condition you have
- 8d • If it would determine whether there was a likelihood that you had a disease or condition you could pass on to your children
- 8e • If it would determine your children's risk of developing a genetic disease or condition (NOTE: if asked, this includes children from birth to age of majority)
- 8f • To contribute to medical research

9 Why would you have genetic tests for some purposes, but not others?

10a b • Some people say that genetic testing is morally wrong, and whatever benefits that might come from such tests do not outweigh the moral issues involved. Others say that the benefits that will come from genetic testing outweigh the moral objections that some people have to this type of testing. Which of these two views is closest to your own? 10a Why is that? 10b

11a→c • How widespread do you think genetic testing is in Canada currently? 11a Are a lot of people having genetic tests? 11b Do you see this as something there will be more of in future? 11c

12 • Have you ever been asked to undergo a genetic test?

13 • Who were you asked by?

14 • Have you or your spouse been tested (including pre-natal diagnosis)?

22

15 • If you have a child under 18 years of age, has your child been tested to determine genetic information?

16 • Were the test results provided to you?

17 • Were the test results explained to you, by a professional counselor/doctor?

Rights Issues (15 min)

There are a number of rights issues that are raised by genetic testing. The right to know information, the right not to know information, and the right of governing systems to place limits on what information is available and not available.

18ab
- Some people say that getting a genetic test is every persons' right, and government has no right getting involved. Other people say that once genetic tests become widespread, some people may feel a whole variety of pressures to take tests they don't want to take, or the tests might be deemed unethical, and therefore government should ban all or some genetic tests. Which of those two views is closest to your own? 18a Why is that? 18b

19ab
1. In the future, home genetic testing kits could be made widely available, potentially offering individuals the ability to conduct such tests on themselves or on others. Should there be a regulatory system that governs the availability of these kits (leaving aside whether they work, which would be regulated)? 19a What is the best way of setting up such a system? 19b

options for 19b
   a. Allow people to use them if they choose, without medical referral or consultation if they wish
   b. Allow people to use them only if they get a medical referral, and consult with their doctor about the results
   c. Allow them to be used, but ban people from using tests on anyone other than themselves or their children without permission
   d. Ban them altogether, because people may use them improperly or not understand the information that results from them

20ab
- In some cases, genetic information can tell you about health and genetic characteristics that may be passed on to your family members.

  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? 20a

  Why is that? 20b

21a 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.

Governance Regime: Awareness and Perceptions (15 min)

2a→g

21b How familiar are you with the laws, regulations and guidelines governing the collection and use of genetic information in Canada?

- In general, would you think the privacy of your personal information well protected, or not very well protected, in the area of genetics? How would it compare to protection in the areas of: 21c
  - Financial information, such as your credit rating or your spending habits? 21d
  - Information about your communications habits, such as your use of the telephone or computer? 21e
  - Medical information 21f

If people think privacy provisions areas are lax, probe reasons why. 21g

22ab Is it your opinion that genetic information is different from other health information (such as a personal medical history or family medical history) or is it essentially the same as other health information? 22a Why is that? 22b

23 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?

24 If you were to have a genetic test, would you think that the information it produced was your property, the property of the organization that administered the test, or the property of both you and the organization that administered the test?

25 If you were to provide a sample for a genetic test (blood or saliva for example), do you believe that **the sample you provided/the genetic information it produced** would be destroyed or preserved and placed into a bio-bank data base of genetic information?

Module: Insurance (30 min)

preamble 26 One of the major areas to discuss in relation to all this involves the insurance industry. Right now, insurance companies can ask for, and the law says applicants have to provide, various kinds of personal information including things like age and sex, personal and family medical histories and financial information. They also have the right to ask applicants to submit to medical tests like a blood test. Obviously genetic information may well be useful too.

26a→e In this area, there are some choices that have to be made about how we want to balance interests and tradeoff objectives. Some people say that insurance companies should be allowed to access genetic information about a person that he or she knows about when they apply for insurance coverage, in order to cover all possible claims. Others say that we should not allow insurance companies to have access to genetic information that a potential client knows about because some people would face higher premiums or may be denied coverage based on those risks. Which is closest to your own view? 26a Why is that the case? (**probe for:** main reasons for views e.g. privacy? Possible discrimination? Concern about family members?) 26b 26c 26d 26e

ab* Q below There are a number of arguments that people in the insurance industry put forth to support their position. I'm going to tell you each of them, and what I want to know is: Are they strong arguments? a and, most importantly, when you hear them does it cause you to change your mind on the issue? b

- 27ab The insurance industry is a business, and insurance coverage is a commercial transaction, not a social right. Discrimination, if that is the appropriate word, is central to the principle of insurance, and this right has been upheld by Canadian courts. Insurance companies have to be able to make business decisions based on the same information that the people it deals with possess, and genetic information is now one of those pieces of information that people can obtain.

- 28abcd If not allowed to have access to this information, insurance companies would be exposed to major financial risks, because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims.
  - **Probe for:** understanding of possible risks (e.g. bankruptcy, risk to policy holders, risk to employment) 28c
  - **Follow up with:** The insurance industry does not make profits like the banking industry – last year for example the industry as a whole paid out \$36 billion in claims, and had \$43 billion in revenues. Does that affect your view? 28d

- 29abc The insurance industry wants to insure more people, not fewer. The insurance industry says that the number of people who would be granted coverage is not likely to significantly change if genetic information were to be accessible by them. Currently 96% of applicants get covered, 92% with standard ratings. Does that affect your view? 29c

- 30abc To some extent, submission of genetic information to insurance companies is already allowed by law now, because it falls into the same category that non-disclosure of a family history would be placed. Does that affect your view? 30c

- 31abc In order to cover losses due to fraudulent use by applicants of genetic information, insurance companies would have to increase premiums for all customers, regardless of the risk they pose. (**probe after discussion:** Would it change you mind if you knew that currently 92% of policy holders come in at the standard (or lowest) rate and might have to pay more?) 31c

- 32 Are you prepared to pay more to cover the 4% of Canadians who are at highest risk?

Let's imagine a different scenario now.

The law could be changed so that insurance companies could NOT ask for genetic information but individuals could VOLUNTEER it to companies if they want in order to get lower rates for themselves by proving they are not predisposed to certain genetic disorders.

33a → c Would you support that sort of change? 33a

Why?/Why not? 33b

33c

(**Probe after discussion**: That might mean that those who volunteer would get lower premiums and others would have to pay more or be denied. Would that change your mind?

34 Is there a scenario you can imagine that could be established to allow insurance companies to have access to genetic information?

I'm going to provide you with a scenario now and I want you to react to it:

- People would only be required to submit genetic information if they had had a genetic test relevant to their insurance coverage (if they did not submit such information insurance claims would be invalidated, just as if they did not submit certain information on their original insurance form). Is that a reasonable compromise? 35

Module: Health Research (20 min)

Increased scientific knowledge about our genetic characteristics has implications for health and medical research. Many 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.

36a → c In the future, how important 36a a role do you think genetic information will play in health research and development in Canada? What is the main benefit of this type of research? **Probe** treatments & economic benefits. 36b 36c

37 If you had a genetic test, would you be willing to contribute the information to a data base that would be used for health research?

38a → d In this area, there are some choices that have to be made about how we want to balance interests and trade off objectives. Some people say that we should take the steps necessary to ensure that scientific researchers and health care companies have access to Canadians' genetic information they need, in order to study genetic traits and develop cures for illnesses. Others say we should place strict limitations on their ability to access to this information, because they might use the information for purposes that people don't agree with. Which is closest to your own view? Do you have a different view about scientific researchers and health care companies on this issue? Why is that? Why are they different? 38d

38b 38a 38c

Sem There are two arguments that those in medical research put forth when arguing for a system that allows them to access the data bases. For each, I' d like you to indicate how strong that argument is, and for those who oppose giving access, whether it changes your mind.
a
b

39ab 1. Allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases.

40ab 2. If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base

41 If scientific researchers or companies that developed these data bases had the consent of those who contributed genetic samples, do they have a right to use them for other genetic research studies in future?

42 Do they have a right to sell that information to those who do other genetic research studies in future, provided they follow the same rules of masking the donor's identity?

Module: Governance/Government Priorities (20 min)

43 I'm going to list for you a series of potential priorities that those governing these genetic information and privacy issues need to take into consideration. What I would like to gather from you is what are the most important priorities that should be pursued?

option

- Strictly protecting the privacy of genetic information
- Promoting Canadian leadership in genetics research and development
- Developing cures to disease
- Ensuring that Canada is not left out of the economic benefits that come with research and development in genetics
- Working with other countries to develop common rules and regulations regarding genetic information
- Preventing discrimination in the work place based on genetic information
- Regulating appropriate access to genetic data bases
- Monitoring the various uses of personal genetic information

44 In some cases two or more of these priorities may come into conflict. If there is a choice between X and Y, which do you think has to be the primary consideration of the two?

45 There are a number of ways in which regulatory and ethical governance systems can be set up to ensure genetic privacy is protected for Canadians. I'd like to give you a general outline of two possible ways of doing this, and I'd like you to indicate which you think is best.

option 1 The medical and research community should play the main role, using professional bodies like medical associations as well as self-governing systems such as safety/ethics committees at research hospitals, and governments should play a secondary role, by laying out national guidelines for the medical research community to follow

0 phra2 The government should play the main role, having laws and enforcing them, with a secondary monitoring role played by professional organizations and ethics committees in the medical and research community

46 Overall, now that we have discussed this issue for a couple of hours, is it your opinion that the benefits of knowing more about our genetic information outweigh the drawbacks, or do the drawbacks outweigh the benefits?

Appendix 2

GENETIC INFORMATION AND PRIVACY
Interview Schedule

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 headed in the right direction	59
Canada is headed in the wrong direction	35
Don't Know/Refused	6

2a→d

2. I'd like to ask you a few questions about your attitudes and perceptions regarding how organizations treat personal information about you, and the confidentiality they assign to that information. Please indicate whether you are extremely concerned, somewhat concerned, not very or not at all concerned about how well this information is protected by organizations that you deal with.

a) Medical information

Extremely concerned	30
Somewhat concerned	30
Not very concerned	24
Not at all concerned	15
Don't Know/Refused	1

b) Information about your genetic characteristics

Extremely concerned	22
Somewhat concerned	25
Not very concerned	26
Not at all concerned	22
Don't Know/Refused	4

c) Financial information, such as your credit rating or your spending habits

Extremely concerned	38
Somewhat concerned	37
Not very concerned	15
Not at all concerned	8
Don't Know/Refused	1

d) Information about your communications habits, such as your use of the telephone or computer

Extremely concerned	24
Somewhat concerned	37
Not very concerned	23
Not at all concerned	15
Don't Know/Refused	1

3a→d

3. Now I'd like to ask you about laws and regulations about the confidentiality of your personal information. For each, please indicate whether you think there are very stringent, somewhat stringent, somewhat lax or very lax laws and regulations governing the personal privacy assigned to this information? (Randomize, but use same sequence as previous battery)

a) Medical information

Very stringent	18
Somewhat stringent	39
Somewhat lax	25
Very lax	9
Don't Know/Refused	8

b) Information about your genetic characteristics

Very stringent	12
Somewhat stringent	26
Somewhat lax	26
Very lax	12
Don't Know/Refused	23

c) Financial information, such as your credit rating or your spending habits

Very stringent	13
Somewhat stringent	26
Somewhat lax	35
Very lax	18
Don't Know/Refused	8

d) Information about your communications habits, such as your use of the telephone or computer

Very stringent	6
Somewhat stringent	25
Somewhat lax	39
Very lax	20
Don't Know/Refused	10

4ab 4a

This 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 that have been passed on through generations. Genetic information can be studied using saliva, hair, blood, or any biological material that contains cells. Over the past few years, there have been some significant scientific breakthroughs in understanding the genetic characteristics of people, one of the most notable being the human genome project.

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

Very familiar	9
Somewhat familiar	51
Not very familiar	27
Not at all familiar	12
Don't Know/Refused	0

5. 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	51
Not very interested	13
Not at all interested	5
Don't Know/Refused	0

6. How interested are you in knowing more about your own genetic characteristics?

Very	26
Somewhat	38
Not very	24
Not at all	12
Don't Know/Refused	1

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

Benefits outweigh drawbacks	63
Drawbacks outweigh benefits	26
Don't Know/Refused	12

8a -> d

8. I'd like to get a sense of your knowledge about what genetic information can tell us about ourselves. I'm going to read you a list of things, and I want to know whether you think they could be determined from genetic information, or not

a) A person's risk of getting certain inherited diseases, like cystic fibrosis or Huntington's Disease

Yes	94
No	4
Don't Know/Refused	2

b) Whether a person has a gene that may cause disease in his or her child, but won't develop in them personally

Yes	92
No	5
Don't Know/Refused	2

c) A person's risk of getting into a car accident

Yes	11
No	87
Don't Know/Refused	2

d) Whether a person's spouse is at risk of developing their partner's inherited disease

Yes	29
No	68
Don't Know/Refused	4

9. Is it your opinion that genetic information is different from other health information (such as a personal medical history or family medical history) or is it essentially the same as other health information?

Different	53
Essentially the same	45
Don't Know/Refused	2

10ab 10a The next set of questions is about genetic testing. 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.

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

Yes	5
No	94
Don't Know/Refused	0

11. (If yes to question 10) Were you asked by:

A Doctor	79
An insurance company	7
Health Organization	6
Family Member	1
Social Services	1
Don't Know/Refused	4

12. Have you or your spouse been tested to determine genetic information (including pre-natal diagnosis)?

Yes, Me	4
Yes, Spouse	3
Yes, Both	1
No	91
Don't Know/Refused	1

13. If you have a child under 18 years of age, has your child been tested to determine genetic information?.

Yes	3
No	88
Don't Know/Refused	9

14. (if yes to either q12 or q13) Were the test results provided to you?

Yes	53
No	36
Don't Know	11

15. (if yes to Q 14) Who explained the test results to you?

Professional counselor	11
Doctor	59
Both	14
Don't Know	16

16. How widespread do you think genetic testing is in Canada currently? Is it very widespread, somewhat widespread, not very widespread or not at all widespread?

Very widespread	5
Somewhat widespread	29
Not very widespread	48
Not at all widespread	11
Don't Know	7

17. If you were to have a genetic test, would you think that the information it produced was your property, the property of the organization that administered the test, or the property of both you and the organization that administered the test?

Your property	43
Property of organization	5
Property of both	50
Don't Know	3

18. If you were to provide a sample for a genetic test (blood or saliva for example), do you believe that the sample you provided would be destroyed or preserved and placed into a bio-bank data base of genetic information?

Destroyed	32
Preserved	59
Don't Know	10

19. If you were to provide a sample for a genetic test (blood or saliva for example), do you believe that the genetic information it produced would be destroyed or preserved and placed into a bio-bank data base of genetic information?

Destroyed	17
Preserved	76
Don't Know	8

From here on in I am going to be asking a lot of questions about personal genetic information, some of which involve problems and issues that may or may not actually ever happen. They are designed to help us understand how you feel about the issue as a whole and its possible implications.

20a → j

20. I'd like to read you a series of statements about genetic testing and genetic information. For each, I would like you to indicate whether you strongly agree, agree, disagree, or strongly disagree. The first one is:

a) I would get genetic testing done to obtain more information about my genetic characteristics

Strongly agree	16
Agree	42
Disagree	33
Strongly disagree	7
Don't Know/Refused	1

b) I would get genetic testing done to determine my risk of developing a genetic disease or condition

Strongly agree	27
Agree	46
Disagree	20
Strongly disagree	5
Don't Know/Refused	1

c) I would get genetic testing done if it would help determine the best medical approach to dealing with a particular disease or condition I have

Strongly agree	49
Agree	46
Disagree	3
Strongly disagree	1
Don't Know/Refused	1

d) I would get genetic testing done if it would determine whether there was a likelihood that I had a disease or condition I could pass on to my children

Strongly agree	46
Agree	43
Disagree	8
Strongly disagree	2
Don't Know/Refused	1

e) I would get genetic testing done on my children if it would determine their risk of developing a genetic disease or condition (NOTE: if asked, this includes children from birth to age of majority)

Strongly agree	34
Agree	44
Disagree	15
Strongly disagree	4
Don't Know/Refused	3

f) I would NOT get genetic testing done on myself because I think it is morally wrong to do it (NOTE: if asked, this includes children from birth to age of majority)

Strongly agree	3
Agree	10
Disagree	52
Strongly disagree	34
Don't Know/Refused	1

g) I would NOT get genetic testing done on my children because I think it is morally wrong to do it (NOTE: if asked, this includes children from birth to age of majority)

Strongly agree	5
Agree	13
Disagree	51
Strongly disagree	27
Don't Know/Refused	3

h) It should be each person's absolute right to determine whether or not they have a genetic test.

Strongly agree	55
Agree	37
Disagree	5
Strongly disagree	1
Don't Know/Refused	2

i) It should be each person's absolute right to determine whether or not they have a genetic test, regardless of the consequences to family members, like their risk of inheriting diseases

Strongly agree	38
Agree	47
Disagree	10
Strongly disagree	3
Don't Know/Refused	2

j) Governments should have the authority to prevent the use of genetic testing if it deems the test's purpose to be unethical

Strongly agree	41
Agree	36
Disagree	14
Strongly disagree	7
Don't Know/Refused	2

In some cases, genetic information can tell you about health and genetic characteristics that may be passed on to your family members. The following questions are about family issues. Please use the same scale you used in the previous questions, indicating whether you strongly agree, agree, disagree, or strongly disagree with the following statements:

21. My family members should have a right to know any information from my genetic test that might tell them something about their health.

Strongly agree	35
Agree	47
Disagree	14
Strongly disagree	4
Don't Know/Refused	1

22. If I were to have a genetic test, my family members have the right to say they do not want to know, even if there is a possible problem for them in the future

Strongly agree	32
Agree	54
Disagree	10
Strongly disagree	2
Don't Know/Refused	1

23. 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?

Has an obligation	61
Does not have an obligation	37
Don't Know/Refused	2

24. Some people say that genetic testing is morally wrong, and whatever benefits that might come from such tests do not outweigh the moral issues involved. Others say that the benefits that will come from genetic testing outweigh the moral objections that some people have to this type of testing. Which of those two views is closest to your own?

Genetic testing is morally wrong	13
Benefits outweigh moral obligation	82
Don't Know/Refused	5

25. In the future, home genetic testing kits could be made widely available, potentially offering individuals the ability to conduct such tests on themselves or on others. In your view, which of the four courses of action is closest to what you believe government should do with regard to these kits?

Use them if they choose	7
Use them only if they get a medical referral	39
Ban people from using on anyone other than themselves	16
Ban them altogether	37
Don't Know/Refused	1

26a

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.

26ab

26. b How familiar are you with the current systems regulating or governing genetic information in Canada at this time?

Very familiar	2
Somewhat familiar	12
Not very familiar	41
Not at all familiar	44
Don't Know/Refused	1

27. Using a scale of 1-7, where 1 is very lax and 7 is very stringent, how stringent do you think the current systems regulating or governing genetic information in Canada are at this time?

Very lax	7
2	8
3	17
4	18
5	20
6	6
Very stringent	5
Don't Know/Refused	20

28a →h

28. A number of people and institutions may or may not be allowed to have access to people's genetic information. In your opinion, do the benefits outweigh the drawbacks or do the drawbacks outweigh the benefits if each of the following had access to a person's genetic information?

a) Doctors

Benefits outweigh the drawbacks	88
Drawbacks outweigh the benefits	10
Don't Know/Refused	3

b) Pharmacists

Benefits outweigh the drawbacks	60
Drawbacks outweigh the benefits	35
Don't Know/Refused	5

c) Nurses

Benefits outweigh the drawbacks	59
Drawbacks outweigh the benefits	36
Don't Know/Refused	5

d) Medical researchers

Benefits outweigh the drawbacks	80
Drawbacks outweigh the benefits	15
Don't Know/Refused	5

e) Governments

Benefits outweigh the drawbacks	20
Drawbacks outweigh the benefits	74
Don't Know/Refused	5

f) Insurance companies

Benefits outweigh the drawbacks	16
Drawbacks outweigh the benefits	81
Don't Know/Refused	4

g) Employers

Benefits outweigh the drawbacks	12
Drawbacks outweigh the benefits	85
Don't Know/Refused	3

h) The person himself or herself

Benefits outweigh the drawbacks	83
Drawbacks outweigh the benefits	11
Don't Know/Refused	5

29. Some people say that getting a genetic test is every persons' right, and government has no right getting involved. Other people say that once genetic tests become widespread, some people may feel a whole variety of pressures to take tests they don't want to take, and therefore government should ban genetic tests. Which of those two views is closest to your own?

Government has not right getting involved	75
Government should ban genetic tests	20
Don't Know/Refused	5

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

Rules should be more strictly regulated	58
Rules should be regulated in the same way	39
Don't Know/Refused	3

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 and development 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	1

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 data base that would be used for health research?

Very willing	34
Somewhat willing	43
Not very willing	11
Not at all willing	10
Don't Know/Refused	3

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

Very willing	56
Somewhat willing	28
Not very willing	7
Not at all willing	8
Don't Know/Refused	1

34. Some people say that we should allow scientific researchers access to Canadians' genetic information in order to study genetic traits and develop cures for illness, as long as people consent to their genetic information being used. Others say we should not allow researchers access to this information because they might use that information for purposes that people don't agree with. Which is closest to your own view?

Should allow access	73
Should not allow access	22
Don't Know/Refused	4

35. Some people say that we should allow health care companies access to Canadians' genetic information in order to study genetic traits and develop cures for illness, as long as people consent to their genetic information being used. Others say we should not allow health care companies access to this information because they might use that information for purposes that people don't agree with. Which is closest to your own view?

Should allow access	47
Should not allow access	49
Don't Know/Refused	5

36. (If do not allow scientific researchers access) Researchers say that allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases. Knowing that these implications are possible if researchers were limited in their access genetic information, would you still say that we should not allow researchers access to it?

Should allow access	35
Should not allow access	59
Don't Know/Refused	6

37. (If do not allow health care companies access) Health care companies say that allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases. Knowing that these implications are possible if they were limited in their access genetic information, would you still say that we should not allow them access to it?

Should allow access	24
Should not allow access	69
Don't Know/Refused	7

38. (If do not allow researchers access) If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base, would you be willing to allow researchers access to genetic information, or would you still say that we should not allow researchers access to this information?

Should allow access	66
Should not allow access	29
Don't Know/Refused	4

39. (If do not allow health care companies access) If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base, would you be willing to allow health care companies access to genetic information, or would you still say that we should not allow them access to this information?

Should allow access	53
Should not allow access	45
Don't Know/Refused	1

40. Would you think that there are currently very stringent, somewhat stringent, somewhat lax or very lax rules in place to govern how these genetic information research databanks are used?

Very stringent	9
Somewhat stringent	27
Somewhat lax	29
Very lax	11
Don't Know/Refused	24

41. If scientific researchers or companies that developed these data bases had the consent of those who contributed genetic samples, do they have a right to use them for other genetic research studies in future?

Yes	63
No	34
Don't Know/Refused	3

42. If scientific researchers or companies that developed these data bases had the consent of those who contributed genetic samples, do they have a right sell that information to those who do other genetic research studies in future provided they mask the donor's identity?

Yes	30
No	68
Don't Know/Refused	2

43. Some people say that we should allow insurance companies to have the right to ask about an individual's genetic information when he or she applies for insurance coverage, in order to determine that person's risk of future health problems. Others say that we should not allow insurance companies to have access to their client's genetic information so that they could not deny coverage as a result. Which is closest to your own view?

Allow insurance companies right to information	8
Not allow insurance companies right to information	91
Don't Know/Refused	2

44. Some people say that insurance companies should be allowed to access genetic information about a person that he or she knows about when they apply for insurance coverage, in order to cover all possible claims. Others say that we should not allow insurance companies to have access to genetic information that a potential client knows about because some people would face higher premiums or may be denied coverage based on those risks. Which is closest to your own view?

