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FOCUS GROUPS ON GENETIC PRIVACY ISSUES

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FINAL REPORT

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

46 Elgin St. Suite 200 Ottawa, Ontario K1P 5K6 Tel: 613 563-4455 Fax: 613 236-9546

Introduction

Earnscliffe Research and Communications is pleased to present this report on a public opinion research program into genetic privacy issues, conducted in January of 2004.

The work involved four focus groups, two in each of St. John's, Newfoundland and Labrador and Calgary, Alberta.

The research was commissioned to investigate in further detail some key issues raised by previous research into genetic information and privacy issues. These locations were chosen for the groups for specific reasons that have to do with real or potential perceptions about genetic information and privacy issues: Newfoundland and Labrador because it is one of the regions of the country where genetic research among large segments of the population is already taking place and is advancing quickly, and Alberta, because in polling research Albertans have demonstrated that their attitudes toward these issues differ somewhat from attitudes in other parts of Canada.

The focus groups concentrated on several issues:

- General familiarity and awareness of genetic information and privacy issues;
- Willingness to undergo, and experience with, genetic testing;
- Willingness to contribute genetic information to research;
- Perceptions of the current and preferred governance models for privacy in connection with personal genetic information; and
- Reaction to a series of possible governance measures to address genetic privacy issues.

Participants were drawn from Earnscliffe's 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.

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

Elly Alboim (elly@earnscliffe.ca)
Jeff Walker (jwalker@earnscliffe.ca)

Summary of Findings

In St. John's and to a lesser extent in Calgary, respondents' initial reactions to genetic testing and genetic privacy revealed a fairly high level of knowledge about genetic research and related issues, higher than has been found in other parts of Canada. A sizeable number of the respondents in St. John's, at least as many as half, had heard about population health studies involving genetic information that were currently taking place in Newfoundland and Labrador, and many knew or knew of individuals who had been invited to participate in such research. Like other Canadians, once engaged in discussion about the topic, participants have no shortage of views about it.

There was evidence that respondents possess good basic understanding about what genetic information might indicate about inherited traits. Most people have no trouble identifying what conclusions might be drawn from genetic information – for instance, the risk of carrying inherited diseases like Huntington's – and what could not – for instance, the risk of passing a genetic disease to a spouse.

The genetic diseases that people tend to be most aware of are breast cancer, Huntington's Disease, and Alzheimer's. 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.

In Calgary, awareness of the topic also appeared to be higher than found in other parts of the country, although the reason was less clear than in Newfoundland and Labrador - some said it had to do with religious groups being more engaged in the issues with, as a result, the media covering it to a greater extent, while others expressed a strong sense of concern about authorities having information about individuals, more so than found in other focus groups in other regions. There were about the same number of respondents who had encountered genetic testing as found in other research that has been done over the past year – 1-2 people out of 10 had been involved in, or knew someone who had recently been involved in genetic testing.

In both centres, people appear to have been exposed to more and have done more thinking about where they stand on the issues involved. However, this did not necessarily lead to a consistent set of attitudes between the groups in the two cities. Indeed, overall levels of favourability to the idea of genetic testing and genetic research were higher in Newfoundland and Labrador than found in other parts of the country, and lower in Calgary. Moreover, concerns about privacy issues associated with genetic information were more pronounced in Calgary than in Newfoundland and Labrador.

Newfoundlanders who participated in these focus groups almost universally believe that knowing more about their genetic information is a good thing. With appropriate provisions, they are generally willing to be tested under certain circumstances, for instance if there were a medical reason to do so. They are also more willing to allow personal genetic information to be used for medical research. The key driver of these attitudes has to do with the idea that they personally or those close to them (family members, close friends) might personally benefit from some of the research that was occurring. There were relatively few who raised strong concerns on an unaided basis about privacy issues, or issues with the idea of genetic testing.

In contrast, there was a much higher level of wariness in Calgary, both about the privacy issues and about the idea of genetic testing. With regard to genetic testing, for some, the concerns had to do with the ethics of having tests and the ethical implications of knowing the results. Most said that there was a circumstance where they might be tested, but it was strongly asserted by some that if there were no treatment available for a potential disease, they would likely not be tested. A factor that was at least as important to peoples' consideration of whether or not to have a test and/or offer the information to genetic researchers had to do with access issues. In a dynamic that was paralleled in other groups in the past, one or two respondents said that they were wary of having tests because organizations (i.e. insurance companies) might want access to information and they do not want it revealed -- so they would not want to get tests done.

What made the Calgary groups unique was that once these one or two people tabled concerns, many of the other participants shifted their point of view, expressing strong reluctance to have tests done because of the potential implications regarding insurance. When it was tabled that insurance companies do not compel people to have tests but only ask that people who have been tested submit the information, skepticism generally grew even more, as did unwillingness to have tests or provide the information to researchers. This was primarily because people feared that this would likely be the "thin edge of the wedge" for insurance companies to gain access to this information.

