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Community engagement with genetics: public perceptions and expectations about genetics research

Holly Etchegary PhD,* Jane Green PhD,† Patrick Parfrey MD,‡ Catherine Street BPharm (Hons)§ and Daryl Pullman PhD¶

*Clinical Research Scientist, Clinical Epidemiology, Eastern Health, St. John's, NL, †Professor, Department of Genetics, Memorial University, St. John's, NL, ‡University Research Professor, Clinical Epidemiology, Memorial University, St. John's, NL, §Research Manager, Population Therapeutics Research Group, Memorial University, St. John's, NL and ¶Professor, Division of Community Health, Memorial University, St. John's, NL, Canada

Correspondence
Holly Etchegary PhD
Clinical Research Scientist
Clinical Epidemiology
Faculty of Medicine
Memorial University
Room H1407, Level 1
Health Sciences Centre
300 Prince Phillip Drive
St. John's
NL A1B 3V6
Canada
E-mail: holly.etchegary@med.mun.ca

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Abstract

Background Knowledge of molecular biology and genomics continues to expand rapidly, promising numerous opportunities for improving health. However, a key aspect of the success of genomic medicine is related to public understanding and acceptance.

Design Using community consultations and an online survey, we explored public attitudes and expectations about genomics research.

Results Thirty-three members of the general public in Newfoundland, Canada, took part in the community sessions, while 1024 Atlantic Canadians completed the online survey. Overall, many participants noted they lacked knowledge about genetics and associated research and took the opportunity to ask numerous questions throughout sessions. Participants were largely hopeful about genomics research in its capacity to improve health, not only for current residents, but also for future generations. However, they did not accept such research uncritically, and a variety of complex issues and questions arose during the community consultations and were reflected in survey responses.

Discussion With the proliferation of biobanks and the rapid pace of discoveries in genomics research, public support will be crucial to realize health improvements. If researchers can engage the public in regular, transparent dialogue, this two-way communication could allow greater understanding of the research process and the design of efficient and effective genetic health services, informed by the public that will use them.

Introduction

Knowledge of molecular biology, genetics and genomics continues to expand rapidly, promising numerous opportunities for improving health.[1,2] Continued developments in genomics have sparked much rhetoric about personalized medicine, promising the potential for unparalleled

improvements in health at the level of the individual. Despite the potential benefits, with few exceptions, exactly how genomic information will be incorporated into health-care practice to realize health improvements remains largely unknown.[3,4]

Certainly, a key aspect of the success of genomic medicine is related to public acceptance. For example, the public must be willing to collect and utilize family history and genomic information, to share this information with health-care providers and to self-monitor and manage health-related behaviours.[4,5]

A critical element in realizing the potential of genomic medicine to improve health is the establishment of biobanks that contain large numbers of individuals' genomic DNA, linked with other health, lifestyle and administrative data.[6,7] Indeed, large prospective cohort studies and biobanks are becoming standard research tools to investigate the separate and interactive effects of genes, environment and lifestyle on health and disease.[8,9] A common challenge for such research is that large samples, typically hundreds of thousands, are needed to detect genetic variants, and the factors that might interact with them to confer a relatively modest increase in disease risk.[8]

Despite the potential for such genomic research to contribute to clinical care and improved health outcomes, the pace of realizing this potential has been slow.[9] Indeed, relatively robust genotype–phenotype associations for common, complex diseases such as cancer, have only been available in the past few years.[9] Compelling evidence of the clinical utility and validity of most genomic applications for the treatment of common, complex diseases is currently limited, dampening the enthusiasm of the potential for genomics to improve health.[10]