Allow insurance companies right to information	9
Not allow insurance companies right to information	90
Don't Know/Refused	2

45. (if not allowed) Some people say that denying insurance companies access to applicants genetic information would mean that they would be exposed to major financial risks, because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims. Would that change your opinion?

Yes	12
No	86
Don't Know/Refused	3

46. (if not allowed) Some people say that denying insurance companies access to genetic information would mean that insurance companies would have to increase premiums for all customers, regardless of the risk they pose. Because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims. Would that change your opinion?

Yes	14
No	83
Don't Know/Refused	4

47. Some people say we should allow Canadians to voluntarily provide their genetic information to insurance companies if they want, to get lower rates for themselves by proving they are not predisposed to certain genetic disorders. Others say we should not allow Canadians to provide this information to their insurance companies even if they want to, because allowing this would probably mean that Canadians who do not provide this information to the insurer could face higher premiums or be denied coverage. Which is closest to your view?

Allow Canadians to provide genetic information	34
Not allow Canadians to provide genetic information	63
Don't Know/Refused	3

48. Some people say that we should provide employers with the right to ask about an individual's genetic information when they apply for work or in the course of employment, because employers have a right to know whether their employees are unhealthy or might develop a health condition. Others say we should not allow employers to ask about an individual's genetic information when they apply for work or in the course of employment, because employers might base their decisions on whether the person is predisposed to a disease or disorder. Which is closest to your own view?

Employers have right to ask genetic information	8
Employers do not have right to ask genetic information	90
Don't Know/Refused	2

49a → h

49. I'm going to list for you a series of potential priorities for government to take into consideration regarding genetic information. What I would like you to do is indicate, on a scale of 1-7, where 1 is not important at all and 7 is extremely important, how important each of these priorities should be in government decision making:

a) Strictly protecting the privacy of genetic information

Not important at all	2
2	1
3	2
4	3
5	9
6	12
Extremely important	69
Don't Know/Refused	1

b) Promoting Canadian leadership in genetics research and development

Not important at all	4
2	4
3	7
4	14
5	25
6	15
Extremely important	29
Don't Know/Refused	2

c) Developing cures to disease

Not important at all	2
2	1
3	2
4	4
5	10
6	14
Extremely important	66
Don't Know/Refused	2

d) Ensuring that Canada is not left out of the economic benefits that come with research and development in genetics

Not important at all	3
2	3
3	5
4	12
5	22
6	17
Extremely important	36
Don't Know/Refused	2

e) Working with other countries to develop common rules and regulations regarding genetic information

Not important at all	4
2	3
3	4
4	8
5	19
6	17
Extremely important	43
Don't Know/Refused	2

f) Preventing discrimination in the work place based on genetic information

Not important at all	4
2	2
3	3
4	3
5	9
6	14
Extremely important	62
Don't Know/Refused	2

g) Regulating appropriate access to genetic data bases

Not important at all	4
2	2
3	3
4	7
5	15
6	16
Extremely important	49
Don't Know/Refused	3

h) Monitoring the various uses of personal genetic information

Not important at all	6
2	2
3	5
4	8
5	15
6	15
Extremely important	48
Don't Know/Refused	2

50. 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?

Govt attempt balance between these two priorities	42
Focus mostly on ensuring privacy	25
Focus mostly on support with research and development	31
Don't Know/Refused	2

51. There are a number of ways in which regulatory and ethical governance systems can be set up to ensure genetic privacy is protected for Canadians. I'd like to give you a general outline of two possible ways of doing this, and I'd like you to indicate which you think is best:

option a) The medical and research community should play the main role, using professional bodies like medical associations as well as self-governing systems such as safety/ethics committees at research hospitals, and governments should play a secondary role, by laying out national guidelines for the medical research community to follow

option b b) The government should play the main role, having laws and enforcing them, with a secondary monitoring role played by professional organizations and ethics committees in the medical and research community

The medical and research community should play the main role	56
The government should play the main role	41
Don't Know/Refused	4

52. Is it your opinion that the benefits of knowing more about our genetic information outweigh the drawbacks, or do the drawbacks outweigh the benefits? (If respondent mentions that they have been asked this question earlier, let them know that it is being asked on purpose, to get a sense of how opinion was affected by discussion of some of the issues involved)

Benefits outweigh drawbacks	77
Drawbacks outweigh benefits	18
Don't Know/Refused	5

Appendix 3

English Questionnaire
Genetic Privacy

Good morning/afternoon/evening. My name is (___) of POLLARA, the national public opinion research organization. We are conducting a survey of attitudes and opinions of Canadians 18 years of age or older. Would you mind if I asked you some questions? All your responses will be kept strictly confidential.

(IF YES) Thank you. (CONTINUE)
(IF NO) When is a better time for me to call back? (SCHEDULE CALL APPOINTMENT)
(IF REFUSED) Thank and terminate.

A. First, do you or does anyone in your household work for a market research firm, a media or telecommunications firm OR a political party?

YES (THANK AND TERMINATE)
NO (CONTINUE)
DK/REFUSED (THANK AND TERMINATE)

B. Would you mind telling me in what year you were born? (RECORD YEAR) (RECODE INTO FOLLOWING CATEGORIES)

Under 18 years of age (ASK FOR SOMEONE 18 +)
18-24
25-34
35-44
45-54
55-64
65 years of age or older

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? (ROTATE ORDER)

   Headed in the right direction
   Headed in the wrong direction
   Don't know/no response

2. I'd like to ask you a few questions about your attitudes and perceptions regarding how organizations treat personal information about you, and the confidentiality they assign to that information. Please indicate whether you are extremely concerned, somewhat concerned, not very or not at all concerned about how well this information is protected by organizations that you deal with (Randomize)

   a) Medical information

   Extremely concerned
   Somewhat concerned
   Not very concerned
   Not at all concerned
   Don't know/no response (DO NOT READ)

   b) Information about your genetic characteristics

   Extremely concerned
   Somewhat concerned
   Not very concerned
   Not at all concerned
   Don't know/no response (DO NOT READ)

   c) Financial information, such as your credit rating or your spending habits

   Extremely concerned
   Somewhat concerned
   Not very concerned
   Not at all concerned
   Don't know/no response (DO NOT READ)

   d) Information about your communications habits, such as your use of the telephone or computer

   Extremely concerned
   Somewhat concerned
   Not very concerned
   Not at all concerned
   Don't know/no response (DO NOT READ)

3. Now I'd like to ask you about laws and regulations about the confidentiality of your personal information. For each, please indicate whether you think there are very stringent, somewhat stringent, somewhat lax or very lax laws and regulations governing the personal privacy assigned to this information? (Randomize)

a) Medical information

Very stringent
Somewhat stringent
Somewhat lax
Very lax
Don't know/no response DO NOT READ)

b) Information about your genetic characteristics

Very stringent
Somewhat stringent
Somewhat lax
Very lax
Don't know/no response DO NOT READ)

c) Financial information, such as your credit rating or your spending habits

Very stringent
Somewhat stringent
Somewhat lax
Very lax
Don't know/no response DO NOT READ)

d) Information about your communications habits, such as your use of the telephone or computer

Very stringent
Somewhat stringent
Somewhat lax
Very lax
Don't know/no response DO NOT READ)

DEFINITION This 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* that have been passed on through generations. *Genetic information can be studied using saliva, hair blood, or any biological material that contains cells.* Over the past few years, there have been some significant scientific breakthroughs in understanding the genetic characteristics of people, one of the most notable being the human genome project.

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

   Very familiar
   Somewhat familiar
   Not very familiar
   Not at all familiar
   Don't know/no response (DO NOT READ)

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

   Very interested
   Somewhat interested
   Not very interested
   Not at all interested
   Don't know/no response (DO NOT READ)

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

   Very interested
   Somewhat interested
   Not very interested
   Not at all interested
   Don't know/no response (DO NOT READ)

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

   Benefits outweigh the drawbacks
   Drawbacks outweigh the benefits
   Don't know/no response (DO NOT READ)

8. I'd like to get a sense of your knowledge about what genetic information can tell us about ourselves. I'm going to read you a list of things, and I want to know whether you think they could be determined from genetic information, or not

   a) A person's risk of getting certain inherited diseases, like cystic fibrosis or Huntington's Disease

      Yes
      No
      Don't know/no response (DO NOT READ)

b) Whether a person has a gene that may cause disease in his or her child, but won't develop in them personally

Yes
No
Don't know/no response (DO NOT READ)

c) A person's risk of getting into a car accident

Yes
No
Don't know/no response (DO NOT READ)

d) Whether a person's spouse is at risk of developing their partner's inherited disease

Yes
No
Don't know/no response (DO NOT READ)

9. Is it your opinion that genetic information is different from other health information (such as a personal medical history or family medical history) or is it essentially the same as other health information?

Different from other health information
Essentially the same as other health information
Don't know/no response (DO NOT READ)

The next set of questions are about genetic testing. 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.

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

Yes
No
Don't know/no response (DO NOT READ)

11. (If yes IN Q. 16) Were you asked by:

2. a doctor
3. an employer
4. an insurance company
5. another organization (specify)

12. Have you or your spouse been tested to determine genetic information (including pre-natal diagnosis)?

Yes me
Yes spouse
Yes me and spouse
No
Don't know/no response

13. If you have a child under 18 years of age, has your child been tested to determine genetic information?

Yes
No
Don't' know/no response (DO NOT READ)

14. (if yes to either q18 or q19) Were the test results provided to you?

Yes
No
Don't know/no response (DO NOT READ)

15. (if yes to Q 14) Were the test results explained to you, by a professional counselor or doctor? (code both separately)

Professional counselor
Doctor
Both
Don't know/no response (DO NOT READ)

16. How widespread do you think genetic testing is in Canada currently? Is it very widespread, somewhat widespread, not very widespread or not at all widespread?

Very widespread
Somewhat widespread
Not very widespread
Not at all widespread
Don't know/no response (DO NOT READ)

17. If you were to have a genetic test, would you think that the information it produced was your property, the property of the organization that administered the test, or the property of both you and the organization that administered the test?

My property
Property of organization that administered
My property and that of the organization that administered it
Don't know/no response (DO NOT READ)

18. SPLIT If you were to provide a sample for a genetic test (blood or saliva for example), do you believe that the sample you provided/the genetic information it produced would be destroyed or preserved and placed into a bio-bank data base of genetic information?

Destroyed
Preserved in bio-bank
Don't know/no response (DO NOT READ)

19. SPLIT If you were to provide a sample for a genetic test (blood or saliva for example), do you believe that the sample you provided/the genetic information it produced would be destroyed or preserved and placed into a bio-bank data base of genetic information?

Destroyed
Preserved in bio-bank
Don't know/no response (DO NOT READ)

From here on in I am going to be asking a lot of questions about personal genetic information, some of which involve problems and issues that may or may not actually ever happen. They are designed to help us understand how you feel about the issue as a whole and its possible implications.

20. I'd like to read you a series of statements about genetic testing and genetic information. For each, I would like you to indicate whether you strongly agree, agree, disagree, or strongly disagree. The first one is: (read and rotate)

    a) I would get genetic testing done to obtain more information about my genetic characteristics

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

b) I would get genetic testing done to determine my risk of developing a genetic disease or condition

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

c) I would get genetic testing done if it would help determine the best medical approach to dealing with a particular disease or condition I have

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

d) I would get genetic testing done if it would determine whether there was a likelihood that I had a disease or condition I could pass on to my children

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

e) I would get genetic testing done on my children if it would determine their risk of developing a genetic disease or condition (NOTE: if asked, this includes children from birth to age of majority)

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

f) (SPLIT) I would NOT get genetic testing done on myself/ my children because I think it is morally wrong to do it (NOTE: if asked, this includes children from birth to age of majority)

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

g) (SPLIT) I would NOT get genetic testing done on myself/ my children because I think it is morally wrong to do it (NOTE: if asked, this includes children from birth to age of majority)

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

h) (SPLIT) It should be each person's absolute right to determine whether or not they have a genetic test/It should be each person's absolute right to determine whether or not they have a genetic test, regardless of the consequences to family members, like their risk of inheriting diseases

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

i) (SPLIT) It should be each person's absolute right to determine whether or not they have a genetic test/It should be each person's absolute right to determine whether or not they have a genetic test, regardless of the consequences to family members, like their risk of inheriting diseases

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

j) Governments should have the authority to prevent the use of genetic testing if it deems the test's purpose to be unethical

Strongly agree
Agree
Disagree
Strongly disagree
Don't know/no response (DO NOT READ)

In some cases, genetic information can tell you about health and genetic characteristics that may be passed on to your family members. The following questions are about family issues. Please use the same scale you used in the previous questions, indicating whether you strongly agree, agree, disagree, or strongly disagree with the following statements:

21. My family members should have a right to know any information from my genetic test that might tell them something about their health.

    Strongly agree
    Agree
    Disagree
    Strongly disagree
    Don't know/no response (DO NOT READ)

22. If I were to have a genetic test, my family members have the right to say they do not want to know, even if there is a possible problem for them in the future

    Strongly agree
    Agree
    Disagree
    Strongly disagree
    Don't know/no response (DO NOT READ)

    End of agree/disagree questions

23. 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?

    Have an obligation to inform family members
    Do not have an obligation to inform family members
    Don't know/no response (DO NOT READ)

24. Some people say that genetic testing is morally wrong, and whatever benefits that might come from such tests do not outweigh the moral issues involved. Others say that the benefits that will come from genetic testing outweigh the moral objections that some people have to this type of testing. Which of those two views is closest to your own?

    Genetic testing is wrong-benefits do not outweigh more issues
    Benefits outweigh moral objections
    Don't know/no response (DO NOT READ)

25. In the future, home genetic testing kits could be made widely available, potentially offering individuals the ability to conduct such tests on themselves or on others. In your view, which of the 4 courses of action is closest to what you believe government should do with regard to these kits?

Allow people to use them if they choose, without medical referral or consultation if they wish
Allow people to use them only if they get a medical referral, and consult with their doctor about the results
Allow them to be used, but ban people from using tests on anyone other than themselves or their children without permission
Ban them altogether, because people may use them improperly or not understand the information that results from them

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.

26. Would you say you are very familiar, somewhat familiar, not very familiar, or not at all familiar with the laws, regulations and guidelines governing the collection and use of genetic information in Canada?

Very familiar
Somewhat familiar
Not very familiar
Not at all familiar
Don't know/no response (DO NOT READ)

27. Using a scale of 1-7, where 1 is very lax and 7 is very stringent, how stringent do you think the current systems regulating or governing genetic information in Canada are at this time?

Very Lax
2
3
4
5
6
Very stringent
Don't know/no response (DO NOT READ)

28. A number of people and institutions may or may not be allowed to have access to people's genetic information. In your opinion, do the benefits outweigh the drawbacks or do the drawbacks outweigh the benefits if each of the following had access to a person's genetic information? (READ AND ROTATE)

a) Doctors

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

b) Pharmacists

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

c) Nurses

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

d) Medical researchers

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

e) Governments

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

f) Insurance companies

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

g) Employers

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)h)The person himself or herself

Benefits outweigh the drawbacks
Drawbacks outweigh benefits
Don't' know/no response (DO NOT READ)

29. Some people say that getting a genetic test is every persons' right, and government has no right getting involved. Other people say that once genetic tests become widespread, some people may feel a whole variety of pressures to take tests they don't want to take, and therefore government should ban genetic tests. Which of those two views is closest to your own?

Government no right to be involved
Government should ban genetic tests
Don't know/no response (DO NOT READ)

30. 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?

More strictly regulated
Regulated in same way as others
Don't know/no response (DO NOT READ)

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 and development in Canada: very, somewhat, not very, not at all?

Very important
Somewhat important
Not very important
Not at all important
Don't know/no response (DO NOT READ)

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

Very willing
Somewhat willing
Not very willing
Not at all willing
Don't know/no response (DO NOT READ)

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

    Very willing
    Somewhat willing
    Not very willing
    Not at all willing
    Don't know/no response (DO NOT READ)

34. (SPLIT) A. Some people say that we should allow scientific researchers access to Canadians' genetic information in order to study genetic traits and develop cures for illness, as long as people consent to their genetic information being used. Others say we should not allow researchers access to this information because they might use that information for purposes that people don't agree with. Which is closest to your own view?

    Should allow access
    Should not allow access
    Don't know/no response (DO NOT READ)

35. (SPLIT)Some people say that we should allow health care companies access to Canadians' genetic information in order to study genetic traits and develop cures for illness, as long as people consent to their genetic information being used. Others say we should not allow health care companies access to this information because they might use that information for purposes that people don't agree with. Which is closest to your own view?

    Should allow access
    Should not allow access
    Don't know/no response (DO NOT READ)

36. (If do not allow scientific researchers access) Researchers say that allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases. Knowing that these implications are possible if researchers were limited in their access genetic information, would you still say that we should not allow researchers access to it?

    Should allow access
    Should not allow access
    Don't know/no response (DO NOT READ)

37. (If do not allow health care companies access) Health care companies say that allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases. Knowing that these implications are possible if researchers were limited in their access genetic information, would you still say that we should not allow researchers access to it?

    Should allow access
    Should not allow access
    Don't know/no response (DO NOT READ)

38. (If do not allow researchers access) If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base, would you be willing to allow researchers access to genetic information, or would you still say that we should not allow researchers access to this information?

    Should allow access
    Should not allow access
    Don't know/no response (DO NOT READ)

39. (If do not allow health care companies access) If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base, would you be willing to allow researchers access to genetic information, or would you still say that we should not allow researchers access to this information?

    Should allow access
    Should not allow access
    Don't know/no response (DO NOT READ)

40. Would you think that there are currently very stringent, somewhat stringent, somewhat lax or very lax rules in place to govern how these genetic information research databanks are used?

    Very stringent
    Somewhat stringent
    Somewhat lax
    Very lax
    Don't know/no response (DO NOT READ)

41. (SPLIT) If scientific researchers or companies that developed these data bases had the consent of those who contributed genetic samples, do they have a right to use them for other genetic research studies in future/sell that information to those who do other genetic research studies in future provided they mask the donor's identity?
    Yes
    No
    Don't know/no response (DO NOT READ)

42. (SPLIT) If scientific researchers or companies that developed these data bases had the consent of those who contributed genetic samples, do they have a right to use them for other genetic research studies in future/sell that information to those who do other genetic research studies in future provided they mask the donor's identity?
Yes
No
Don't know/no response (DO NOT READ)

43. (SPLIT) A. Some people say that we should allow insurance companies to have the right to ask about an individual's genetic information when he or she applies for insurance coverage, in order to determine that person's risk of future health problems. Others say that we should not allow insurance companies to have access to their client's genetic information so that they could not deny coverage as a result. Which is closest to your own view?

Allow insurance companies right to information
Not allow insurance companies right to information
Don't know/no response (DO NOT READ)

44. B. Some people say that insurance companies should be allowed to access genetic information about a person that he or she knows about when they apply for insurance coverage, in order to cover all possible claims. Others say that we should not allow insurance companies to have access to genetic information that a potential client knows about because some people would face higher premiums or may be denied coverage based on those risks. Which is closest to your own view?
Allow insurance companies right to information
Not allow insurance companies right to information
Don't know/no response (DO NOT READ)

45. **(if not allowed)** Some people say that denying insurance companies access to applicants genetic information would mean that they would be exposed to major financial risks, because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims. Would that change your opinion?

Yes
No
Don't know/no response (DO NOT READ)

46. **(if not allowed)** Some people say that denying insurance companies access to genetic information would mean that insurance companies would have to increase premiums for all customers, regardless of the risk they pose. because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims. Would that change your opinion?

    Yes
    No
    Don't know/no response (DO NOT READ)

47. Some people say we should allow Canadians to voluntarily provide their genetic information to insurance companies if they want, to get lower rates for themselves by proving they are not predisposed to certain genetic disorders. Others say we should not allow Canadians to provide this information to their insurance companies even if they want to, because allowing this would probably mean that Canadians who do not provide this information to the insurer could face higher premiums or be denied coverage. Which is closest to your view?

    Allow Canadians to provide genetic information
    Not allow Canadians to provide genetic information
    Don't know/no response (DO NOT READ)

48. Some people say that we should provide employers with the right to ask about an individual's genetic information when they apply for work or in the course of employment, because employers have a right to know whether their employees are unhealthy or might develop a health condition. Others say we should not allow employers to ask about an individual's genetic information when they apply for work or in the course of employment, because employers might base their decisions on whether the person is predisposed to a disease or disorder. Which is closest to your own view?

    Employers have right to ask genetic information
    Employers do not have right to ask genetic information
    Don't know/no response (DO NOT READ)

49. I'm going to list for you a series of potential priorities for government to take into consideration regarding genetic information. What I would like you to do is indicate, on a scale of 1-7, where 1 is not important at all and 7 is extremely important, how important each of these priorities should be in government decision-making: (read and rotate)

a) Strictly protecting the privacy of genetic information

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

b) Promoting Canadian leadership in genetics research and development

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

c) Developing cures to disease

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

d) Ensuring that Canada is not left out of the economic benefits that come with research and development in genetics

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

e) Working with other countries to develop common rules and regulations regarding genetic information

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

f) Preventing discrimination in the work place based on genetic information

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

g) Regulating appropriate access to genetic data bases

Not important at all
2
3
4
5
6
Extremely important

Don't know/no response (DO NOT READ)

h) Monitoring the various uses of personal genetic information

Not important at all
2
3
4
5
6
Extremely important
Don't know/no response (DO NOT READ)

50. 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?

Gov't attempt balance between these two priorities
Focus mostly on ensuring privacy
Focus mostly on support with research and development
Don't know/no response (DO NOT READ)

51. There are a number of ways in which regulatory and ethical governance systems can be set up to ensure genetic privacy is protected for Canadians. I'd like to give you a general outline of two possible ways of doing this, and I'd like you to indicate which you think is best

a) The medical & research community should play the main role, using professional bodies like medical associations as well as self governing systems such as safety/ethics committees at research hospitals, and governments should play a secondary role, by laying out national guidelines for the medical research community to follow

b) The government should play the main role, having laws and enforcing them, with a secondary monitoring role played by professional organizations and ethics committees in the medical & research community

The medical and research company should play the main role
The government should play the main role
Don't know/no response (DO NOT READ)

52. Is it your opinion that the benefits of knowing more about our genetic information outweigh the drawbacks, or do the drawbacks outweigh the benefits? (If respondent mentions that they have been asked this question earlier, let them know that it is being asked on purpose, to get a sense of how opinion was affected by discussion of some of the issues involved)

Benefits outweigh drawbacks
Drawbacks outweigh benefits
Don't know/no response (DO NOT READ)

DEMOGRAPHICS

I'd like to ask you some questions about your level of involvement in current issues, if you don't mind. For each of the following, I'd like you to tell me, with a yes or no answer, whether you have done this **in the last year.** How about: (ROTATE)

53. Spoken at a public meeting
    Yes
    No
    Don't know/no response (DO NOT READ)

54. Written a letter to a newspaper editor
    Yes
    No
    Don't know/no response (DO NOT READ)

55. Called a television or radio talk show that deals with public affairs issues
    Yes
    No
    Don't know/no response (DO NOT READ)

56. Written an article for a publication
    Yes
    No
    Don't know/no response (DO NOT READ)

57. Been a member of a community service organization
    Yes
    No
    Don't know/no response (DO NOT READ)

58. Served as an officer of a non-governmental organization, that deals with public policy issues
    Yes
    No
    Don't know/no response (DO NOT READ)

59. Written to an elected representative
    Yes
    No
    Don't know/no response (DO NOT READ)

60. Been a member of or worked for a political party
    Yes
    No
    Don't know/no response (DO NOT READ)

END OF ROTATION

61. What is the highest level of education you have completed?

    Some high school or less
    High school graduate
    Some college or technical School/CEGEP
    college or technical school/CEGEP graduate
    Some university
    University graduate
    Or post graduate studies (Masters/Doctoral)
    REFUSE

62. Which one of the following best describes your employment situation? (READ LIST)

    Employed Full-Time For Pay
    Employed Part-Time For Pay
    Self-employed
    Currently Seeking Work
    Homemaker
    Student
    Disabled
    Retired
    Don't know/no response (DO NOT READ)

63. Are you a union member or not?

    Yes
    No
    Don't know/no response (DO NOT READ)

64. In which of the following categories does your total household income, before taxes, fit? (10k increments)

65. Do you currently have life or health insurance coverage you purchased on your own (not through the organization you work for)?
    Yes
    No
    Don't know/no response (DO NOT READ)

66. Would you describe your health as excellent, good, fair or poor?
    Excellent
    Good
    Fair
    Poor
    Don't know/no response (DO NOT READ)

67. What is the postal code for your home mailing address? (RECODE INTO URBAN/RURAL)

Appendix 4

French Questionnaire
Genetic Privacy

Bonjour, bonsoir, ici (__) de POLLARA, une organisation nationale de recherche en opinion publique. Nous menons une étude sur les attitudes et les opinions des Canadiens de 18 ans et plus. Pourrais-je vous poser quelques questions? Toutes vos réponses seront tenues strictement confidentielles.