In this context, focus group respondents in both cities, but more so in Calgary, began discussing governance questions, seeking assurance that there are protections for privacy, anonymity and the security of databases in genetic research. People in the Calgary groups also raised concerns about those in other countries testing Canadians for genetic information, as there are no specific international governance rules on this topic and they are getting a bit anxious about it.

Perceptions of the current governance regime for genetic information varied significantly among respondents, and tended to be related to their level of concern about privacy issues. Overall, few suggested that they had any real sense of what the

governance regime consisted of. In offering views, most relied on perceptions about governance of areas of privacy, or of other regulatory functions of government. If people had high levels of concern about privacy generally or were skeptical of other regulatory functions of government, they tended to be skeptical of the governance regime in this field. The other consideration that tended to play out in discussions was the notion that this is a new field that is rapidly evolving, and as such government probably would have a difficult time "keeping up" with the technologies and their implications for things like privacy.

In these focus groups, as in other work that has been conducted previously by Earnscliffe, people believe that genetic information is fundamentally different than other medical information, because it is more personal, and has potentially more significant implications for those who might gain access to it than most other types of medical information. When asked about the rules governing this information, most initially said that they would like access to genetic information to be more strictly regulated than other health information, and wished for a parallel privacy system. In the Calgary groups, there were people who work in the health care field, who were very critical of the privacy levels assigned to medical information in hospitals and clinics – they did not suggest that there were purposeful compromises of privacy, but lax measures in terms of storing and filing medical information.

Upon discussion, in both Calgary and St. John's, people acknowledged the practical difficulties of trying to establish parallel information systems for medical and genetic information, and in general, people sought to find a compromise that revolved around the notion of including genetic information with other medical information, but setting the privacy bar for the total envelope of this information at a higher level.

On the core question about what considerations should be most important for government to take into account in the area of genetic privacy, the groups differed somewhat. In St. John's, the vast majority wanted governments to strike a balance between protection of privacy and facilitating health research – owing in large part to perceptions that the types of research that were already underway in Newfoundland and Labrador were likely to bear fruit for them or their families or friends. In Calgary, a majority, but only a slim majority, concurred with this view. The rest wanted stronger measures to be put in place to protect privacy, before they were willing to work toward "striking the balance" that other research has identified as the majority opinion among Canadians. They were less likely to make a direct connection between the research and the potential for them or their loved ones to benefit from the research.

The Calgary groups showed the clearest evidence thus far of a chill effect beginning to reveal itself in this area — people unwilling to be tested or provide their genetic information to research in the absence of what people perceive as firm rules about what information is protected and from whom.

These focus groups reinforced a sense that there is a potential for growing urgency around these issues, with people seeking more information and clarity around the prevailing governance rules, and possibly more steps to protect genetic privacy. Without some of these measures, it is possible that - prevailing views in favour of striking a balance could over time change, specifically by eroding support for facilitating R&D (or striking a balance between privacy and R&D), until people are given clarity or assurance of some sort about what is and is not allowed. Without that clarity, it may become the case that people will begin leaning toward asking government to err on the side of protecting privacy, instead of striking a balance between privacy and R&D.

A series of potential governance measures to address genetic privacy issues were tested in these focus groups. Clear, consistent priorities emerged, although most of the measures were seen as important. The top priority was the revision of the Privacy Act to specifically protect genetic information. The second priority was to cover discrimination on the basis of genetic predispositions in the Canadian Human Rights legislation, and the third was to work with the medical research community to establish standards.

The idea of making changes to legislation is seen as the most important step, for two key reasons: First of all focus group participants see it as entrenching specific measures in law that cannot be contravened later. Secondly, they see legislative change as signaling government's attention to the file. The groups in Calgary tended to be the most focused on these measures, primarily because of the level of concern they expressed about the access issues regarding insurance.

With regard to these legal measures, the same issue is in evidence here as was with the reproductive technologies bill regarding cloning. People want language specificity regarding specific types of protection – even if experts say something is implicit in the existing legal framework -- because it provides both personal comfort and confidence in the government's attention to the file.

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

One other dimension of this issue that was raised and discussed in detail in these groups regarded the issue of jurisdiction. Few, if any, realized that many of the

contentious issues associated with this area are actually within the parameters of provincial jurisdiction. Once people are made aware of this, the issue of the federal and provincial governments working collectively to address these issues rises to nearly the top of the priority list. It is then seen as equally important to the other three top areas of priority (revising the Privacy Act, revising the Human Rights Act, and working with the medical community to develop standards.)

Conclusions

The focus groups conducted in Calgary and St. John's reveal that there are many similarities among Canadians on these issues, while beneath them some key differences of opinion can be found. These differences are fuelled by drivers that are more pronounced in certain regions (and among certain populations) in society. While the process involved only four focus groups and cannot be called statistically significant, there were a number of findings revealed that point toward some of the different issues and considerations that people take into account, and variances in the weight that people assign to these issues and considerations when looking at a subject like genetic information and privacy.