Despite the lack of a robust evidence base, however, some academic centres have begun genomic medicine programmes, and emphasis is soon expected to shift from the use of single genetic variants of large effect (such as in Huntington disease or cystic fibrosis) to using multiple genetic variants in clinical care decisions. This shift is forecast because of the rapidly expanding knowledge base, but also because the cost and logistics of assessing multiple variants simultaneously is approaching that of single gene testing.[8,9] In their recent review, Manolio *et al.*[9] outline at least four genomic applications that are already being used in regular clinical care, such as tumour genotyping of malignant tumours to guide cancer treatment decisions and the use of pharmacogenomics to guide medication decisions in patients genetically unable to activate certain drugs. They argue that such examples suggest 'genomic medicine is no longer on the threshold; it has arrived'. (p.3)

Although it is widely recognized that biobanks and associated genomic research are important resources for advancing treatment knowledge and improving health, a number of potential risks and participant concerns have been identified, not least including appropriate consent models, ownership and data sharing policies and the return of individual research results.[6,7,11] There is currently no consensus on how to resolve these issues, causing uncertainties and inconsistencies in research ethics board's (REB) decisions about genetics and genomics research. In part because of the multiple concerns with large-scale genomics research and the fact that there is no general agreement on how best to resolve them, some argue there is a need for public engagement on the complex issues raised by this research.[7,11]

The endorsement of 'public engagement' with complex societal issues has become quite popular in recent history. Indeed, encouraging public participation in policy decisions is not new; however, recent years have seen a growing emphasis in both academic and policy circles on the necessity and importance of public involvement.[12] Public input into policy decisions is increasingly being promoted as 'decision makers and other stakeholders recognize the need to generate a wider range of policy options, increase the legitimacy of public policies and, more generally, improve the public's understanding of science'.[12, p. 262]

A growing literature is examining public attitudes towards genetics and genomics research.

In the United States, for example, there was widespread support (84%) for the creation of a large genetic cohort study with 60% of Americans, indicating they would participate.[13] Support for the study and willingness to participate varied very little among demographic groups, although aspects of the research such as study burden and whether individual results would be returned to participants did affect willingness to participate. Similarly, majorities (83%) of Veterans Affairs health patients representing a broad range of demographic groups indicated their support for the creation of a large genomic research database, and 71% indicated they would probably or definitely participate.[8] Similar support for genomics research was observed in Canada[14] and Sweden.[15] The National Human Genome Research Institute hosts a series of community engagement programmes including the Family History Demonstration projects and the Community Genetics Forum that have been well received by the public.[16] These forums are designed to facilitate community dialogues about the connections between genetics and health and provide educational programmes and model materials for community groups and others wishing to engage with issues around genetics.[16]

Understanding how the public perceives genetics and genomics research, what their concerns are, and their attitude towards using genomic information in health decisions is critically important for the planning and provision of genetic services, as well as for related policy and ethical decision making. In the province of Newfoundland and Labrador (NL), there has been an active programme of genetics research for many years. Research has tended to revolve around those disorders that are most relevant for the NL population. Ninety percentage of NL's 520 000 residents can trace their family ancestry to 20 000–30 000 immigrants who came from Ireland and England in the 18th and 19th centuries.[17] This founder effect has resulted in a higher-than-average incidence of some autosomal recessive disorders such as fatal neurological disease, inherited eye disorders and inherited forms of hearing loss.[17] Newfoundland and Labrador also has the highest incidence of colorectal cancer (CRC) in Canada and one of the highest rates of familial CRC in the world.[18] Finally, in 2007, it was found that arrhythmogenic right ventricular cardiomyopathy (ARVC) is more prevalent in NL; it is a cause of sudden cardiac death predominantly in young- to middle-aged males due to lethal dysrhythmias caused by a founder mutation in the gene *TMEM43*.[19]

While these active programmes of molecular and clinical research continue, there has not been a complimentary programme of research on public awareness and attitudes towards genetics research in our jurisdiction. In 2009, we began a pilot project on public attitudes to address this gap.