(SI OUI) Merci
(SI NON) Quand pourrais-je vous rappeler? (PRENEZ RENDEZ-VOUS POUR RAPPELER)
SI REFUS) Remerciez et terminez

Bonjour, bonsoir, ici (__) de POLLARA, une organisation nationale de recherche en opinion publique. Nous menons une étude sur les attitudes et les opinions des Canadiens de 18 ans et plus. Pourrais-je vous poser quelques questions? Toutes vos réponses seront tenues strictement confidentielles.

(SI OUI) Merci
(SI NON) Quand pourrais-je vous rappeler? (PRENEZ RENDEZ-VOUS POUR APPELER)
(SI REFUS) Remerciez et terminez

Tout d'abord, est-ce que vous travaillez, ou est-ce que quelqu'un dans votre ménage travaille, pour une entreprise d'études de marché, un média, une entreprise de télécommunication OU un parti politique?

OUI (Remerciez et terminez)
NON
NSP/REFUS (Remerciez et terminez)

B. En quelle année êtes-vous né?
Puis-je parler avec quelqu'un agé d'au moins 18 ans, S-V-P?

1. Certaines personnes disent que même si le Canada a certains problèmes présentement, il est généralement dans la bonne voie. D'autres personnes disent qu'il y a plus de choses allant mal que de choses allant bien présentement au Canada et que le pays est dans la mauvaise voie.

Lequel de ces deux énoncés reflète le mieux votre opinion?

2. J'aimerais vous poser quelques questions sur vos attitudes et vos perceptions par rapport à la façon dont certaines organisations traitent vos renseignements personnels, et la confidentialité qu'ils accordent à

ces renseignements.

Veuillez indiquer si vous êtes extrêmement préoccupé, assez préoccupé, pas très préoccupé ou pas préoccupé du tout par la mesure dans laquelle ces renseignements sont bien protégés par les organisations avec lesquelles vous faites affaire

a) Les renseignements médicaux
b) Les renseignements sur vos caractéristiques génétiques
c). Les renseignements financiers comme votre cote de crédit ou vos habitudes d'achat
d) Les renseignements sur vos habitudes en matière de communication, comme l'utilisation que vous faites du téléphone ou de l'ordinateur

3.J'aimerais maintenant vous poser quelques questions sur les lois et les règlements concernant le caractère privé de vos renseignements personnels. Pour chacun, veuillez indiquer si vous croyez qu'il existe des lois et des règlements très stricts, plutôt stricts, plutôt relâchés ou très relâchés régissant le caractère privé de ces renseignements?

a) Les renseignements médicaux
b) Les renseignements sur vos caractéristiques génétiques
c) Les renseignements financiers comme votre cote de crédit ou vos habitudes d'achat
d) Les renseignements sur vos habitudes en matière de communication, comme l'utilisation que vous faites du téléphone ou de l'ordinateur

DÉFINITION
Cette étude porte sur l'information génétique personnelle. L'information génétique est l'information contenue dans l'ADN humain. Cette information nous révèle les caractéristiques génétiques et les traits héréditaires, comme la couleur des yeux, qui nous ont été transmis au cours des générations. L'information génétique peut être étudiée en utilisant de la salive, le sang contenu dans les cheveux ou tout matériel biologique contenant des cellules. Au cours des quelques dernières années, il y a eu des percées scientifiques considérables permettant de comprendre les caractéristiques génétiques des gens, dont la plus notoire est le projet du génome humain.

4. Diriez-vous que les enjeux liés à l'information génétique vous sont
très familiers, plutôt familiers, pas très familiers ou pas familiers du tout?

5. Vous diriez-vous très intéressé, plutôt intéressé, pas très intéressé ou pas intéressé du tout par cet enjeu?

6. Dans quelle mesure êtes-vous intéressé à en savoir davantage sur vos propres caractéristiques génétiques? Très, assez, pas très ou pas du tout?

7. Croyez-vous que les avantages d'en savoir plus long sur notre information génétique sont plus importants que les inconvénients, ou croyez-vous que les inconvénients sont plus importants que les avantages?

8. J'aimerais avoir une idée de vos connaissances par rapport à ce que l'information génétique peut nous révéler sur nous-mêmes. Je vais vous lire une liste de choses et j'aimerais savoir si vous croyez qu'elles peuvent ou non être déterminées à partir de l'information génétique.

a. La probabilité qu'une personne souffre de certaines afflictions héréditaires comme la fibrose kystique ou la chorée de Huntington la maladie de Huntington).

b. Savoir si une personne porte un gène risquant de transmettre une maladie à son enfant, sans toutefois que cette personne ne développe elle-même SHOW cette maladie.

c. La probabilité qu'une personne ait un accident de voiture

d. Savoir si le conjoint ou la conjointe d'une personne court le risque de développer la maladie héréditaire de son ou sa partenaire

9. Croyez-vous que l'information génétique est différente des autres renseignements sur la santé (comme les antécédents médicaux personnels ou les antécédents médicaux de la famille) ou est-ce essentiellement la même chose que les autres renseignements sur la santé?

La prochaine série de questions porte sur le dépistage génétique. Le dépistage génétique est un processus scientifique permettant d'identifier l'information génétique d'une personne en testant du matériel biologique, comme le sang ou la salive, pour en révéler les caractéristiques génétiques. L'information est utilisée pour déterminer dans quelle mesure les gens risquent de développer des maladies héréditaires comme la chorée de Huntington ou la fibrose kystique.

10. Vous a-t-on déjà demandé de vous soumettre à un test de dépistage génétique?
Oui
Non
Ne sait pas/Pas de réponse

11. (SI OUI) Qui vous l'a demandé?
a. un médecin
b. un employeur
c. une compagnie d'assurances
d. une autre organisation (précisez) (NE LISEZ PAS)
e. Ne sait pas/Pas de réponse (NE LISEZ PAS)

12. Est-ce que vous ou votre conjoint(e) avez subi des tests pour déterminer votre information génétique (y compris un diagnostique prénatal)?
Oui, moi
Oui, époux/épouse
Oui, les deux
Non
Ne sait pas/Pas de réponse

13. Si vous avez un enfant de moins de 18 ans, votre enfant a-t-il déjà subi des tests pour déterminer son information génétique?
Oui
Non
Ne sait pas/Pas de réponse

14. (SI OUI Q.18, Q.19) Vous a-t-on remis les résultats de ces tests?
Oui
Non
Ne sait pas/Pas de réponse

15. (SI OUI Q.20) Les résultats de ces tests vous ont-ils été expliqués par un conseiller professionnel ou par un médecin?
Conseiller professionnel
un médecin
Les deux (VOLUNTEERED)
Ne sait pas/Pas de réponse (NE LISEZ PAS)

16. D'après vous, dans quelle mesure le dépistage génétique est-il courant au Canada à l'heure actuelle? Est-il très courant, assez courant, pas très courant
ou pas courant du tout?

17. Si vous subissiez un test de dépistage génétique, croyez-vous que les renseignements en résultant seraient votre propriété, la propriété de l'organisation ayant fait le test ou que vous et l'organisation ayant fait le test seriez conjointement propriétaires de l'information?

18. Si vous fournissiez un échantillon pour un test génétique (comme du sang ou de la salive), croyez-vous que l'échantillon que vous donneriez serait détruit(e ou préservé(e) dans la base de données d'une bio-banque d'information génétique?/

19.Si vous fournissiez un échantillon pour un test génétique (comme du sang ou de la salive), croyez-vous que l'information génétique en résultant serait détruit(e) ou préservé(e) dans la base de données d'une bio-banque d'information génétique?

D'ici la fin du questionnaire, je vais vous poser de nombreuses questions sur l'information génétique personnelle, dont certaines traiteront de problèmes et d'enjeux qui pourraient ou non se produire. Ces questions sont conçues pour nous aider à comprendre ce que vous pensez de l'enjeu dans son ensemble et des implications possibles.

20.Je vais vous lire une série d'énoncés sur le dépistage génétique et l'information génétique. Pour chacun, j'aimerais que vous me disiez si vous êtes tout à fait d'accord, d'accord, en désaccord ou tout à fait en désaccord. Voici le premier:

a). Je me soumettrais à un test de dépistage génétique pour obtenir plus renseignements sur mes

caractéristiques génétiques.
b) Je me soumettrais à un test de dépistage génétique pour déterminer le risque que j'ai de développer une maladie ou une condition génétique
c) Je me soumettrais à un test de dépistage génétique si cela aidait à déterminer la meilleure approche médicale pour traiter une maladie ou une condition dont je souffre. "

d) Je me soumettrais à un test de dépistage génétique si cela permettait de déterminer la probabilité que j'aie une maladie ou condition pouvant être transmise à mes enfants.

e) Je soumettrais mes enfants à un test de dépistage génétique si cela déterminait la probabilité qu'ils souffrent d'une maladie ou d'une condition génétique. (REMARQUE:Si le répondant le demande: Cela inclut les enfants de la naissance à l'âge de majorité)

f)-g). Je ne me soumettrais PAS à un test de dépistage génétique, car je crois que cela n'est pas moral (REMARQUE:Si le répondant le demande: Cela inclut les enfants de la naissance à l'âge de majorité)/Je ne soumettrais pas mes enfants à un test de dépistage génétique, car je crois que cela n'est pas moral (REMARQUE:Si le répondant
le demande: Cela inclut les enfants de la naissance à l'âge de majorité)

h)-i) Chaque personne devrait avoir le droit absolu de déterminer si elle veut ou non se soumettre à un test de dépistage génétique./Chaque personne devrait avoir le droit absolu de déterminer si elle veut ou non se soumettre à un test de dépistage génétique, peu importe les conséquences pour les membres de sa famille et le risque qu'on leur transmette des maladies.

j). Les gouvernements devraient avoir le pouvoir d'empêcher l'utilisation du dépistage génétique s'il juge que les buts du test sont contraires à l'étique.

Dans certains cas, l'information génétique peut vous renseigner sur la santé et les caractéristiques génétiques pouvant être transmises aux membres de votre famille. Les questions suivantes portent sur les enjeux familiaux. Pour y répondre, veuillez utiliser la même échelle que pour la série de questions précédentes et indiquer si vous êtes tout à fait d'accord, d'accord, en désaccord ou tout à fait en désaccord avec les énoncés suivants:

21. Les membres de ma famille devraient avoir le droit de connaître les résultats de mon test de dépistage génétique qui pourraient leur révéler quelque chose sur leur santé.

22. Si je me soumettais à un test de dépistage génétique, les membres de ma famille auraient le droit de dire qu'ils ne veulent pas en connaître les résultats, même si l'avenir leur réserve un problème potentiel

23. Certaines personnes sont d'avis qu'une personne se soumettant à un test de dépistage génétique a l'obligation d'informer les membres de sa famille des résultats si quelque chose risque d'affecter ces membres de la famille. D'autres disent qu'une personne se soumettant à un test de dépistage génétique n'a pas l'obligation d'informer les membres de sa famille des résultats même si quelque chose risque de les affecter, que la décision de partager de tels renseignements est une décision fondamentalement

personnelle.
Lequel de ces deux points de vue reflète le mieux le vôtre?

24. Certaines personnes disent que le dépistage génétique n'est pas moral et que les avantages de ces tests ne pèsent pas plus lourd que les questions morales en jeu. D'autres disent que les avantages qui résulteront du dépistage génétique sont beaucoup plus importants que les objections morales de certaines personnes par rapport à ce type de tests.
Lequel de ces deux points de vue reflète le mieux le vôtre?

25. A l'avenir, des trousses de dépistage maison pourraient être offertes à grande échelle, donnant potentiellement aux gens la capacité de faire de tels tests sur eux-mêmes ou sur les autres. D'après vous, lequel des 4 plans d'action suivants le gouvernement devrait-il adopter par rapport à ces trousses?
A.Permettre aux gens de les utiliser s'ils désirent le faire, sans recommandation médicale ni consultation.

B. Permettre aux gens de les utiliser seulement s'ils obtiennent une indication médicale et consultent leur médecin par rapport aux résultats.

C. Permettre l'utilisation de telles trousses, mais interdire aux gens de soumettre qui que ce soit aux tests sans permission, mis à part eux-mêmes et leurs enfants.

D. Les interdire complètement, car les gens risquent de ne pas les utiliser de la bonne façon et de ne pas comprendre l'information en résultant.

E. Ne sait pas/Pas de réponse (NE LISEZ PAS)

Les questions suivantes portent sur l'information génétique et les droits en matière de domaine privé. Ces droits ont trait aux lois, aux règlements et aux normes régissant la confidentialité dans la cueillette et l'utilisation de l'information génétique. Les droits concernant le domaine privé peuvent restreindre ce que les gens ont le droit de savoir sur vous, et peuvent également protéger la confidentialité de votre information génétique une fois qu'elle est recueillie.

26. Diriez-vous que les lois, les règlements et les normes régissant la cueillette et l'utilisation de l'information génétique au Canada vous sont très familiers, plutôt familiers, pas très familiers ou pas familiers du tout?

27. A l'aide d'une échelle allant de 1 à 7, où 1 signifie très relâchés et 7 signifie très stricts, dans quelle mesure croyez-vous que les systèmes régissant ou gouvernant actuellement l'information génétique au Canada sont stricts?

28. Un certain nombre de personnes et d'institutions auront peut-être ou peut-être pas accès à l'information génétique des gens. D'après-vous, est-ce que les avantages surpasseraient les inconvénients ou est-ce que les inconvénients surpasseraient les avantages si chacun des groupes suivants avaient accès à l'information génétique d'une personne?

a)Les médecin

B) Les pharmaciens
C)Les infirmières
D)Les chercheurs médicaux
E)Les gouvernements
F)Les compagnies d'assurances"
G)Les employeurs
H)La personne même

29. Certaines personnes disent qu'obtenir un test de dépistage génétique est le droit de toute personne et que le gouvernement n'a aucun droit de s'en mêler. D'autres personnes disent qu'une fois que les tests génétiques seront très répandus, certaines personnes se sentiront peut-être forcées de subir des tests qu'ils ne veulent pas subir, et que le gouvernement devrait interdire les tests génétiques. Lequel de ces deux points de vue reflète le mieux le vôtre?

30. Croyez-vous que les règlements régissant l'accès à l'information génétique devraient être plus stricts que ceux régissant les autres renseignements sur la santé ou croyez-vous que l'information génétique devrait être réglementée de la même façon que les autres renseignements sur la santé?

Le fait d'avoir des connaissances scientifiques accrues sur nos caractéristiques génétiques a des implications pour la recherche en santé et en médecine.

De nombreux chercheurs dans le domaine de la santé et de la médecine se consacrent à en découvrir davantage sur les façons dont l'information génétique détermine comment et pourquoi certaines personnes développent des maladies et des afflictions, en étudiant l'information génétique provenant d'importants groupes de personnes.

31. A l'avenir, dans quelle mesure croyez-vous que l'information génétique jouera un rôle important dans la recherche et le développement en matière de santé au Canada: très important, assez important, pas très important ou pas important du tout?

32. Si vous vous soumettiez à un test génétique, seriez-vous très disposé, plutôt disposé, pas très disposé ou pas disposé du tout à remettre l'information à une base de données qui serait utilisée pour la recherche en santé.

33. Si vous vous soumettiez à un test génétique, seriez-vous très disposé, plutôt disposé, pas très disposé ou pas disposé du tout à remettre l'information à une base de données qui serait utilisée pour la recherche en santé, si votre identité était retirée de la banque de données?

34. Si les gens consentent à ce que leur information génétique soit utilisée, certaines personnes disent qu'on devrait permettre aux chercheurs scientifiques d'avoir accès à l'information génétique des Canadiens pour qu'ils puissent étudier les traits génétiques et développer des cures pour les maladies. D'autres disent qu'on ne devrait pas permettre aux chercheurs d'avoir accès à cette information, car il est possible qu'ils l'utilisent à des fins avec lesquelles les gens ne sont pas d'accord. Lequel de ces deux points de vue reflète le mieux le vôtre?

35. Les chercheurs affirment que l'accès à cette information est essentiel à la recherche génétique au Canada, et que sans accès suffisant, il y aura moins de nouveaux traitements pour ceux qui souffriront ou souffrent déjà de maladies héréditaires. En sachant que ces implications sont possibles si l'accès des chercheurs à l'information génétique est limité, diriez-vous toujours qu'on ne devrait pas permettre aux chercheurs d'y avoir accès?

36. Si les gens consentaient à ce que leur information génétique soit utilisée en recherche, et que leur nom était simplement retiré des bases de données de recherche, seriez-vous disposé à permettre aux chercheurs d'avoir accès à l'information génétique, ou diriez-vous toujours qu'on ne devrait pas permettre aux chercheurs d'avoir accès à cette information?

37. Les compagnies dans le domaine de la santé affirment que l'accès à cette information est essentiel à la recherche génétique au Canada, et que sans accès suffisant, il y aura moins de nouveaux traitements pour ceux qui souffriront ou souffrent déjà de maladies héréditaires. En sachant que ces implications sont possibles si l'accès des compagnies dans le domaine de la santé à l'information génétique est limité, diriez-vous toujours qu'on ne devrait pas permettre aux chercheurs d'y avoir accès?

38. Si les gens consentaient à ce que leur information génétique soit utilisée en recherche, et que leur nom était simplement retiré des bases de données de recherche, seriez-vous disposé à permettre aux compagnies dans le domaine de la santé d'avoir accès à l'information génétique, ou diriez-vous toujours qu'on ne devrait pas permettre aux chercheurs d'avoir accès à cette information?

40. Présentement, croyez-vous qu'il existe des règles très strictes, plutôt strictes, plutôt relâchées ou très relâchées pour gouverner la façon dont ces bases de données sur l'information génétique sont utilisées?

41. Si les chercheurs ou les compagnies scientifiques ayant développé ces bases de données avaient le consentement de ceux ayant fourni des échantillons génétiques, auraient-ils le droit de les utiliser pour d'autres recherches scientifiques à l'avenir si l'identité du donneur est masquée?

Oui
Non
Ne sait pas/Pas de réponse

42. Si les chercheurs ou les compagnies scientifiques ayant développé ces bases de données avaient le consentement de ceux ayant fourni des échantillons génétiques, de vendre cette information à ceux qui feront d'autres recherches scientifiques à l'avenir, si l'identité du donneur est masquée?

Oui
Non
Ne sait pas/Pas de réponse

43. Certaines personnes disent qu'on devrait donner aux compagnies d'assurances le droit d'interroger les gens sur leur information génétique lorsqu'ils font une demande d'assurance, pour déterminer leur risque de souffrir de problèmes de santé à l'avenir. D'autres personnes disent qu'on ne devrait pas permettre aux compagnies d'assurances d'avoir accès à l'information génétique de leurs clients, pour éviter qu'elles refusent d'assurer quelqu'un. Lequel de ces deux points de vue reflète le mieux le vôtre?

1 Donner aux compagnies d'assurances le droit d'interroger les gens sur leur information génétique
2 ne devrait pas permettre aux compagnies d'assurances d'avoir accès à l'information génétique
3 Ne sait pas/Pas de réponse

44. Lorsqu'une personne fait une demande d'assurance, certains sont d'avis que les compagnies d'assurances devraient pouvoir accéder à l'information génétique que cette personne connaît sur elle-même afin, d'être en mesure de couvrir toutes les demandes d'indemnités possibles. D'autres personnes disent qu'on ne devrait pas permettre aux compagnies d'assurances d'accéder à l'information génétique connue d'un client potentiel, car certaines personnes auraient à payer des primes plus élevées ou pourraient être refusées en raison des risques. Lequel de ces points de vue reflète le mieux le vôtre?

45. Certaines personnes disent que refuser d'accorder aux compagnies d'assurances le droit d'accéder à l'information génétique des proposants exposerait les compagnies à des risques financiers majeurs, car certaines personnes sachant qu'il est probable qu'elles souffrent d'une maladie ou d'une invalidité pourraient acheter de l'assurance supplémentaire, mais la compagnie ne serait pas en mesure d'augmenter le prix de la police pour refléter le risque plus élevé et couvrir les demandes de règlement additionnelles.
Cela changerait-il votre opinion?

46. Certaines personnes disent qu'empêcher les compagnies d'assurances d'accéder à l'information génétique signifie que les compagnies d'assurances devraient augmenter les primes de tous leurs clients, peu importe le risque que ces personnes posent, car certaines personnes sachant qu'il est probable qu'elles souffrent d'une maladie ou d'une invalidité pourraient acheter de l'assurance supplémentaire, mais la compagnie ne serait pas en mesure d'augmenter le prix de la police pour refléter le risque plus élevé et couvrir les demandes de règlement additionnelles.
Cela changerait-il votre opinion?

47. Certaines personnes disent qu'on devrait permettre aux Canadiens de donner volontairement leur information génétique aux compagnies d'assurances s'ils veulent obtenir des primes plus basses en prouvant qu'ils ne sont pas prédisposés à certaines maladies génétiques. D'autres personnes disent qu'on ne devrait pas permettre aux Canadiens de donner ces renseignements à leur compagnie d'assurance, même s'ils veulent le faire, car cela signifierait probablement que les Canadiens ne remettant pas ces renseignements à leur assureur auraient à payer des primes plus élevées ou qu'on refuserait de les assurer. Lequel de ces points de vue reflète le mieux le vôtre?

48. Certaines personnes disent qu'on devrait donner aux employeurs le droit de demander l'information génétique d'une personne lorsqu'elle postule pour un emploi ou au cours de la période d'emploi, car les employeurs ont le droit de savoir si leurs employés sont en mauvaise santé ou risquent de développer une maladie. D'autres disent qu'on ne devrait pas permettre aux employeurs de demander l'information génétique d'un individu lorsqu'il postule pour un emploi ou au cours de la période d'emploi, car les employeurs pourraient baser leur décision sur le fait que la personne est prédisposée à une certaine maladie ou à une certaine affliction. Lequel de ces deux points de vue reflète le mieux le vôtre?

49. Je vais vous lire une série de priorités potentielles dont le gouvernement pourrait tenir compte par rapport à l'information génétique. J'aimerais que vous m'indiquiez, sur une échelle allant de 1 à 7, où 1 signifie pas important du tout et 7 signifie extrêmement important, dans quelle mesure chacune de ces priorités devrait être importante dans le processus décisionnel du gouvernement:

a)Protéger strictement le caractère privé de l'information génétique
b)Promouvoir le leadership canadien en matière de recherche et de développement en génétique

c)Développer des cures pour les maladies
d)S'assurer que le Canada ne passe pas à côté des avantages économiques liés à la recherche et au développement en génétique
e)Travailler de concert avec d'autres pays pour développer des règlements communs par rapport à l'information génétique
f)Empêcher la discrimination au travail sur la base de l'information génétique.
g)Réglementer l'accès approprié aux bases de données génétiques
h)Surveiller les divers usages de l'information génétique personnelle

50. En ce qui concerne l'information génétique, un des rôles du gouvernement fédéral est d'assurer le caractère privé de l'information, car la protection du domaine privé est importante pour les Canadiens. Le gouvernement doit également jouer un autre rôle; appuyer la recherche et le développement dans le domaine de la santé, car cela entraîne la production de produits de santé et contribue à créer des emplois et à attirer des investissements. Selon vous, le gouvernement devrait-il tenter d'arriver à un équilibre entre ces deux priorités, devrait-il surtout se concentrer sur la protection du domaine privé ou devrait-il surtout se concentrer sur la promotion de la recherche et du développement?