In St. John's, the promise of the genetic research that is now already underway has fostered a strong sense of hope, which can be linked directly to the expectation that they, or at least those close to them, are potential beneficiaries of the research. With that has come greater willingness to contribute genetic information to the cause, as well as a lower level of concern about provisions to guard against contraventions of privacy. Although not investigated in detail in these groups, may be that Newfoundland and Labrador residents possess a higher level of trust of those in authority, like governments and the medical research community, to ensure that appropriate measures are in place to protect privacy and ensure that research is done to the benefit of Canadians.

In Calgary, people were much less likely to see specific benefits to them or those close to them from genetic research right now, although they did believe there would likely be benefits at some point in future. There was also an undercurrent of concern about some of the moral implications of genetic research, specifically genetic testing, and the implications of the widespread introduction of such tests. Finally, they were also much less trustful of those in authority, both governments and the medical community, to ensure that appropriate measures are being taken to protect privacy. In contrast to most of the participants in Newfoundland and Labrador, in the absence of information, more tended to default to a position of uncertainty about the stringency of the governance regime, which in turn fuelled unease about the field as a whole.

Biotechnology GI&P Focus Groups
Moderator's Guide

Warm-up (5 min)

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

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

Introduction to Genetic Information and Privacy (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 or having a gene for an inherited disease that has been passed on through generations.

- What can genetic information tell us about ourselves? (Open-ended)
- Is it your opinion that knowing more about our own genetic information is a good thing, or a bad thing? Why is that?
- In your opinion, how important will genetic information and genetic research be to the future of health research?
- How familiar are you with issues involving genetic information? Have you seen, read, heard anything about this subject lately?

Genetic Testing (15 min)

The first set of questions I would like to ask you about regard 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.

- Have you ever been asked to undergo a genetic test?

- How widespread do you think genetic testing is in Canada currently? Are a lot of people having genetic tests? Do you see this as something there will be more of in future? Why/Why not?

- Is genetic testing something that you might do at some point or for some reason, or something you would probably not do on yourself for any reason?

- Why/why not?

Would you have a genetic test?

- To obtain more information about your genetic characteristics
- To determine your risk of developing a genetic disease or condition
- If it would help determine the best medical approach to dealing with a particular disease or condition you have
- If it would determine whether there was a likelihood that you had a disease or condition you could pass on to your children
- To contribute to medical research

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

- Some people say that genetic testing is morally wrong, and whatever benefits 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? Why is that?

Governance Regime: Awareness and Perceptions (20 min)

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

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

46 Elgin St. Suite 200 Ottawa, Ontario K1P 5K6 Tel: 613 563-4455 Fax: 613 236-9546

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

If people think privacy provisions on genetic information and privacy are lax, probe reasons why.

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? Why is that?

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?

Module: R&D (30 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 makeup determines how and why certain people develop disorders and illnesses by studying genetic information from large groups of people.

What is the main benefit of health genetic research? Probe treatments and economic benefits.

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

What if you were approached to contribute your genetic information to a study of particular diseases that tend to affect people that share similar characteristics as you? For example, right now there is some research underway that studies genetic characteristics among populations like the residents of Newfoundland and Labrador. In fact, Newfoundland and Labrador has been noted by experts as a location where a lot of this type of research may be pursued in future, because of the relatively low level of immigration to this province - the genetic composition of Newfoundlanders is relatively similar, more so than among most populations in this part of the world. Iceland is

another place where a lot of this kind of research is taking place. If you were to get a letter tomorrow indicating that your genetic information is being sought for one of these studies of the Newfoundland and Labrador population, would you participate?

18 If position differs between the theoretical question and the Newfoundland and Labrador specific question, probe why opinion differs.

19 *In this area, there are some choices that have to be made about how government should balance interests and trade-off objectives. Is it your view that the laws and rules that govern this research should be written mostly to protect genetic privacy, mostly to ensure that health genetic research goes forward, or that a balance be struck between the two sets of considerations?*

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

21 Do they have a right to sell those samples or the information contained in them to others?

Governance Regime: Priorities (30 min)

Instructions + Info

The federal government is considering undertaking a series of initiatives in the area of genetic information and privacy. The basic goal of this effort is to enhance Canadians' privacy protection and freedom from discrimination while enabling them to benefit from genetic research and health innovation.

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

Q22. a-g each option on the handout

HANDOUT

Options

22a • Change Canada's Privacy Act to make it clear that genetic samples and information from those samples are protected as types of personal information.

22b • Change the Canadian Human Rights Act to clarify that discrimination on the basis of genetic predispositions is covered.

22c
- Ensure that the collection and use of genetic information for genetic research meet new criteria for privacy protection above and beyond the current criteria that apply to health research?

22d
- Developing a complementary code of ethics to guide the collection and use of genetic information for a range of possible uses.

22e
- Work with the medical research community to establish standards and guidelines for use of genetic information in health research or health care services

22f
- Work with other countries to establish similar systems to govern how genetic information is used in health research or health care services

22g
- Engaging provincial governments on genetic information issues, to share information about federal government initiatives, and to share information on aspects that fall within provincial responsibility, like employment and insurance

options/ elements on the handout * important

23 For those at the top (2-3) of the list, why are these the most important to you?

24 Are there other measures that you might hope/expect government to pursue in this regard?

25 What might those things include?

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

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

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