Methods

The project received approval from the Research Ethics Board (REB) at Memorial University. This pilot project had two components: (i) community consultation sessions designed to better understand how the public perceives various aspects of genomics research, and (ii) a short, online survey designed to compare the attitudes of NL participants on key aspects of genomics research with participants from the other Atlantic provinces. In this study, we present results from both components.

Community consultations

A growing literature reveals a wide variety of community engagement methods and practices from which to choose,[20–23] although no gold standard exists as approaches are dependent on goals, research questions and local decision-making contexts.[20] Focus groups, surveys, interviews, deliberative democracy events such as citizens' juries, as well as the development of consensus development and community advisory panels are just some of the methods that have been used to engage community stakeholders with genetics and genomics research.[20–23] Thus, community engagement methods are

diverse, taking into account both the research goals and the unique characteristics of the local community to be engaged. We chose a hybrid information–consultation model for our pilot consultation sessions. We anticipated that many would not be familiar with basic genetics terminology, such as genes, chromosomes, inheritance patterns, nor with specific research projects that had been on-going in the province for many years. Thus, we aimed to first provide information for participants, but also to provide a space for discussion on a variety of issues related to genomics research. We aimed to let participant questions and interests drive the discussion.

We contracted a communications firm with experience in public consultation work to organize the community sessions. We organized sessions in four communities across the province: St. John's (the capital city, two sessions), Clarenville, Gander and Corner Brook. Communities were chosen to represent a mix of urban (St. John's, Corner Brook) and rural (Clarenville, Gander) settings, as well as Eastern, Central and Western areas of the province. Sessions were open to any member of the general public over the age of 18 and were held in the evenings at community sites (e.g. college campus, church halls).

Public recruitment

Intensive efforts were undertaken to advertise the sessions. In all advertisements, individuals were invited to call a toll-free number to register for the session; there was no compensation provided to those who attended.

To promote awareness about the project, members of the research team developed two publication pieces for local media about genetics research in the province and the community consultations specifically. These were published by two local newspapers prior to sessions. The consultant also developed and distributed public service announcements, which were sent to media outlets in each of the communities where sessions would take place (e.g. local radio stations and newspapers), as well as provincial media (e.g. the provincial newspaper, *The Telegram*). Announcements and posters advertising the sessions were sent to various community organizations and associations and their respective newsletters, websites and membership lists. Finally, sessions were advertised on Facebook, and members of the research team extended personal invitations to their networks (e.g. church groups).

Session materials

Sessions were designed as a hybrid information–consultation session. We aimed to provide participants with information about the research being undertaken in the province, as well as to elicit their views about various aspects of genetics/genomics research (e.g. their perceptions of the risks, benefits and harms). We administered short, anonymous surveys before and following the sessions; all questions were open-ended. Pre-session surveys inquired about participants' primary interests and concerns, their attitudes about genetics research and what area they would like to know more about. Post-session surveys measured participants' feedback about the session so as to assist in evaluating the evening, but also asked respondents to identify what they had learned and any changes in their priorities/concerns as a result of the session.

Session facilitation

Community sessions followed a standard format. They began with a welcome from the consultant, followed by a short powerpoint presentation (20–30 min) by a geneticist and project team member (Dr. J. Green). The presentation reviewed some basic genetic concepts (e.g. cells, chromosomes, genes, DNA, inheritance patterns) before providing information about specific research projects in our jurisdiction. Both the consultant and Dr. Green are experienced public speakers who facilitated all sessions. From the beginning, the project team attempted to design a neutral presentation, taking care not to bias participants' opinions about genetic research and testing by presenting an unfairly positive picture of the topic. As the geneticist, Dr. Green explained many of the limitations of the genetic research progress (e.g. length of time

for gene discovery, uncertainty around many genes and their effects, etc.), and both facilitators took care not to impose their own views and opinions on the subsequent discussion.

Following the presentation, there was a question and answer period with Dr. Green that had no set time limit and began with four questions on a powerpoint slide:

1. What does genetic research mean to you?
2. What concerns you/interests you most about genetic research?
3. Do you think genetic research makes a difference in your life?
4. What information do you need to make decisions about your health?