51. Il existe un certain nombre de façons dont les systèmes réglementaires et les systèmes de conduite étique des affaires publiques peuvent être organisés pour assurer le respect du domaine privé des Canadiens en matière de génétique. Je vais vous donner un aperçu général de deux façons possibles d'y arriver et j'aimerais que vous me disiez laquelle est la meilleure selon vous.

a) La communauté médicale et scientifique devrait jouer le rôle majeur, en faisant appel à des corps professionnels comme les associations médicales et aux systèmes autogérés tels que les comités de sécurité ou d'éthique dans les hôpitaux faisant de la recherche, et le gouvernement devrait jouer un rôle secondaire en définissant des normes nationales que la communauté de recherche médicale devrait observer.

b) Le gouvernement devrait jouer le rôle principal, en ayant des lois et en les faisant respecter, et les organisations professionnelles et les comités d'éthique de la communauté médicale et scientifique devraient jouer un rôle secondaire de surveillance.

52. Croyez-vous que les avantages d'en savoir plus long sur notre information génétique sont plus importants que les inconvénients, ou croyez-vous que les inconvénients sont plus importants que les avantages?
(Si le répondant dit qu'on lui a déjà posé cette question plus tôt, dite-lui qu'on la pose par exprès, pour voir dans quelle mesure l'opinion a été affectée par la discussion de certains des enjeux concernés)

Si vous le permettez, j'aimerais vous poser quelques questions sur votre niveau de participation à certains enjeux. Pour chacune des catégories suivantes, j'aimerais que vous me disiez, en répondant oui ou non, si vous avez fait cette activité au cours de la dernière année. Qu'en est-il:

OUI ...
NON ...
Ne sait pas/Pas de réponse

53. De prendre la parole lors d'un rassemblement public
54. D'écrire une lettre au rédacteur ou à la rédactrice en chef d'un journal
55. De téléphoner à une émission de radio ou de télévision traitant d'affaires publiques
56. D'écrire un article destiné à être publié
57. D'être membre d'une organisation de service communautaire
58. D'être membre de la direction d'une organisation non-gouvernementale traitant d'enjeux de politique publique
59. D'écrire à un représentant élu
60. D'être membre ou de travailler pour un parti politique

61. Tout d'abord, quel est le plus haut niveau de scolarité que vous avez terminé?
(LISEZ)
École élémentaire
École secondaire
Cégep, collège communautaire
Quelques années d'université
Diplôme universitaire
Études ou diplôme de deuxième ou troisième cycle 7 Ne sait pas (NE LISEZ PAS)
Refus (NE LISEZ PAS)

62. Laquelle des catégories suivantes décrit le mieux votre situation d'emploi? Etes-vous...
(LISEZ LA LISTE)
Employé à temps plein contre rémunération

Employé à temps partiel contre rémunération
Travailleur, travailleuse autonome
Présentement à la recherche de travail
Au foyer
Étudiant(e)
Handicapé
Retraité
Autre (NE LISEZ PAS)
Ne sait pas (NE LISEZ PAS)
Refus

63. Etes-vous membre d'un syndicat?

OUI
NON
REFUS

64. Avant l'impôt, dans quelle catégorie se situe le revenu total de votre ménage parmi les catégories suivantes?

Moins de 25 000 $
25 000 $ à 34 000 $
35 000 $ à 44 000 $
45 000 $ à 54 000 $
55 000 $ à 64 000 $
65 000 $ à 74 000 $
75 000 $ à 100 000 $
Plus de 100 000 $
Ne sait pas (NE LISEZ PAS)
10 Refus (NE LISEZ PAS)

65. Possédez-vous présentement une assurance-santé ou une assurance-vie que vous avez achetée vous-même? (c.-à-d. pas obtenue par l'intermédiaire de l'organisation pour laquelle vous travaillez)?

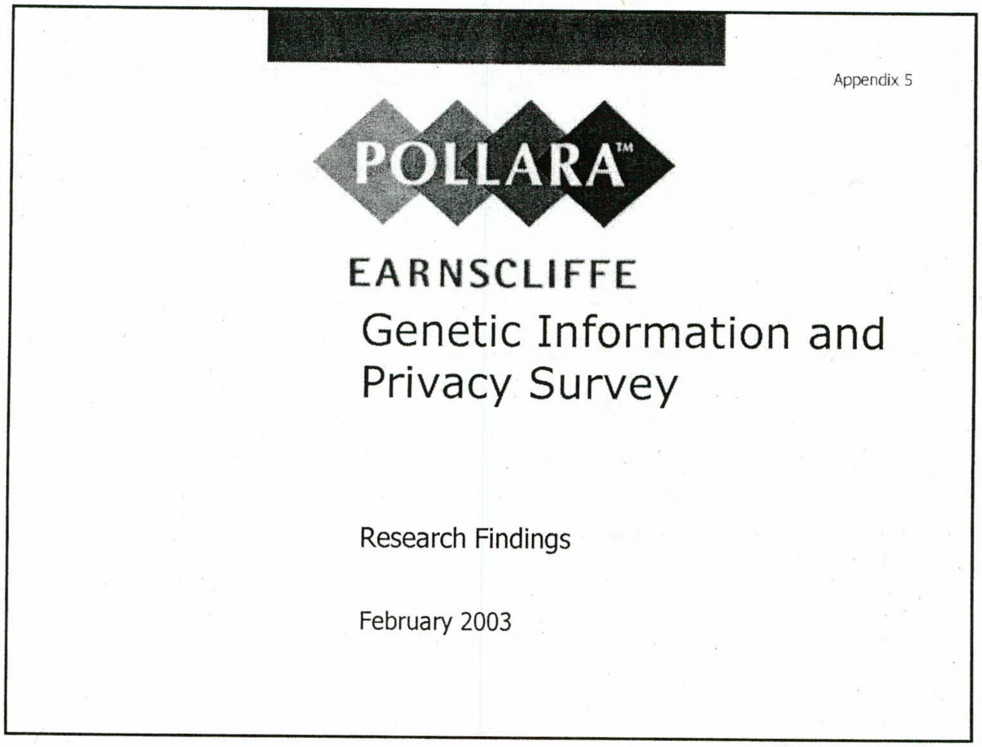
OUI
NON
REFUS

66. Diriez-vous que votre santé est excellente, bonne, moyenne ou mauvaise?

Excellente
Bonne
Moyenne
Mauvaise
Ne sait pas/Pas de réponse

67. Afin que nous puissions analyser ces données de façon plus détaillée, pourriez-vous me donner votre code postal?

(SI REFUS - «Les trois premières lettres seront suffisantes»)



Appendix 5

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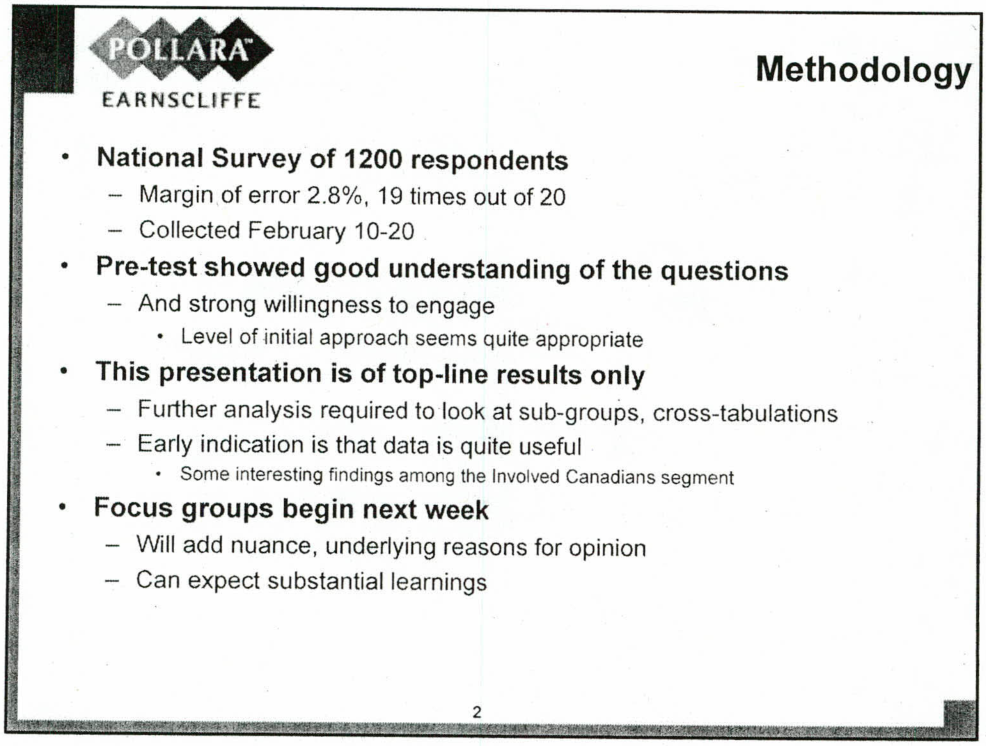
Genetic Information and Privacy Survey

Research Findings

February 2003



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Methodology

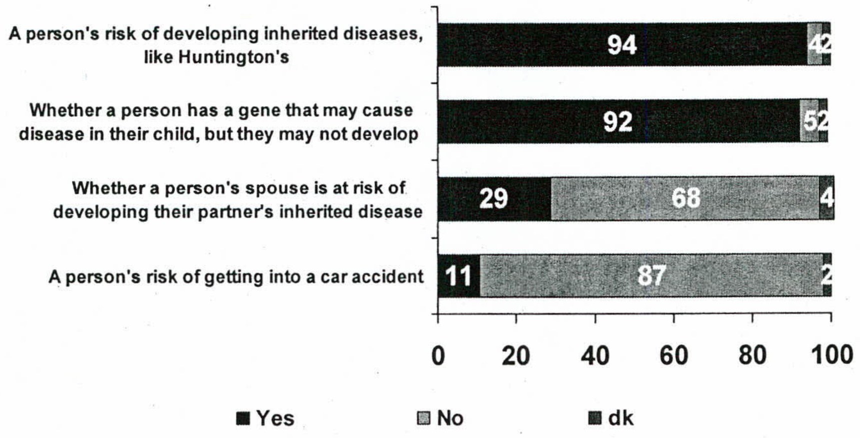
- **National Survey of 1200 respondents**
  - Margin of error 2.8%, 19 times out of 20
  - Collected February 10-20
- **Pre-test showed good understanding of the questions**
  - And strong willingness to engage
    - Level of initial approach seems quite appropriate
- **This presentation is of top-line results only**
  - Further analysis required to look at sub-groups, cross-tabulations
  - Early indication is that data is quite useful
    - Some interesting findings among the Involved Canadians segment
- **Focus groups begin next week**
  - Will add nuance, underlying reasons for opinion
  - Can expect substantial learnings

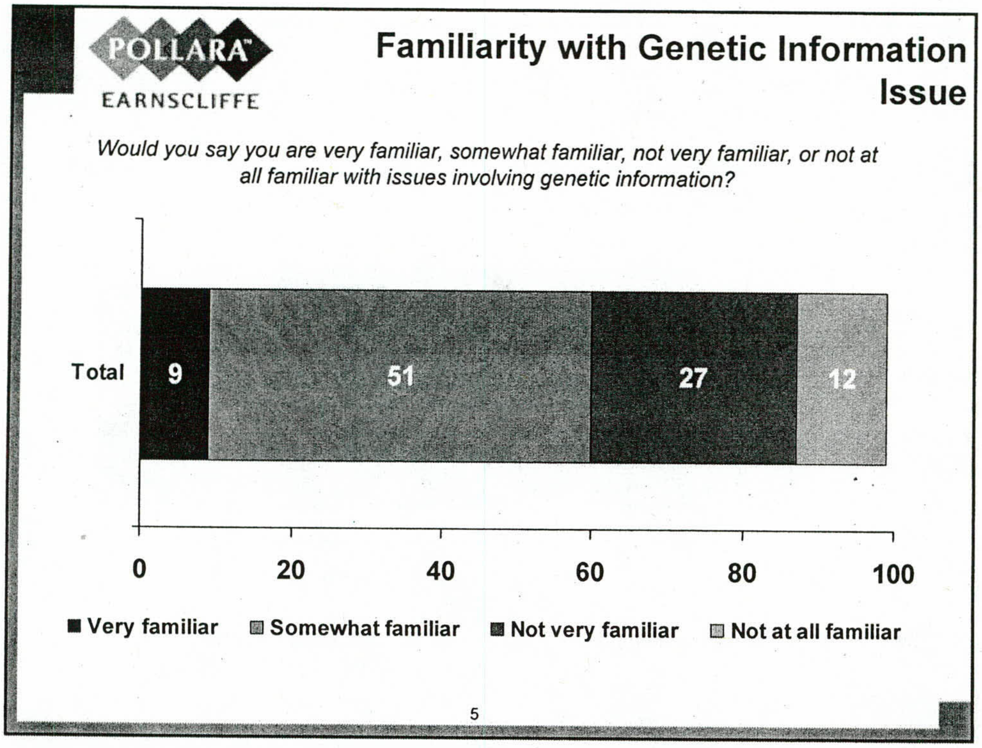
Knowledge, Familiarity, Interest

- **There appears to be basic understanding about what genetic information might indicate about inherited traits**
  - Although some overestimate what genetic information can do
    - One in four think it can indicate spouse's risk of inherited disease
- **Self-assessed knowledge about the field of genetic information and the issues it raises is relatively low, but interest is higher**
  - Fewer than one in ten say they are "very" knowledgeable
  - One in three "very" interested
- **A large majority believes the benefits of knowing more about genetic information outweigh the potential drawbacks**

Knowledge: What Genetic Information Can Tell Us

I'd like to get a sense of your knowledge about what genetic information can tell us about ourselves. I'm going to read you a list of things, and I want to know whether you think they could be determined from genetic information, or not.





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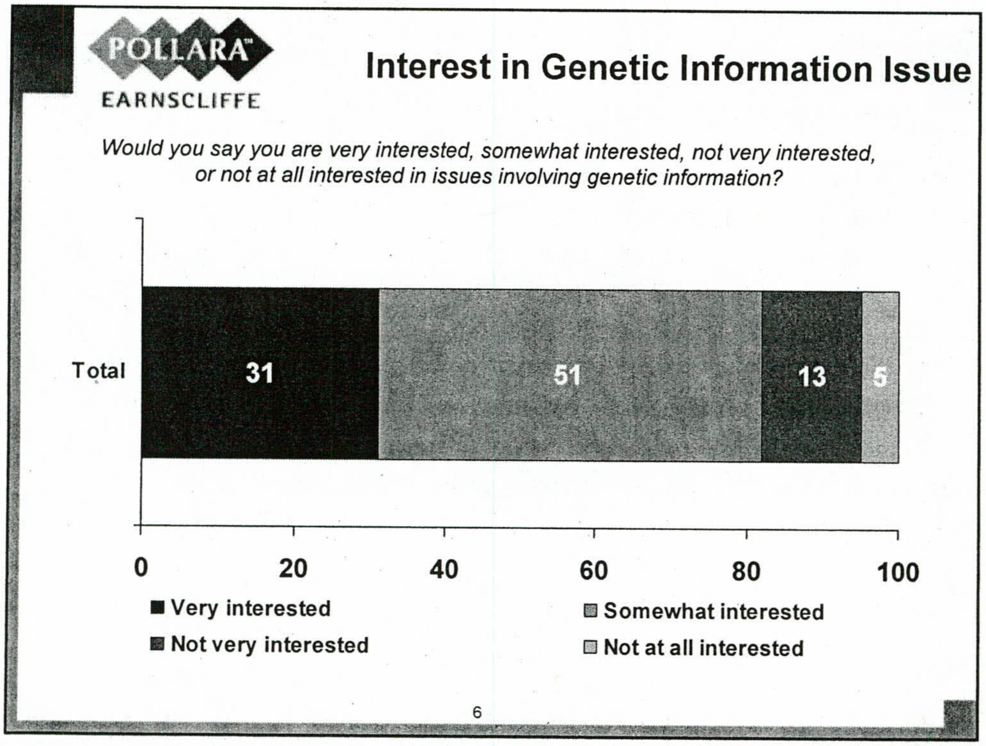
Familiarity with Genetic Information Issue

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



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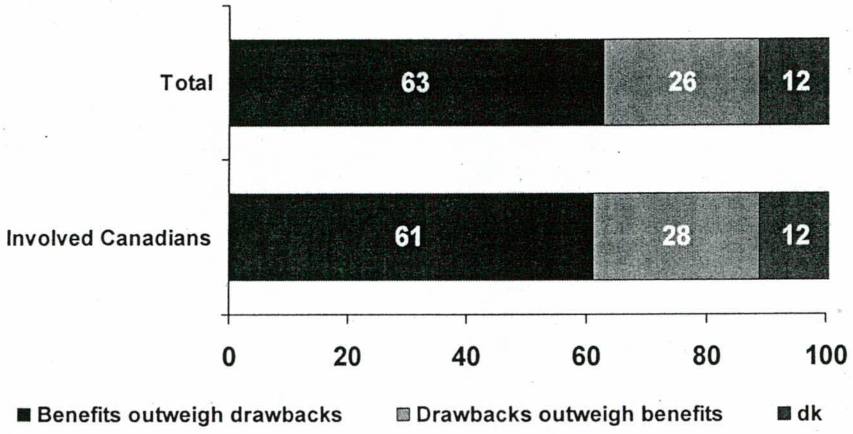
Interest in Genetic Information Issue

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

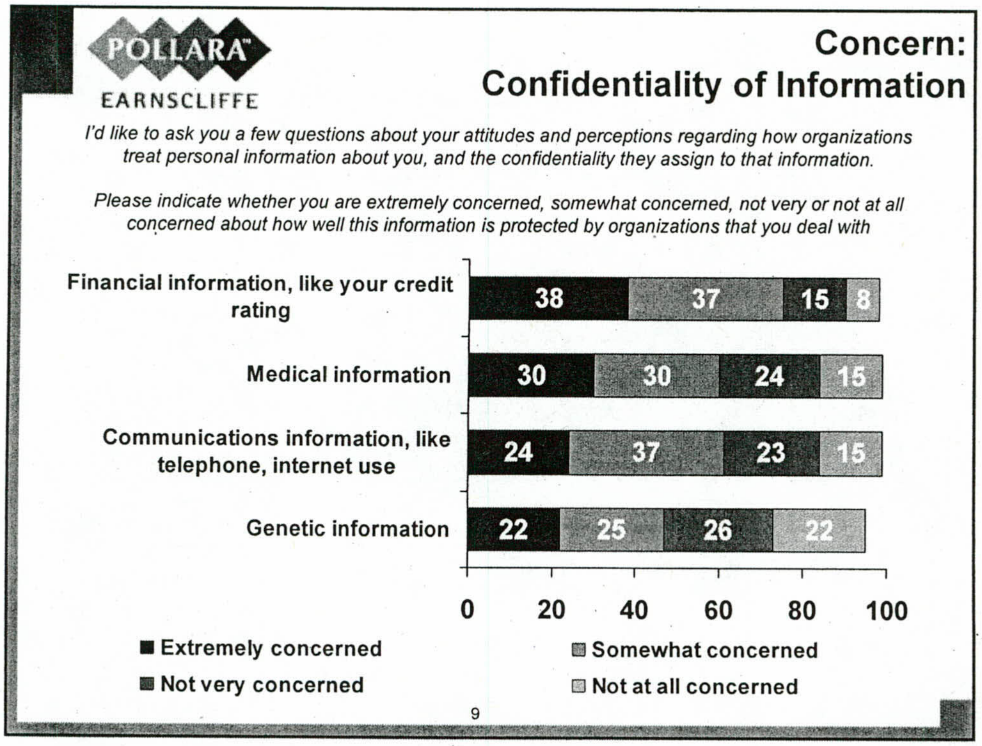
Overall: Benefits vs. Drawbacks

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



Level of Concern & Perceptions about Governance

- **Concern about the confidentiality of personal information is very high**
  - – But confidentiality of genetic information is of less concern than other confidentiality issues
    - Like financial and health information
- **Medical information is seen to be regulated more stringently than other areas**
  - – Regulation involving communications information seen to be most lax
- **Virtually no one is familiar with regulations and guidelines governing the collection and use of genetic information**



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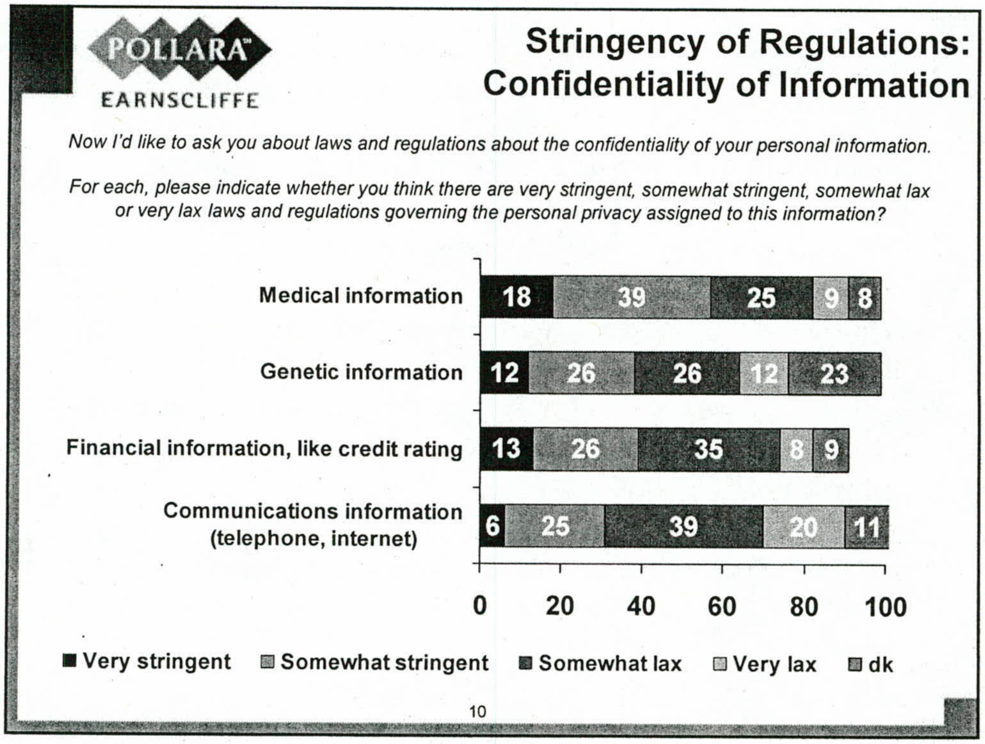
Concern: Confidentiality of Information

I'd like to ask you a few questions about your attitudes and perceptions regarding how organizations treat personal information about you, and the confidentiality they assign to that information.

Please indicate whether you are extremely concerned, somewhat concerned, not very or not at all concerned about how well this information is protected by organizations that you deal with



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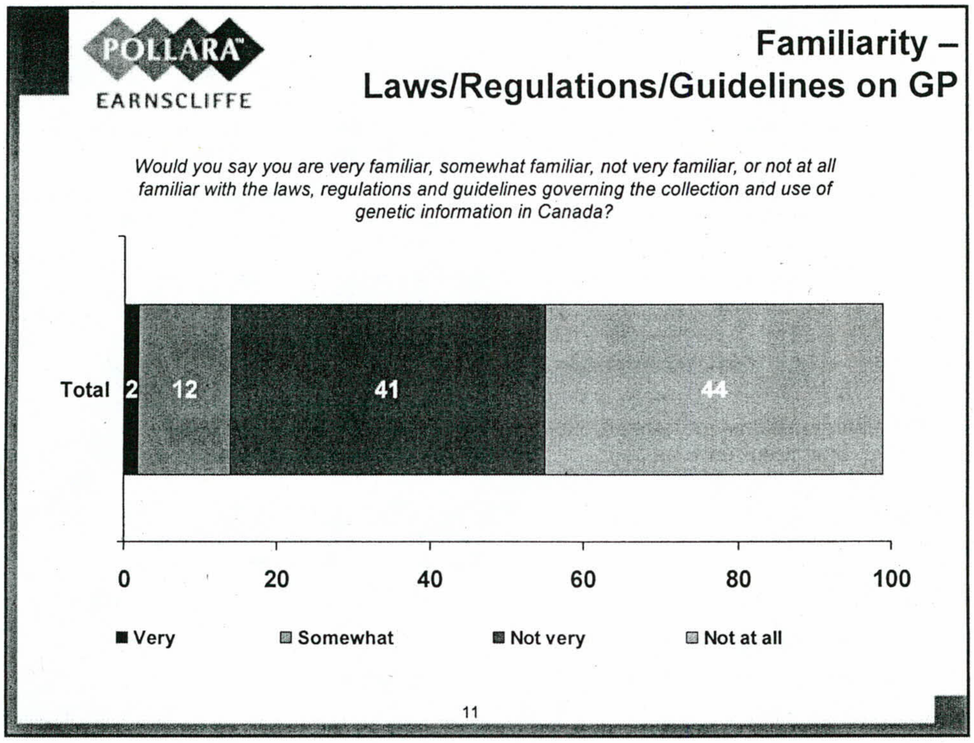
Stringency of Regulations: Confidentiality of Information

Now I'd like to ask you about laws and regulations about the confidentiality of your personal information.

For each, please indicate whether you think there are very stringent, somewhat stringent, somewhat lax or very lax laws and regulations governing the personal privacy assigned to this information?



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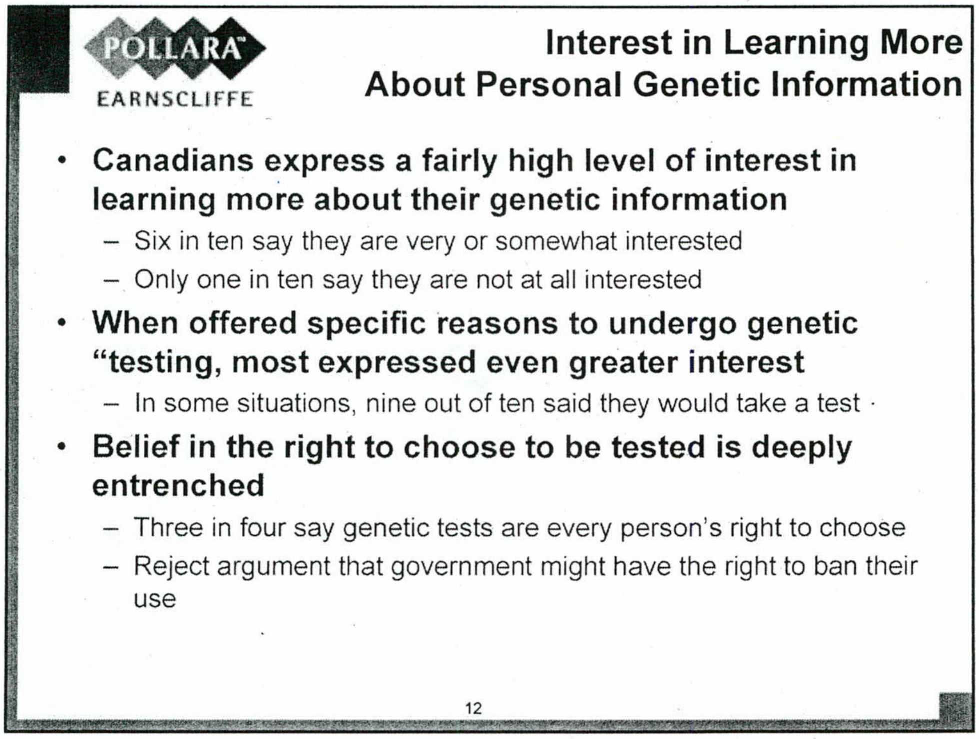
Familiarity – Laws/Regulations/Guidelines on GP

Would you say you are very familiar, somewhat familiar, not very familiar, or not at all familiar with the laws, regulations and guidelines governing the collection and use of genetic information in Canada?



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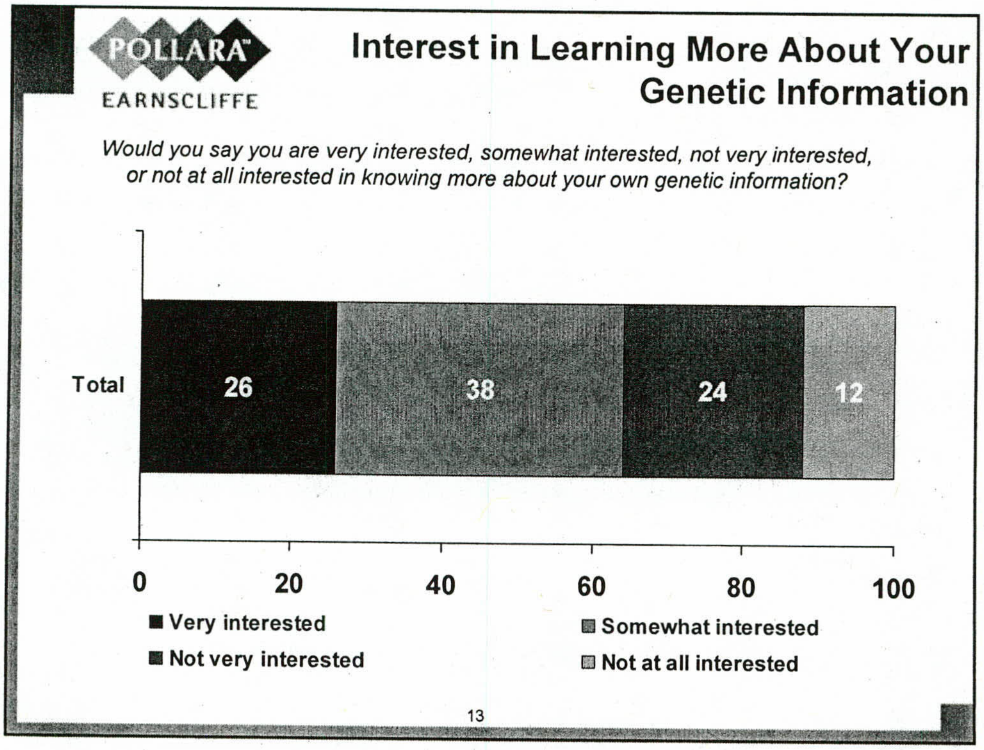
Interest in Learning More About Personal Genetic Information

- **Canadians express a fairly high level of interest in learning more about their genetic information**
  - Six in ten say they are very or somewhat interested
  - Only one in ten say they are not at all interested
- **When offered specific reasons to undergo genetic "testing, most expressed even greater interest**
  - In some situations, nine out of ten said they would take a test
- **Belief in the right to choose to be tested is deeply entrenched**
  - Three in four say genetic tests are every person's right to choose
  - Reject argument that government might have the right to ban their use



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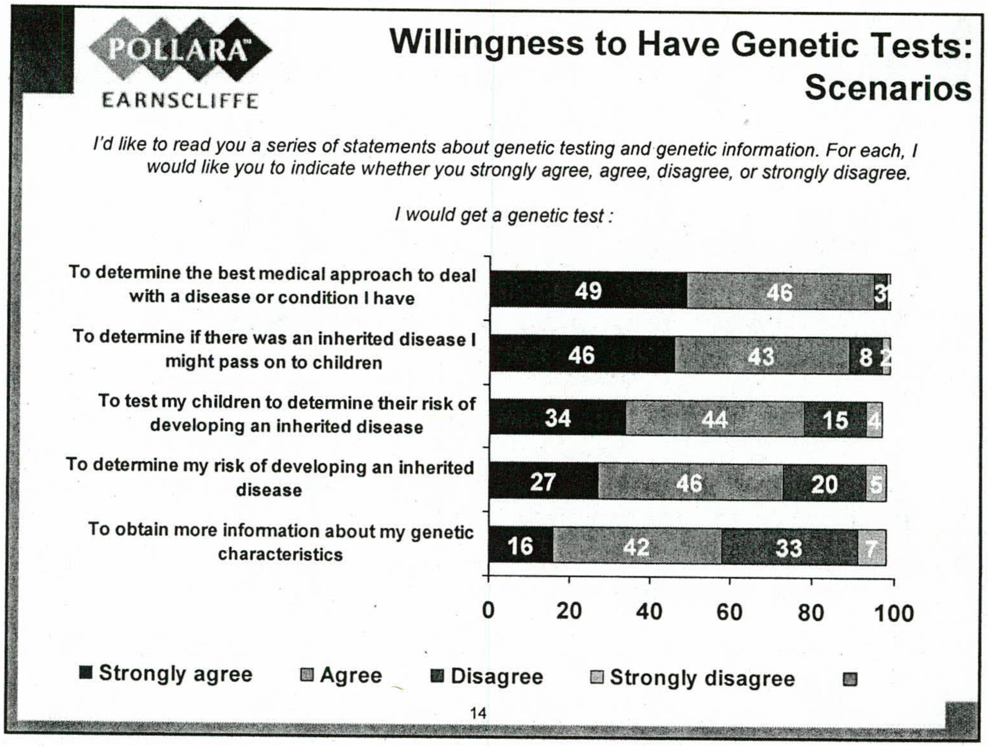
Interest in Learning More About Your Genetic Information

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?



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Willingness to Have Genetic Tests: Scenarios

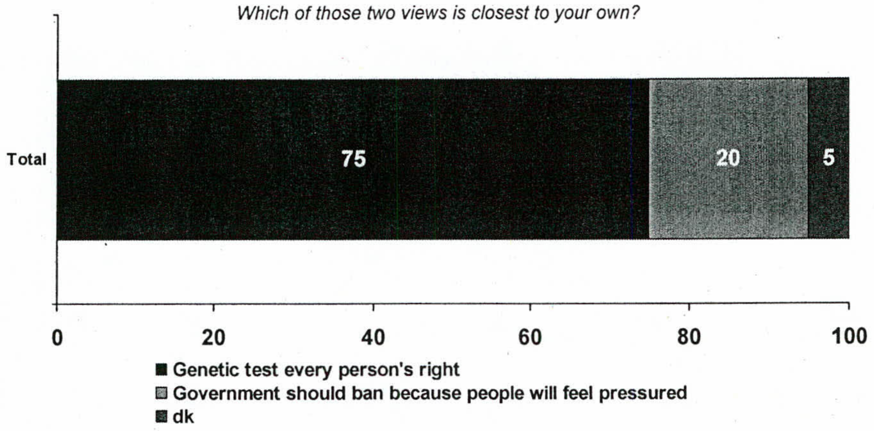
I'd like to read you a series of statements about genetic testing and genetic information. For each, I would like you to indicate whether you strongly agree, agree, disagree, or strongly disagree.

I would get a genetic test :

Forced Choice: Government Ban Because People Feel Pressured

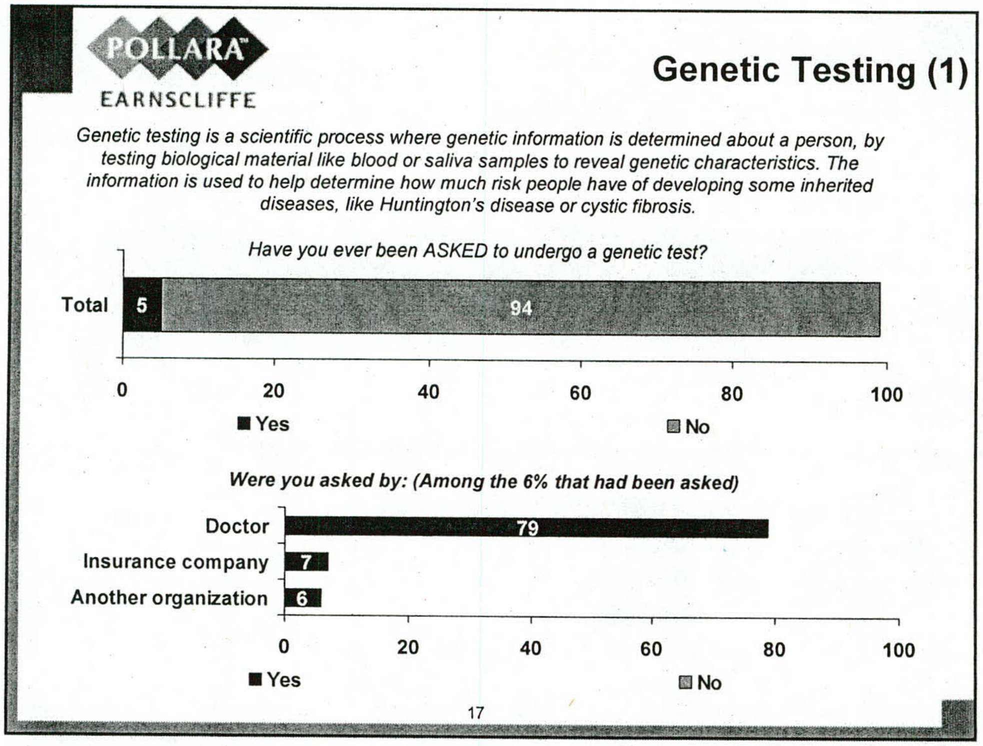
Some people say that getting a genetic test is every person's right, and government has no right getting involved. Other people say that once genetic tests become widespread, some people may feel a whole variety of pressures to take tests they don't want to take, and therefore government should ban genetic tests.

Which of those two views is closest to your own?



Experience with Genetic Testing

- **Most believe that genetic testing is not common**
  - Fewer than one in ten report that they have been asked to undergo a genetic test
    - Almost always the request came from a doctor
- **About 10% say they or a family member have (knowingly) had a genetic test**
  - Most were provided the results by a doctor, professional counselor, or both
- **Professional involvement appears to be an important element of the testing process**
  - Most would like to see home genetic testing kits made available only with medical referral, or banned altogether



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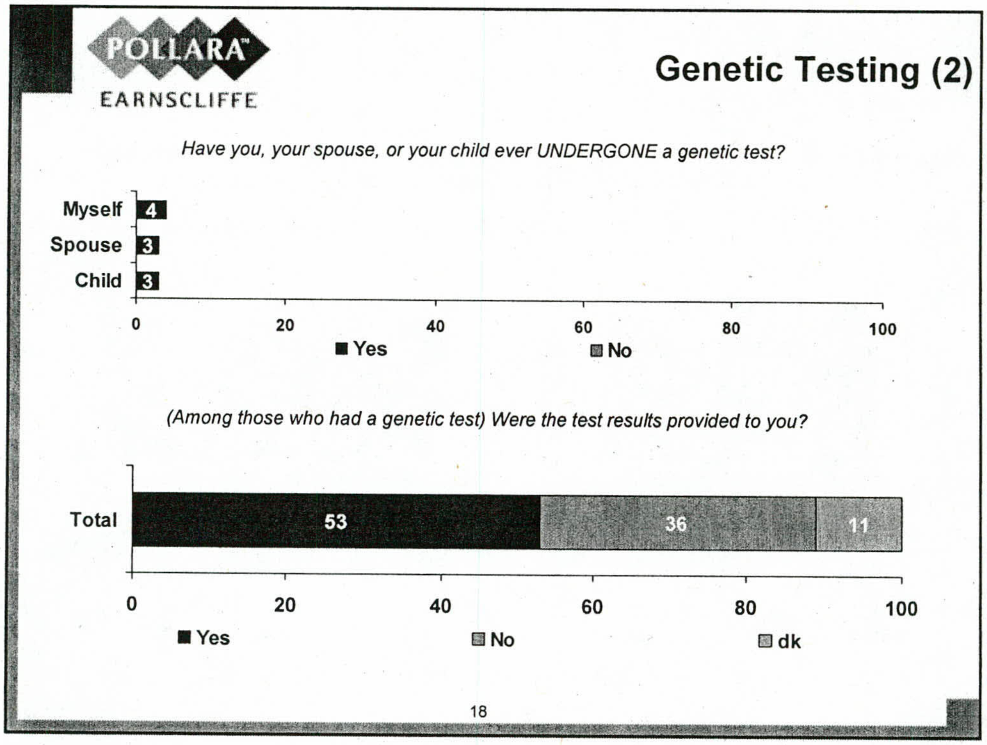
Genetic Testing (1)

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?

Were you asked by: (Among the 6% that had been asked)



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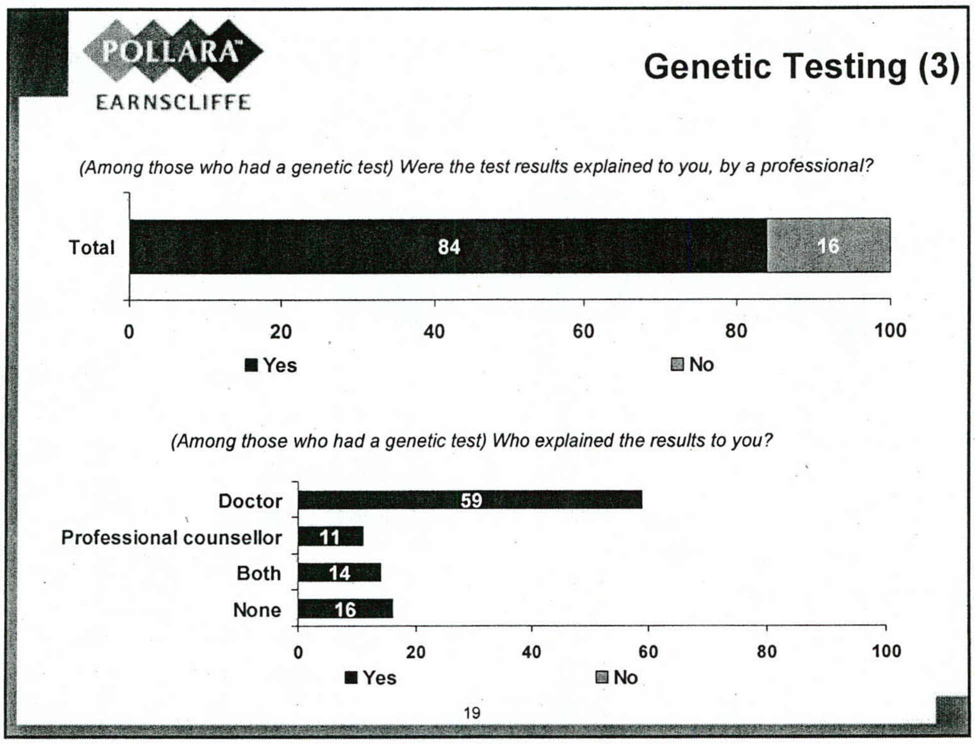
Genetic Testing (2)

Have you, your spouse, or your child ever UNDERGONE a genetic test?

(Among those who had a genetic test) Were the test results provided to you?



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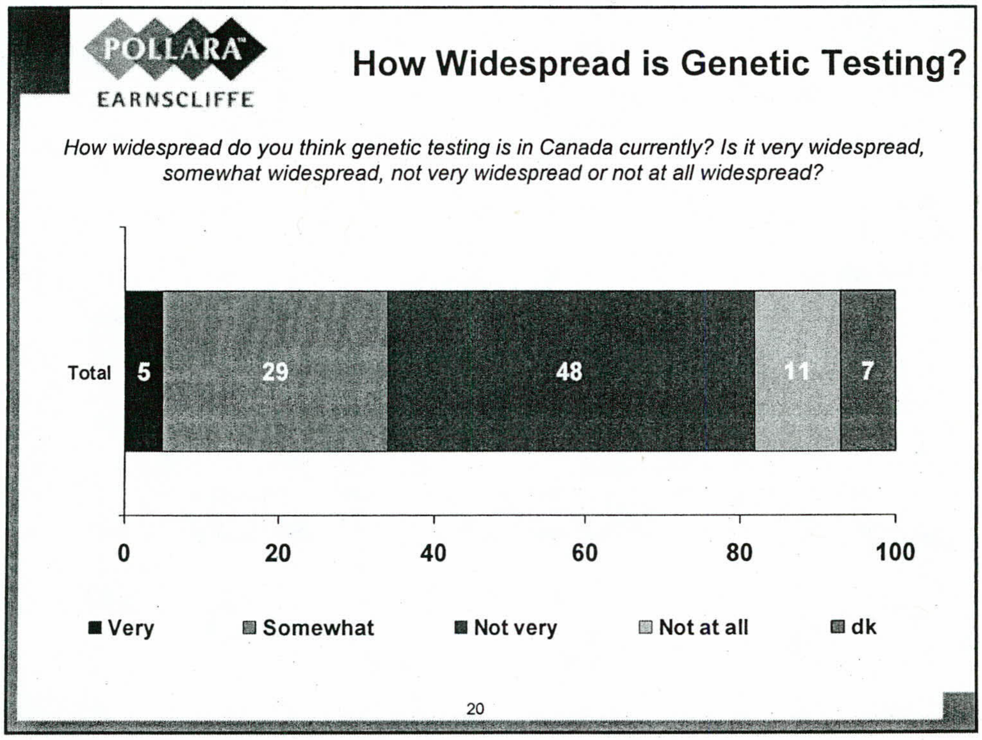
Genetic Testing (3)

(Among those who had a genetic test) Were the test results explained to you, by a professional?

(Among those who had a genetic test) Who explained the results to you?



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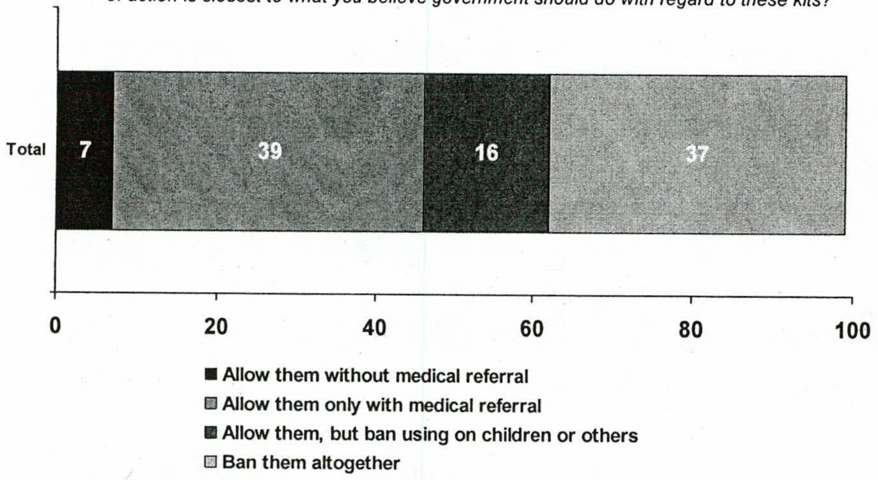
How Widespread is Genetic Testing?

How widespread do you think genetic testing is in Canada currently? Is it very widespread, somewhat widespread, not very widespread or not at all widespread?