Participants were asked to use these as a springboard for thinking and discussion or to pose their own questions and comment on anything they wished. Following the discussion, participants were asked to complete their post-session surveys. The discussion was not audiotaped, but flip charts were used to record key discussion points, and extensive notes were also taken by additional team members attending the sessions.

Analysis

Qualitative description[24] was used to explore and summarize participant comments. This is a form of naturalistic inquiry that makes no *a priori* theoretical or philosophical assumptions about the data. Rather, it seeks to present the data in the language of participants, without aiming to present the data in more theoretical ways. The end result is a comprehensive summary of the event in question.

Transcripts were coded by two team members (HE and the consultant) and analysed using a modified grounded theory approach, incorporating principles of constant comparison and qualitative description.[24,25] First, comments from participants (as recorded on flip charts, field notes and the pre- and post-session short surveys) were read and re-read independently by the two team members to identify and index emerging categories of participants' comments.[25] Using the principle of constant comparison, all data were first compared within consultation session, before being compared across sessions. For example, notes, flip charts and surveys were analysed for session 1, before moving on to session 2, and so on. Analysis for each individual session was completed before comparing the data across sessions. Once independent coding was complete, investigators' thematic analysis of the comments was compared and found to be very similar (>90% agreement); differences tended to be minor and involved subcodes (e.g. 'privacy concerns' vs. 'concerns about who could access private genetic information').

Online survey

Recruitment

Following analysis of the community sessions, we contracted Ipsos Reid, a North American public opinion firm to conduct a brief, online survey of Atlantic Canadians. Because NL had been the site of decades of genetics research, we wondered if opinions on key issues would be different outside the province. As such, we surveyed a random sample of Atlantic Canadians (NL, Nova Scotia, New Brunswick and Prince Edward Island) through Ipsos Reid's Canadian Omnibus Survey. These surveys contain questions on a number of topics and typically take about 10 min to complete. Omnibus surveys are commonly used by governments, social scientists and others to gauge public opinion on a multitude of issues, as well as track reactions and opinions on specific issues. Surveys were administered by Ipsos between April 6 and 11, 2010.

The survey was completed by members of the Ipsos-I-Say panel, a panel of almost 200 000 Canadians. Panellists were sent an e-mail invitation and given a minimum of 3 days to complete the survey. Members of the I-Say panel are recruited in a variety of ways, including using telephone surveys and purchased lists. The panel is continuously refreshed using a number of sources and methods, the most important being affiliate networks. Specifically, affiliate networks allow Ipsos to recruit from many different sources as affiliates run

recruitment campaigns in partnership with 20–40 different websites at any one time. Ipsos also recruits through social networks, e-mail lists, banners, websites and text ads, and search engine marketing methods.

Power and analysis

With a sample of 1024 Canadians, one can say with 95% certainly that the results are within ±3.1 percentage points of what they would have been had the entire population of Atlantic Canada been surveyed. Final data were weighted by age, sex and region to reflect the population of Atlantic Canada according to 2006 Canadian Census data. *T*-test significance testing was applied at the 95% confidence interval to determine whether there were differences in opinion on the five survey items between groups (e.g. sex, region, education).

Survey items

Items were chosen based on prior opinion studies (e.g.[26,27]), topics raised in the pilot community sessions and the research team's interests. Items measured perceptions of the importance of genetic tests, their usefulness in health decision making, as well as concerns such as the privacy of genetic information (Table 2).

Results

Community sessions – Session statistics

The five sessions lasted an average 1.5 h and included 33 participants (16 males, 17 females). We aimed to hold sessions in both rural and urban areas: two sessions were held in the capital city of St. John's (Eastern NL), with one each in Clarenville (also Eastern NL), Gander (Central NL) and Corner Brook (Western NL).