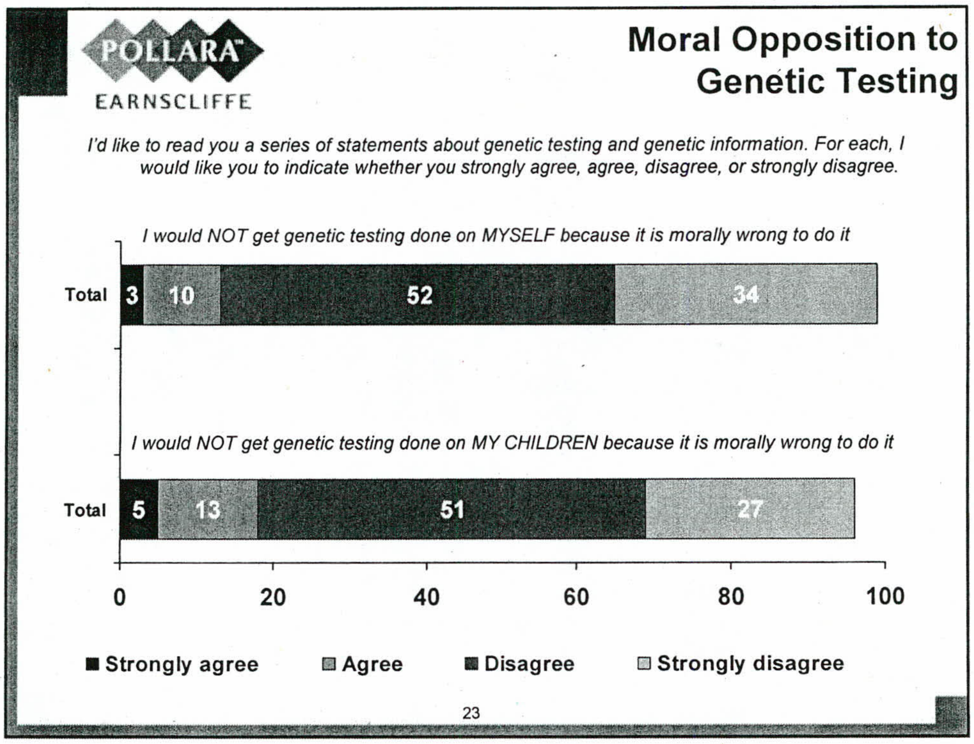
Home Genetic Testing Kits

In the future, home genetic testing kits could be made widely available, potentially offering individuals the ability to conduct such tests on themselves or on others. In your view, which of the 4 courses of action is closest to what you believe government should do with regard to these kits?



Moral and Rights Issues

- **There seems to be very little moral dimension to determining attitudes towards testing**
  - Most reject the thesis that it is morally wrong
    - Overwhelming numbers say the benefits outweigh the moral issues
  - However, if the purpose of the testing raises ethical issues, most believe government a role to play in preventing the testing
- **Individual and family rights are a much more complex issue**
  - Most believe the decision to test is a profoundly personal one
  - But once the results are known, potential consequences to others become more important in the equation
    - As do their rights



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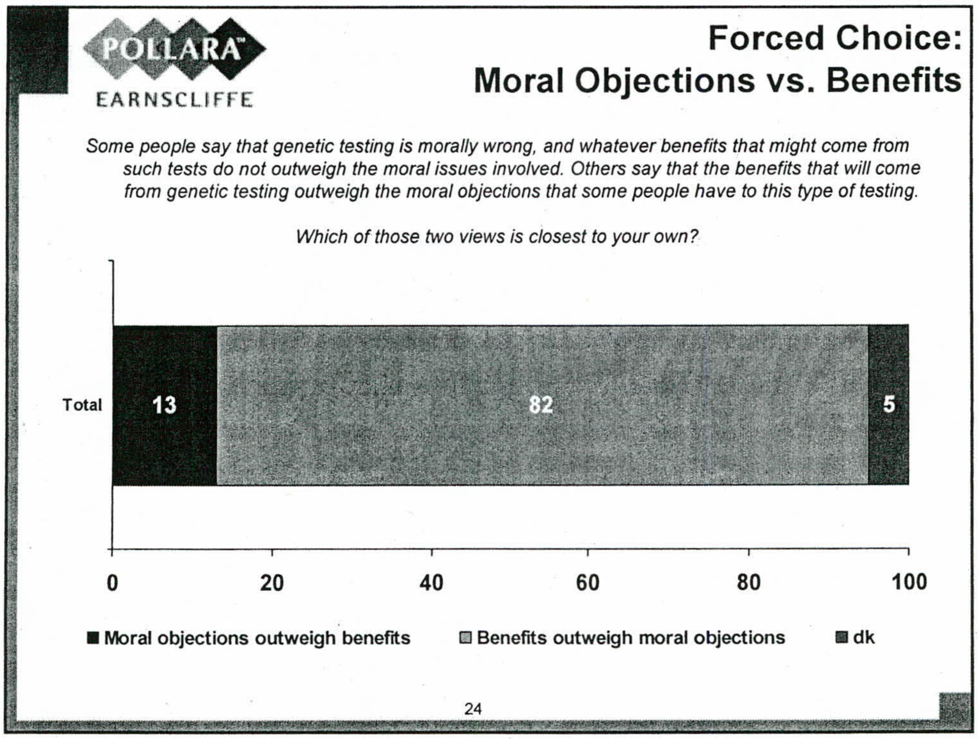
Moral Opposition to Genetic Testing

I'd like to read you a series of statements about genetic testing and genetic information. For each, I would like you to indicate whether you strongly agree, agree, disagree, or strongly disagree.



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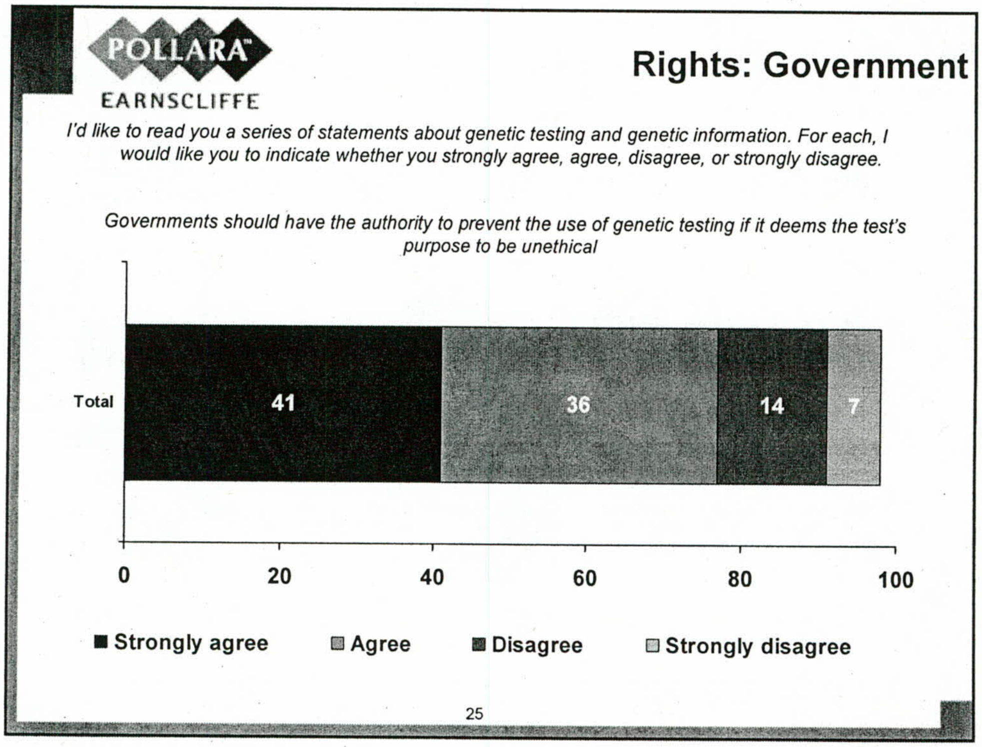
Forced Choice: Moral Objections vs. Benefits

Some people say that genetic testing is morally wrong, and whatever benefits that might come from such tests do not outweigh the moral issues involved. Others say that the benefits that will come from genetic testing outweigh the moral objections that some people have to this type of testing.

Which of those two views is closest to your own?



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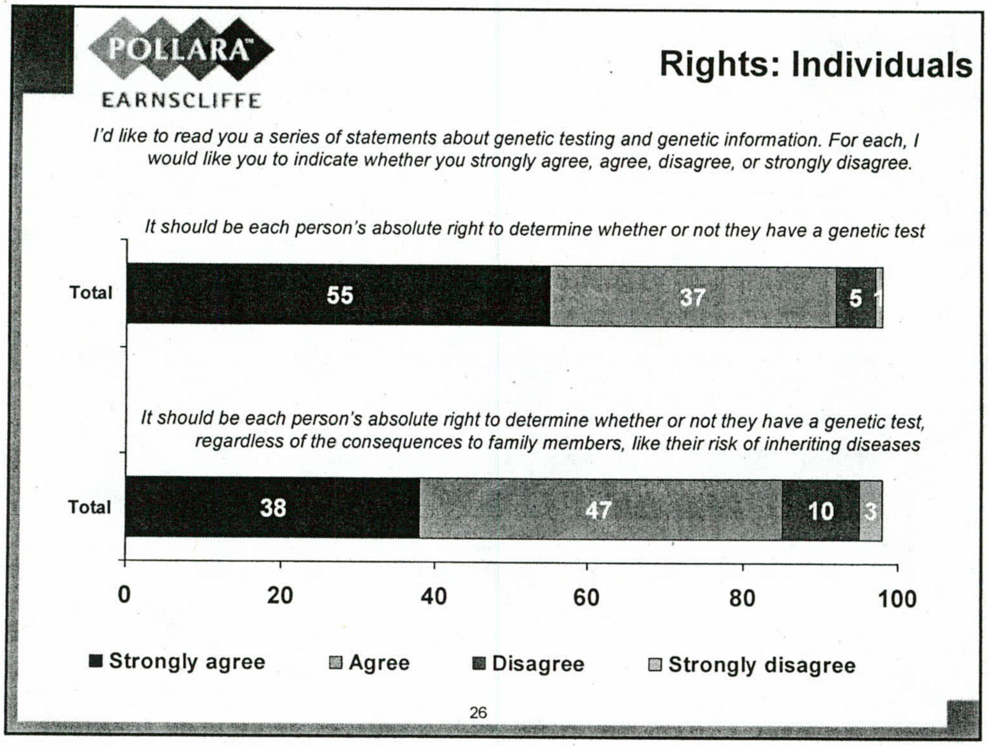
Rights: Government

I'd like to read you a series of statements about genetic testing and genetic information. For each, I would like you to indicate whether you strongly agree, agree, disagree, or strongly disagree.

Governments should have the authority to prevent the use of genetic testing if it deems the test's purpose to be unethical



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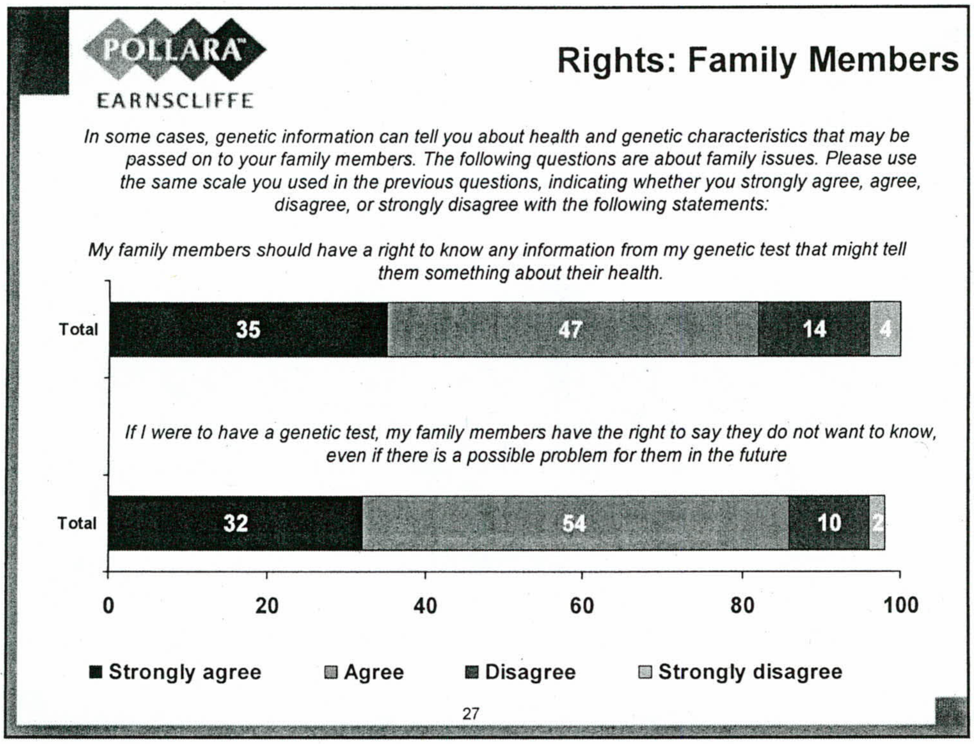
Rights: Individuals

I'd like to read you a series of statements about genetic testing and genetic information. For each, I would like you to indicate whether you strongly agree, agree, disagree, or strongly disagree.

It should be each person's absolute right to determine whether or not they have a genetic test

It should be each person's absolute right to determine whether or not they have a genetic test, regardless of the consequences to family members, like their risk of inheriting diseases



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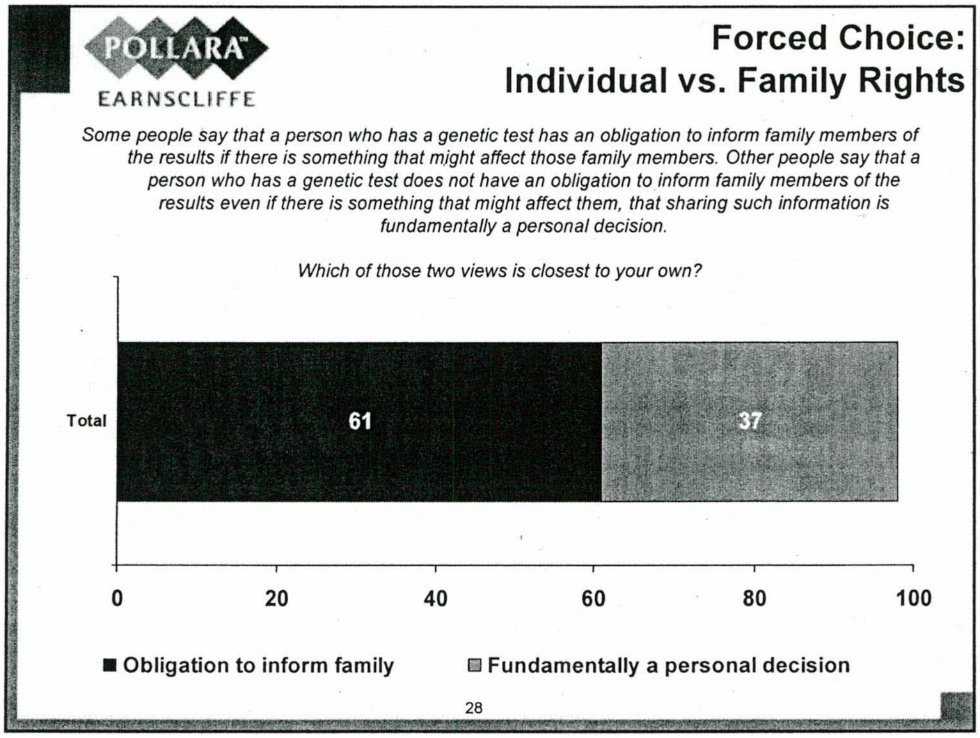
Rights: Family Members

In some cases, genetic information can tell you about health and genetic characteristics that may be passed on to your family members. The following questions are about family issues. Please use the same scale you used in the previous questions, indicating whether you strongly agree, agree, disagree, or strongly disagree with the following statements:

My family members should have a right to know any information from my genetic test that might tell them something about their health.

If I were to have a genetic test, my family members have the right to say they do not want to know, even if there is a possible problem for them in the future



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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?

Use of samples and information

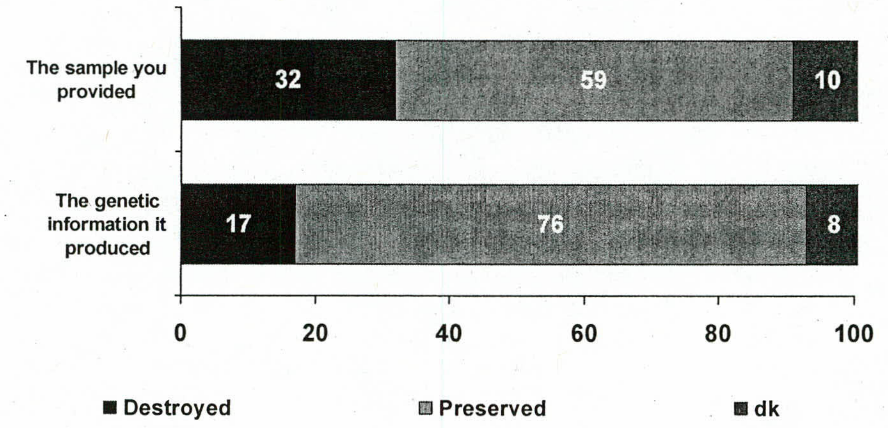
- **Most think both genetic information and the samples are preserved, rather than destroyed**

- **There is divided opinion on who owns the samples and information**
  - Significant numbers believe that there is joint ownership between the individual and the testing organization

---

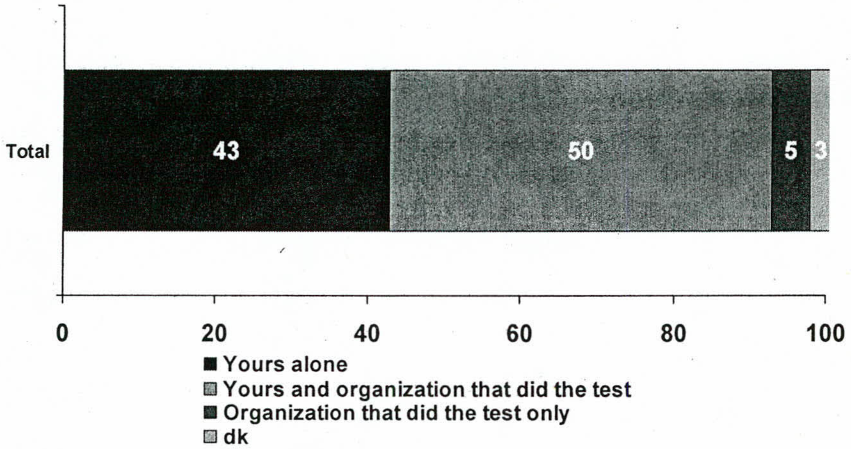
Destroyed or Preserved?

If you were to provide a sample for a genetic test (blood or saliva for example), do you believe that ***the sample you provided/the genetic information it produced*** *would be destroyed or preserved and placed into a bio-bank data base of genetic information?*



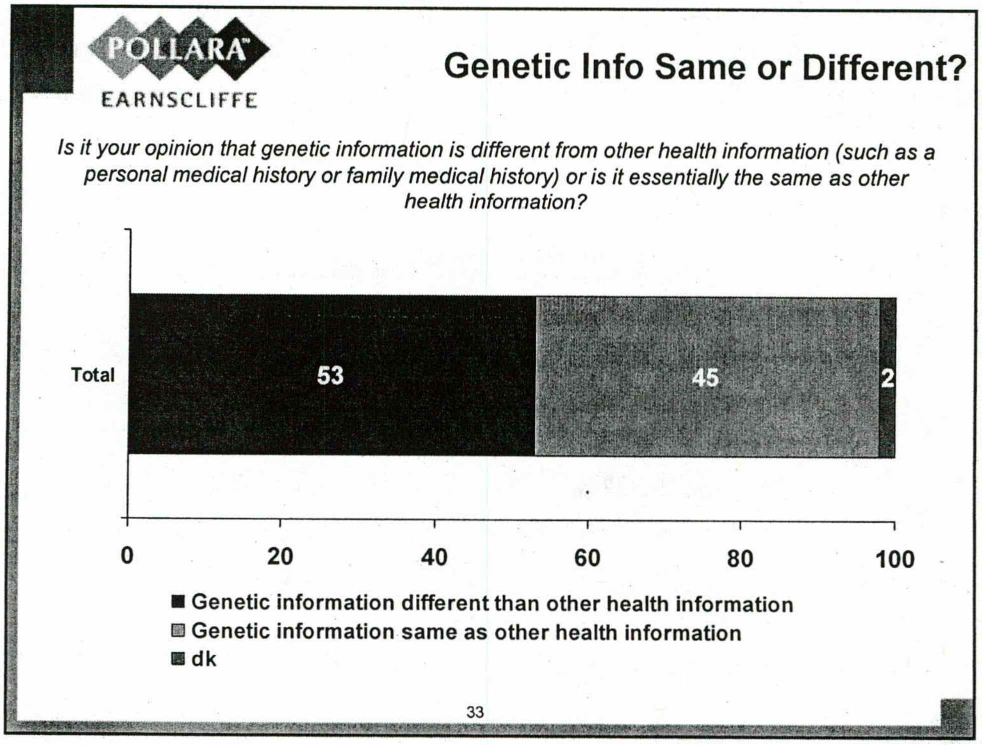
Whose Property?

If you were to have a genetic test, would you think that the information it produced was your property, the property of the organization that administered the test, or the property of both you and the organization that administered the test?



Access

- **At first glance, Canadians are divided about whether genetic information is fundamentally different than health information**
  - However, they also indicate that they expect access to this information to be more strictly regulated than other medical information
    - Reveals underlying opinion
- **Canadians express widely divergent views in terms of comfort with different groups/individuals having access to genetic information**
  - They express a high level of comfort with doctors and medical researchers having access to their genetic information
    - They exhibit a very low level of comfort with insurance companies, employers and governments having access to this information



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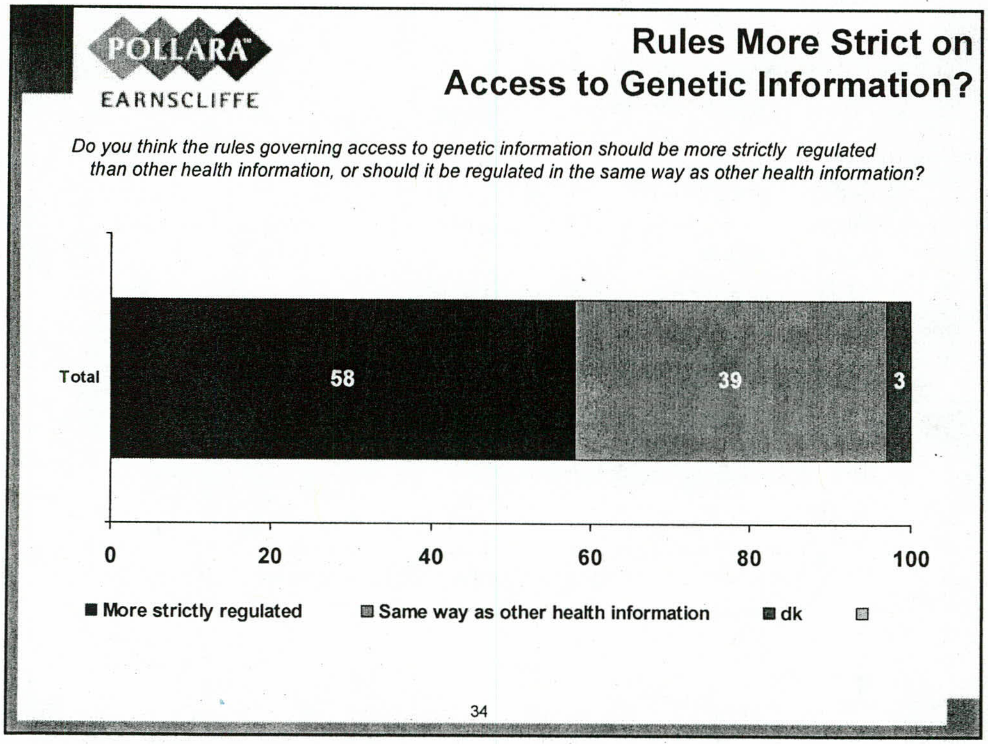
Genetic Info Same or Different?

Is it your opinion that genetic information is different from other health information (such as a personal medical history or family medical history) or is it essentially the same as other health information?



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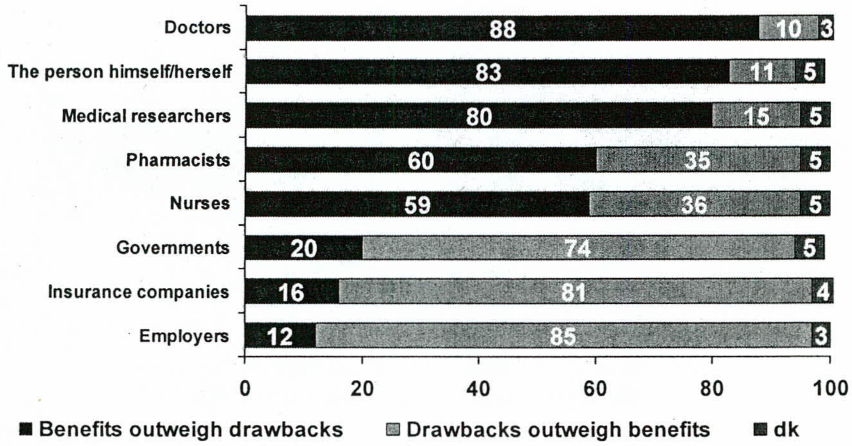
Rules More Strict on Access to Genetic Information?

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?

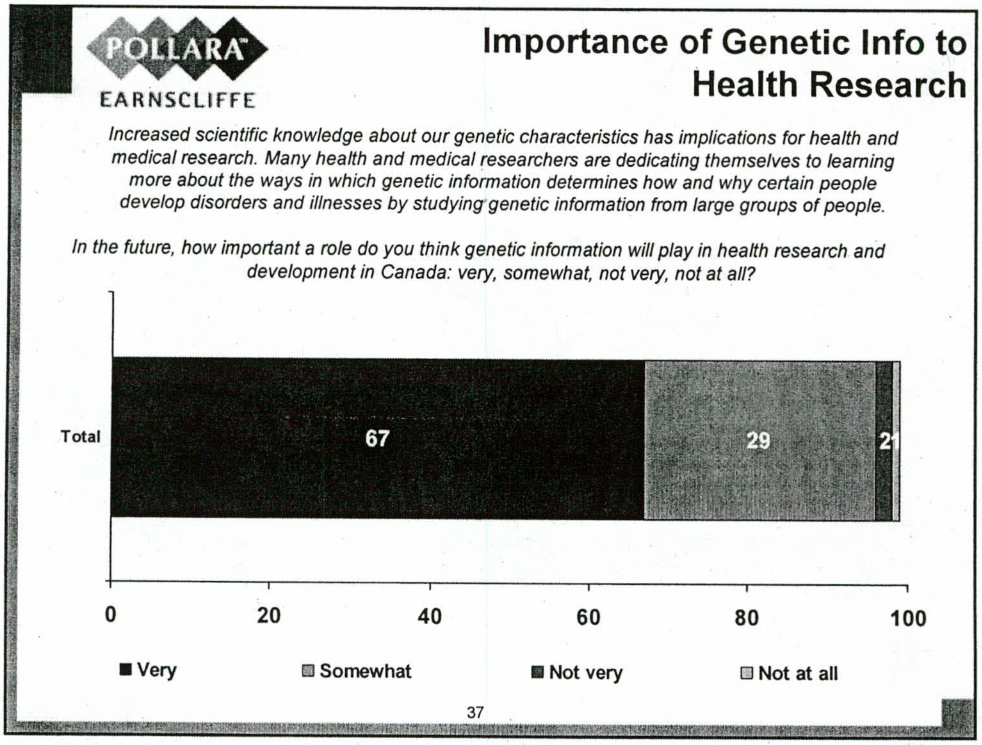
Comfort with Access to Personal Genetic Information

A number of people and institutions may or may not be allowed to have access to people's genetic information. In your opinion, do the benefits outweigh the drawbacks or do the drawbacks outweigh the benefits if each of the following had access to a person's genetic information?



Health/R&D

- **An overwhelming number of Canadians see 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 arguments are introduced
  - Willingness reaches its highest point when privacy provisions are introduced, like stripping identity from the data base
- **Differing acceptability of access for "health care companies" versus "medical researchers"**
  - Medical researchers are given much more latitude
    - Consistent with other research, Canadians express more resistance to the idea of enabling "profit" in the field of healthcare than they do to what they perceive as "altruistic" types of research



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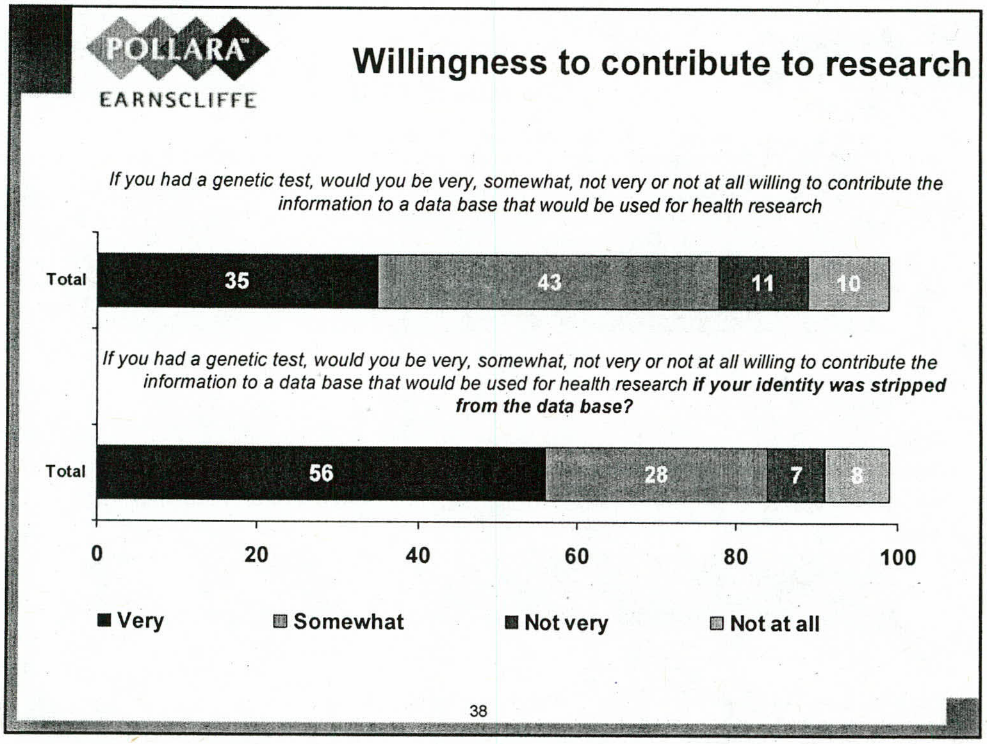
Importance of Genetic Info to Health Research

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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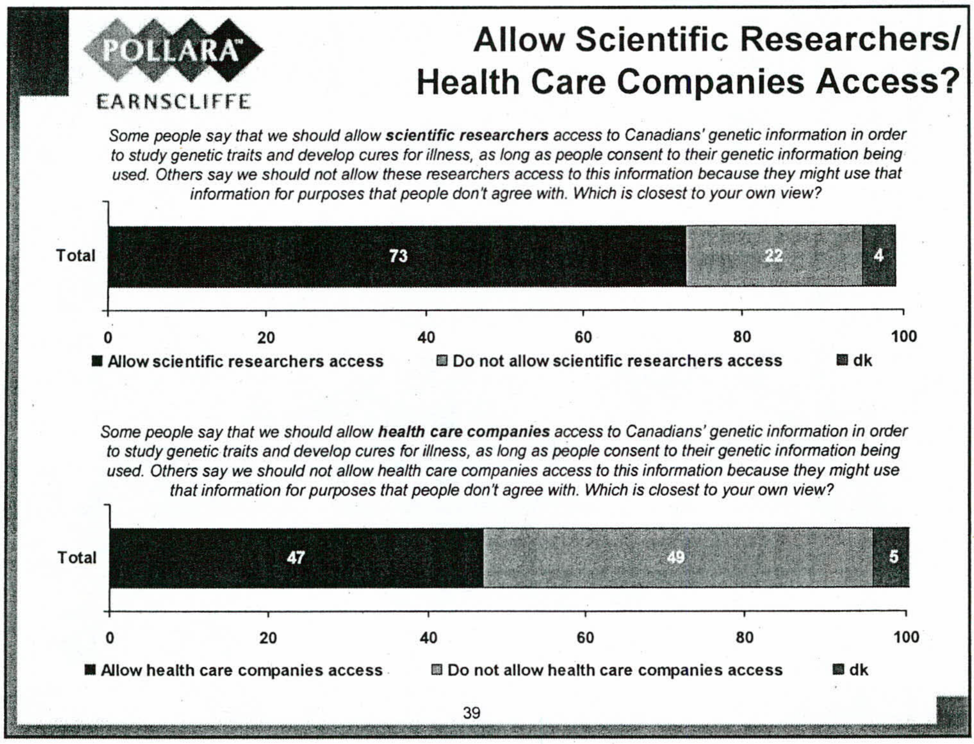
Willingness to contribute to research

If you had a genetic test, would you be very, somewhat, not very or not at all willing to contribute the information to a data base that would be used for health research

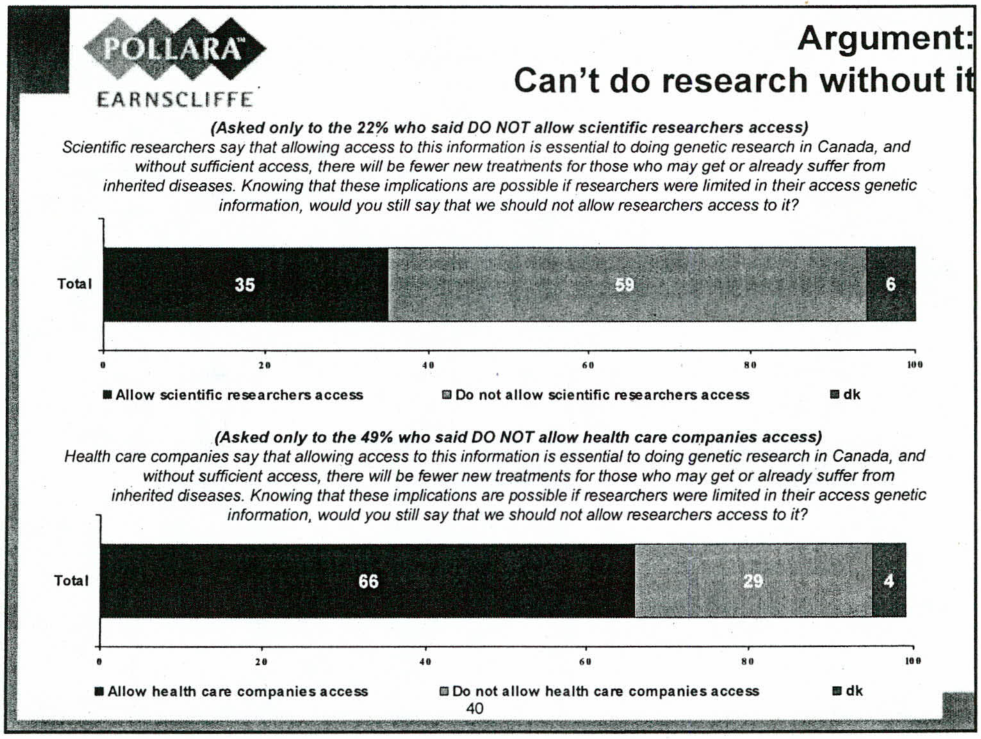
If you had a genetic test, would you be very, somewhat, not very or not at all willing to contribute the information to a data base that would be used for health research ***if your identity was stripped from the data base?***



Allow Scientific Researchers/ Health Care Companies Access?

Some people say that we should allow ***scientific researchers*** *access to Canadians' genetic information in order to study genetic traits and develop cures for illness, as long as people consent to their genetic information being used. Others say we should not allow these researchers access to this information because they might use that information for purposes that people don't agree with. Which is closest to your own view?*

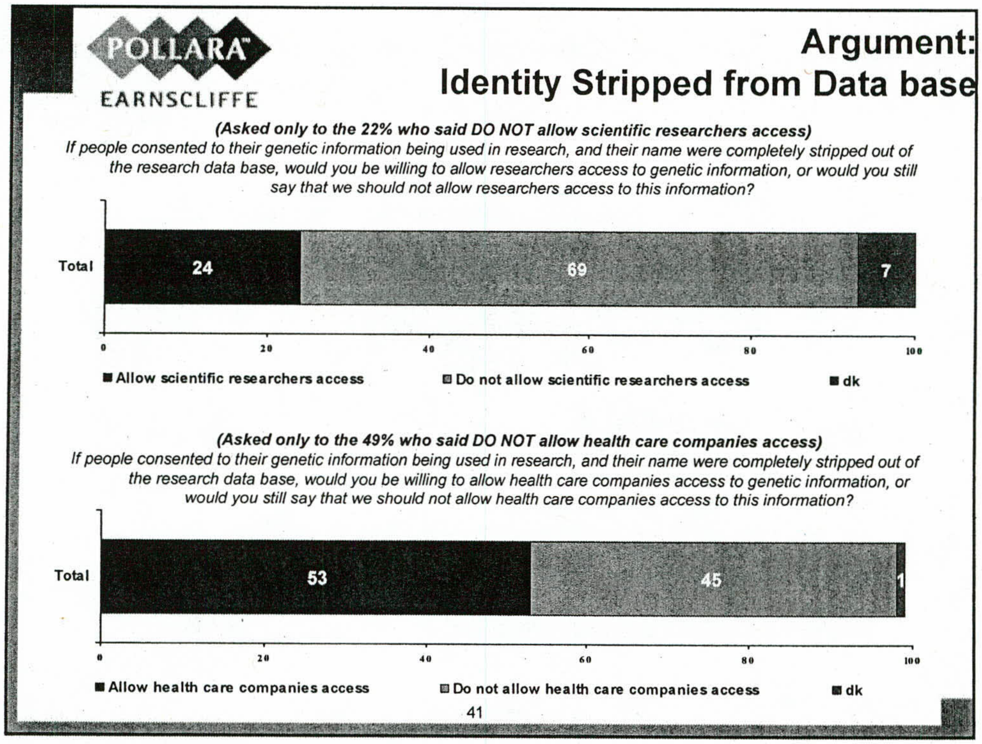
Some people say that we should allow ***health care companies*** *access to Canadians' genetic information in order to study genetic traits and develop cures for illness, as long as people consent to their genetic information being used. Others say we should not allow health care companies access to this information because they might use that information for purposes that people don't agree with. Which is closest to your own view?*



Argument: Can't do research without it

(Asked only to the 22% who said DO NOT allow scientific researchers access)
Scientific researchers say that allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases. Knowing that these implications are possible if researchers were limited in their access genetic information, would you still say that we should not allow researchers access to it?

(Asked only to the 49% who said DO NOT allow health care companies access)
Health care companies say that allowing access to this information is essential to doing genetic research in Canada, and without sufficient access, there will be fewer new treatments for those who may get or already suffer from inherited diseases. Knowing that these implications are possible if researchers were limited in their access genetic information, would you still say that we should not allow researchers access to it?



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Argument: Identity Stripped from Data base

(Asked only to the 22% who said DO NOT allow scientific researchers access)

If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base, would you be willing to allow researchers access to genetic information, or would you still say that we should not allow researchers access to this information?

(Asked only to the 49% who said DO NOT allow health care companies access)

If people consented to their genetic information being used in research, and their name were completely stripped out of the research data base, would you be willing to allow health care companies access to genetic information, or would you still say that we should not allow health care companies access to this information?

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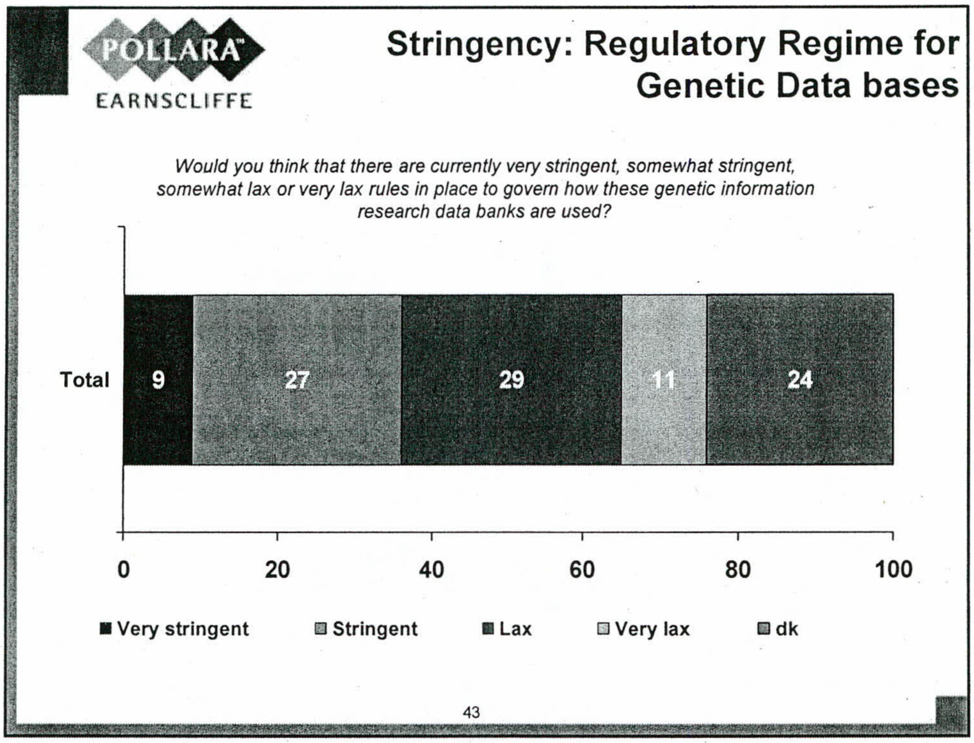
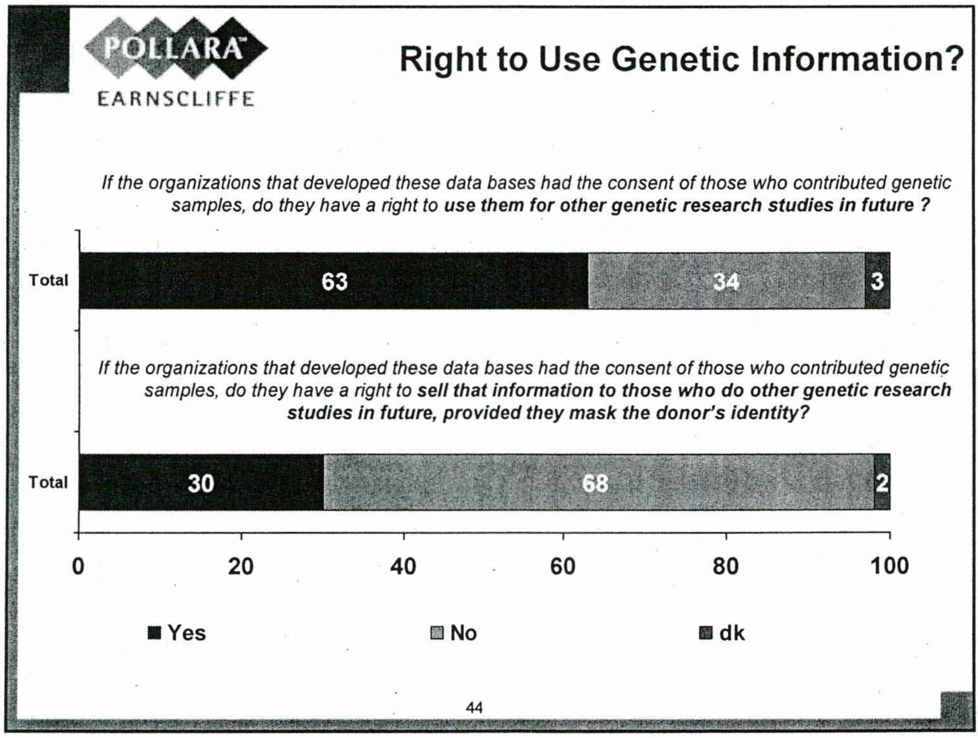
Bio-banks/Genetic Data bases

- **Bit of a presumption that bio-banks probably have lax governance**
  - Though many don't know
- **A majority are comfortable with the idea of bio-banks using information collected for other studies**
  - Driven by desire to gain the benefits of the research
- **But there is deep resistance to the idea of bio-banks "selling" genetic data bases to others doing research, even with consent**
  - Probably more a view on the role of profit in health care than a real objection to selling with consent



Stringency: Regulatory Regime for Genetic Data bases

Would you think that there are currently very stringent, somewhat stringent, somewhat lax or very lax rules in place to govern how these genetic information research data banks are used?



Right to Use Genetic Information?

*If the organizations that developed these data bases had the consent of those who contributed genetic samples, do they have a right to **use them for other genetic research studies in future** ?*

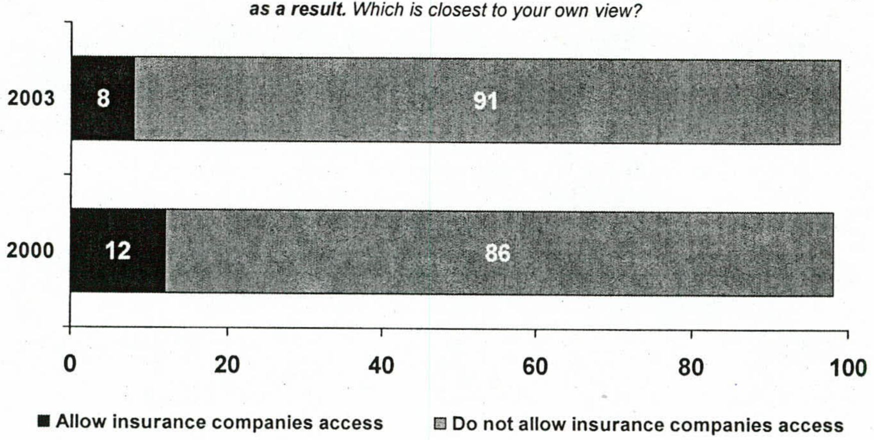
*If the organizations that developed these data bases had the consent of those who contributed genetic samples, do they have a right to **sell that information to those who do other genetic research studies in future, provided they mask the donor's identity?***

Insurance/Employment

- **Wide majority rejects right of insurance companies to ask for genetic information**
  - Even if applicants know they have a genetic condition
    - Tracking data suggests that Canadians are even more opposed to this than they were three years ago
- **Arguments about fiscal consequences and moral hazard convince only one of five to change**
  - Most not swayed
- **One third support the *individual* providing genetic information in their own interest (reducing premiums)**
  - Again tracking data says Canadians more resistant to this idea than they were three years ago
  - Past focus groups indicate that the support dissipates quickly after discussion
- **Same level of resistance to employers asking for genetic information**

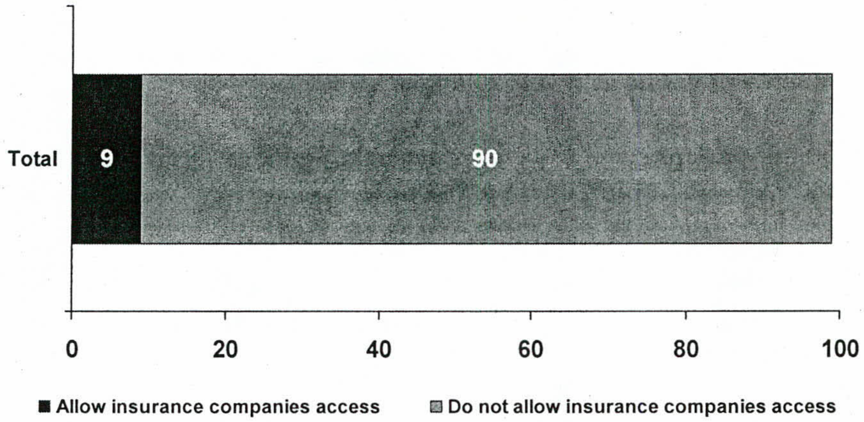
Insurance Access (1)

*Some people say that we should allow insurance companies to have the right to ask about an individual's genetic information when he or she applies for insurance coverage, in order to determine **that person's risk of future health problems**. Others say that we should not allow insurance companies to have access to their client's genetic information **so that they could not deny coverage as a result**. Which is closest to your own view?*



Insurance Access (2)

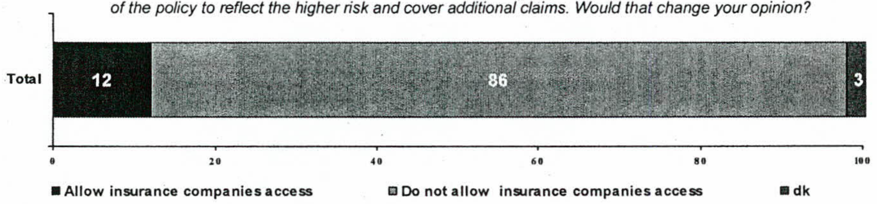
Some people say that insurance companies should be allowed to access genetic information about a person that he or she knows about when they apply for insurance coverage, ***in order to cover all possible claims.*** *Others say that we should not allow insurance companies to have access to genetic information that a potential client knows about* ***because some people would face higher premiums or may be denied coverage based on those risks.*** *Which is closest to your own view?*



Insurance Arguments: Financial Risks/Increased Premiums

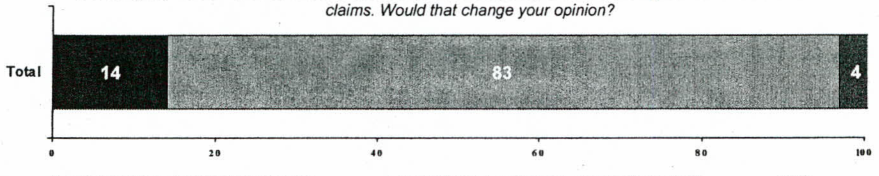
(Asked of the 90% who said DO NOT allow insurance companies access)

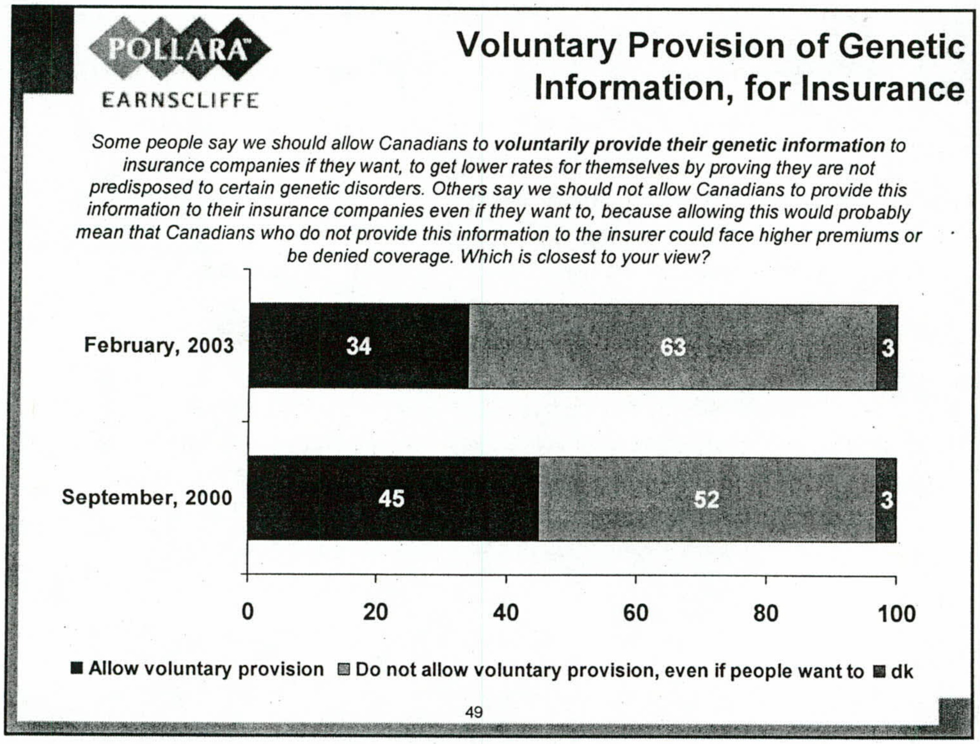
ARGUMENT 1: If Some people say that denying insurance companies access to applicants genetic information would mean that ***they would be exposed to major financial risks****, because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims. Would that change your opinion?*



(Asked of the 90% who said DO NOT allow insurance companies access)

ARGUMENT 2: Some people say that denying insurance companies access to genetic information would mean that insurance companies ***would have to increase premiums for all customers****, regardless of the risk they pose. because some people who know they are likely to contract a disease or disability might buy extra insurance, but the company would not be able to increase the price of the policy to reflect the higher risk and cover additional claims. Would that change your opinion?*





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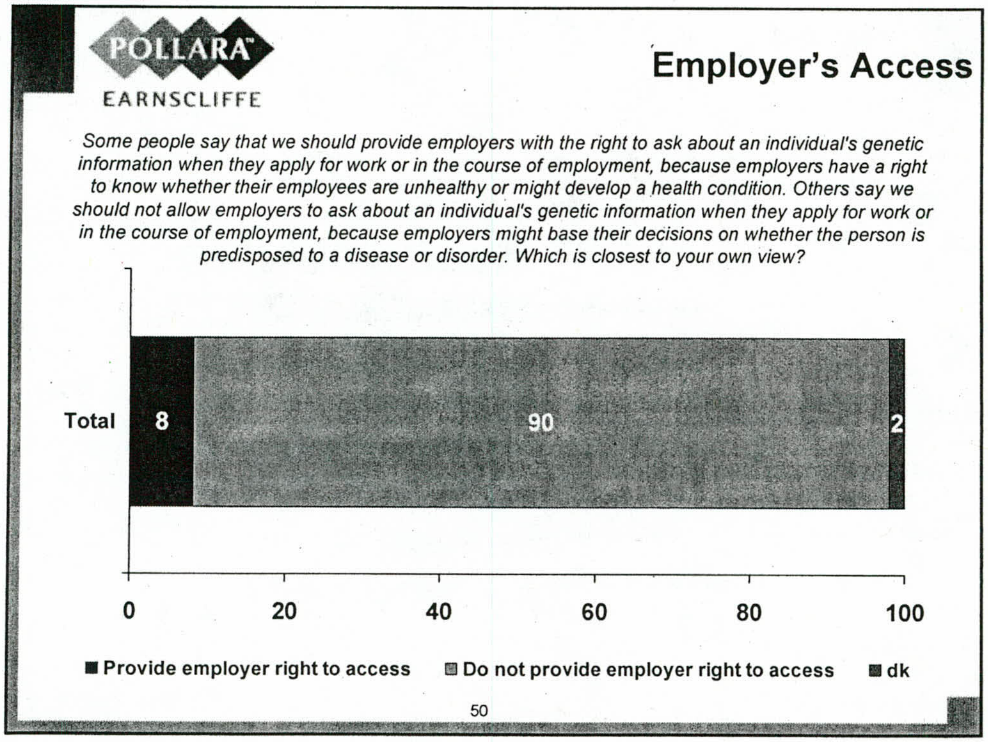
Voluntary Provision of Genetic Information, for Insurance

*Some people say we should allow Canadians to **voluntarily provide their genetic information** to insurance companies if they want, to get lower rates for themselves by proving they are not predisposed to certain genetic disorders. Others say we should not allow Canadians to provide this information to their insurance companies even if they want to, because allowing this would probably mean that Canadians who do not provide this information to the insurer could face higher premiums or be denied coverage. Which is closest to your view?*



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Employer's Access

Some people say that we should provide employers with the right to ask about an individual's genetic information when they apply for work or in the course of employment, because employers have a right to know whether their employees are unhealthy or might develop a health condition. Others say we should not allow employers to ask about an individual's genetic information when they apply for work or in the course of employment, because employers might base their decisions on whether the person is predisposed to a disease or disorder. Which is closest to your own view?

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Governance Priorities

- **The top priority Canadians assign to government is protecting the privacy of genetic information**
  - – But the data suggests that this is far from the only priority
  - – Health/R&D/developing cures to disease almost as important
    - Economic benefits not as important
- **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
  - – Of those who choose, slight tilt towards research and development
- **Many Canadians assign a central role to the medical community to govern genetic privacy issues that rise from medical research**
  - – In fact a majority assign them the main role, not government

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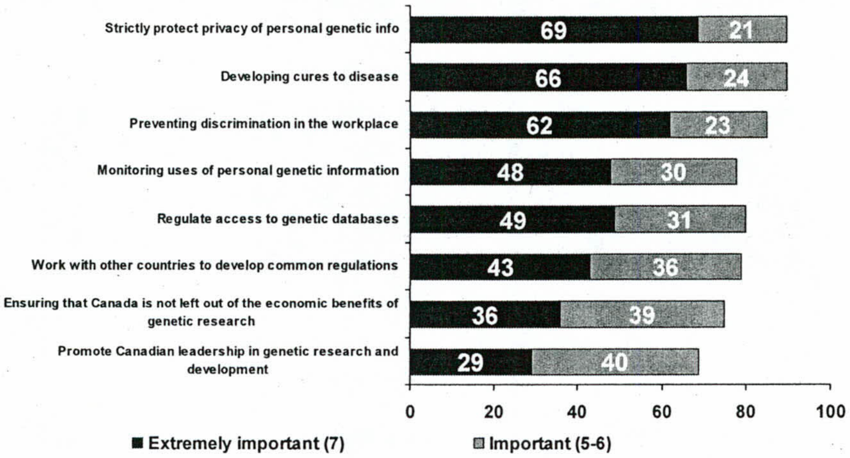
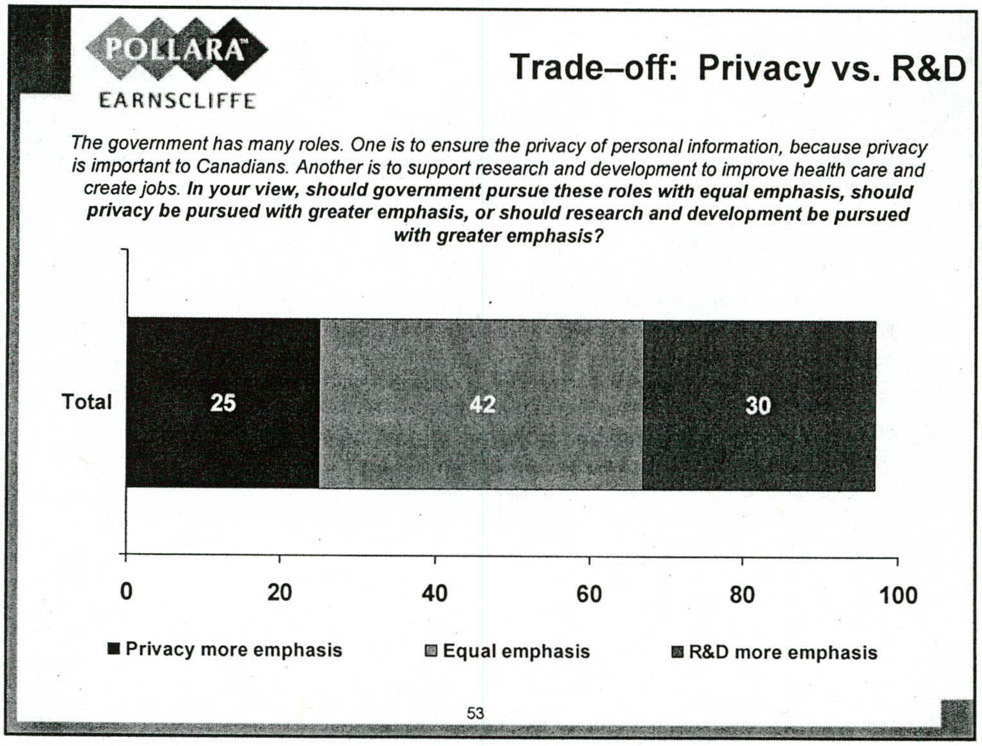
Government Priorities

I'm going to list for you a series of potential priorities for government to take into consideration regarding genetic information. What I would like you to do is indicate, on a scale of 1-7, where 1 is not important at all and 7 is extremely important, how important each of these priorities should be in government decision making:





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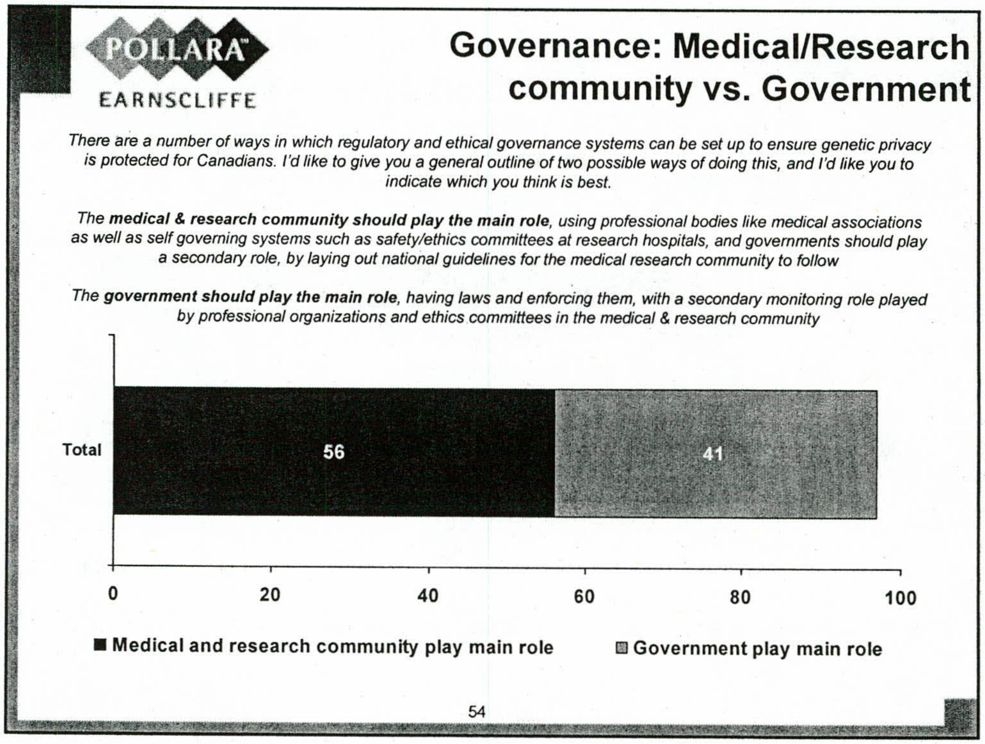
Trade–off: Privacy vs. R&D

The government has many roles. One is to ensure the privacy of personal information, because privacy is important to Canadians. 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?***



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Governance: Medical/Research community vs. Government

There are a number of ways in which regulatory and ethical governance systems can be set up to ensure genetic privacy is protected for Canadians. I'd like to give you a general outline of two possible ways of doing this, and I'd like you to indicate which you think is best.

The ***medical & research community should play the main role****, using professional bodies like medical associations as well as self governing systems such as safety/ethics committees at research hospitals, and governments should play a secondary role, by laying out national guidelines for the medical research community to follow*

The ***government should play the main role****, having laws and enforcing them, with a secondary monitoring role played by professional organizations and ethics committees in the medical & research community*

Pre/Post Benefits versus Drawbacks

- **Discussion and knowledge appear to increase the conviction that the benefits outweigh the drawbacks**
  - At the conclusion of the survey, the "benefits-drawbacks" question was repeated to gain a sense of how opinion might shift once people were introduced to the various issues and considerations surrounding genetic privacy
- **The results suggest that there is broad comfort with, and support for a regime that supports priorities other than just the strict protection of genetic information**
  - Facilitating access to genetic information is seen to have a number of very important corollary benefits, particularly in the area of health
- **Upon discussion of issues and considerations, Involved Canadians become even more favourable than the general public**
  - A reversal of the findings at the outset of the survey
  - Suggests that once Involveds are given a sense that those responsible governing the issues are thinking about and working to taking care of the issues, their concerns abate somewhat

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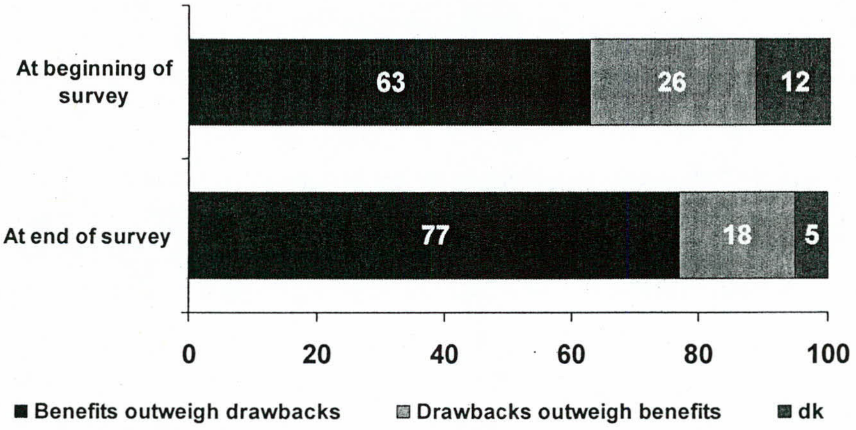
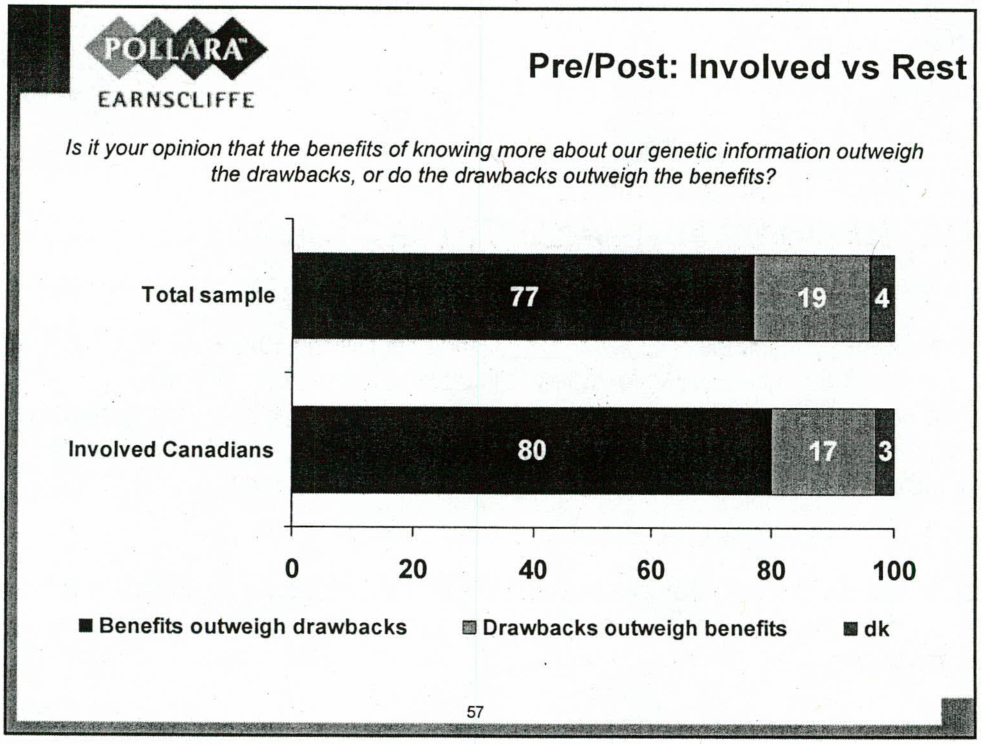
Pre/Post:
Overall Benefits vs. Drawbacks

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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Pre/Post: Involved vs Rest

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

Appendix 6

RECRUITMENT SCREENER
GENETIC INFORMATION AND PRIVACY #2453

Good Afternoon/Evening. My name is _____________ and I am calling from POLLARA, the national public opinion research firm. I would like to invite you to attend a discussion group on ____________ to discuss current events. If you qualify and attend this group, you will receive $50.00 for participating. However, we have to ask you a few questions to be sure that you qualify. Your responses will be kept strictly confidential.

1. First, do you or any member of your household or your immediate family work for either a market research company, a media company (print, radio, tv.), a public relations firm, or the Federal Government?

   IF YES (THANK AND TERMINATE)
   IF NO (CONTINUE)
   IF REFUSED (THANK AND TERMINATE)

2. Are you familiar with the concept of a focus group?

   IF YES (CONTINUE)
   IF NO (EXPLAIN FOLLOWING: "*a focus group consists of eight to ten participants and one moderator. During a two-hour session, participants are asked to discuss a wide range of issues related to the topic being examined.*")

3. How comfortable are you in expressing your views in public?

   Very Comfortable
   Somewhat Comfortable
   Somewhat Uncomfortable (THANK & TERMINATE)
   Very Uncomfortable (THANK & TERMINATE)

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

   YES (CONTINUE)
   NO (SKIP TO Q.6 AND CONTINUE)

5. IF YES IN Q.4

How long ago was that? ______
(TERMINATE CALL IF LESS THAN 6 MTHS)

What topic(s) were discussed in the focus groups that you attended? _______________
(TERMINATE IF DEALT WITH PERSONAL GENETIC INFORMATION)

How many have you been involved with? ________
(TERMINATE IF MORE THAN 5 FOCUS GROUPS)

6. Now I'm going to ask you some questions about your level of involvement in current issues, if you don't mind. For each of the following, I'd like you to tell me with a YES or NO answer, whether you have done this in the past year:

PART ONE:	YES/NO		
1a)	Made a speech to a public audience	YES	NO
1b)	Written an article for a publication	YES	NO
1c)	Served as an officer for a club or organization	YES	NO

PART TWO:	YES/NO		
2a)	Written a letter to an editor	YES	NO
2b)	Called a television or radio talk show about public affairs issues	YES	NO

INVOLVED CANADIAN
Respondent must answer YES to 3 of the 5 statements to qualify
BOTH GROUPS ARE WITH INVOLVED CANADIANS

7. RECORD GENDER: Male
Female

(Note: Ensure a good mix)

8. What level of education have you completed (READ LIST)

Elementary School
High School
Community College
Some University
Completed University

(Note: Ensure a good mix)

9. What of the following categories best represents your household's annual total income?

   Under $25,000
   $25,000 to $45,000
   $45,000 to $75,000
   $75,000 or more

   Note: Ensure a good mix)

10. What is your current marital status? ______________________________

    (Ensure a good mix)

11. And do you have any children living in your household? ______________

12. Are you currently …

    -Working full time (35 hours +)
    -Working part time (under 35 hours)
    -Unemployed
    -A homemaker
    -Student
    -Retired

13. (IF EMPLOYED IN Q.12) What is your current occupation? _____________________
    (RECORD VERBATIM)

14. (IF MARRIED/COMMON LAW IN Q.10) What is your spouse's/partner's occupation?__________________

    (TERMINATE IF RELATED TO MARKET RESEARCH, MARKETING, PUBLIC RELATIONS, ANY MEDIA (PRINT, RADIO, TV.), OR GOVERNMENT)

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

    18-34
    35-54
    55+

    (Note: Ensure a good mix)

16. Sometimes participants are asked to write down their answers to certain questions or to read some materials. Is there any reason why you could not participate? If you need glasses to read, please remember to bring them.

Yes (THANK AND TERMINATE)
No

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

Toronto:

- INVOLVED CANADIANS	Wed. March 5, 2003	5:30 P.M.
- INVOLVED CANADIANS	Wed. March 5, 2003	7:30 P.M.

As I said earlier, if you attend, you will receive a participation fee of $50.00 and refreshments (for 5:30pm group - and a light supper) will be served.

The discussion group will be held at _________ commencing at (5:30PM/7:30PM). Please arrive 15 minutes prior to this time for registration. We will be calling you back a few days before the discussion group to confirm your participation.

PLEASE NOTIFY OUR OFFICE BY CALLING ___________ SHOULD YOU HAVE ANY DIFFICULTY ATTENDING THIS GROUP SESSION THANK YOU.

Recruitment Specs:
Time: 5:30pm and 7:30pm

IN EACH GROUP...
- Recruit 12 for 10 to show
- Both groups are involved Canadians
- Mix of men and women
- Mix of ages, income and education groups
- Screen out market researchers, media, government employees and public relations workers
- Record occupation

Incentive: $50