We did not record demographic information on surveys, but the majority of participants appeared to be in the 50–60 year age range. The first session in St. John's comprised five participants, the second 14. Thirteen participants attended the session in Clarenville, one for the session in Gander and nobody in Corner Brook. In the Gander session, the participant sat with presenters and reviewed hard copies of the presentation slides. As in all sessions, he was given the opportunity to ask questions and have a discussion with the presenters following the review of slides.

Themes raised during discussion

Overall, many participants noted they lacked knowledge about genetics and associated research and took the opportunity to ask numerous questions throughout sessions. Participants were largely hopeful about genetics research in its capacity to improve health, not only for current residents, but also for future generations. However, they did not accept such research uncritically, and a variety of complex issues and questions arose during the community consultations. These are captured in the following four themes, and we discuss each in turn: (i) Privacy and confidentiality of genetic information, (ii) Need for accurate information, (iii) Applications and (mis)use of genetic information, and (iv) Value of public input.

Privacy and confidentiality of genetic information

Across all sessions, participants voiced concern over the privacy of genetic information. It should be noted that no participant suggested their privacy concerns were so heightened they did not support genetics research or they would refuse to take part in a research study. However, participants clearly questioned who had access to their data and how it would be protected. For example:

> Will insurance withdraw coverage? How are genetics and privacy connected? (St. Johns', Session 1)

> What if I am an insurance agent? I would want to know because the levels of risk on my clients mean money considerations. (Clarenville Session)

Participants were aware genetic information could be insecure and questioned how their sample might be protected in a research study:

> The news lately is replete with stories about people leaving computers and papers around. What

> kind of security is there that this data is protected? (St. John's, Session 2)

Following from this discussion, another participant noted a different aspect of genetic privacy:

> There's an emphasis today on privacy. But you have to get a lot of personal and family history [for these studies]. So, say one sibling says yes, but another says no, does this disrupt the study? What about the common good? (St. John's, Session 2)

The need for accurate information

In all sessions, participants noted the necessity for accurate information to make informed decisions, not only about participating in genetics research, but also for decisions about genetic testing. Participants had many questions for the presenter (as noted, a geneticist):

> When you look for a specific hereditary disease, say I wanted the test. What if they found something else, would they tell me? Would I have the right to refuse? (St. John's, Session 1)

> Can anyone get a genetic test? A random request? (St. John's, Session 1)

> How up to date are GPs on this? Do they know about genetic testing and counseling? (Clarenville Session)

Review of the pre- and post-session forms also highlighted participants' need for accurate information:

> How is research information being used in health care and in giving family planning advice?

> Regarding testing, is a physician referral necessary?

> Where can a family with concerns obtain information?

Applications and (mis)use of genetic information

While participants were very positive about the potential for genetic research to improve health, they also questioned its application, use and governance:

> What about controversy? Some people feel we should find genetic links for homosexuality, or certain races. The issue of eugenics should be discussed. (Clarenville Session)

> Is there legislation for genetic research and the use of results? We have had companies take samples and then market a product. Are participants told about the results? (Clarenville Session)

> My interest in genetics is with public policy. I am concerned how priorities are set for applications for research. What gets chosen for study and financing? (St. John's, Session 2)

Beyond these broader societal concerns, participants also raised questions about the use and impact of genetic information within families:

> I have some fears. What about emotional stress on a family who knows a condition exists? Genetic research could be beneficial and extend life, but how do we deal with the emotional impact on a person's health? Can we reduce stress by having more knowledge? (St. John's, Session 1)

> Sometimes, too much information is not a good thing. Knowing you may be predisposed to a certain risk of developing 'something' but may never develop it, and have spent a lifetime worrying about it. (Clarenville, Pre-Session form)

Value of public input

In reading post-session forms in particular, participants were unanimous in their endorsement of public sessions such as these and suggested they be held regularly:

> I would be interested in learning about new techniques and technologies being developed, as well as significant findings related to disease etiology and treatment. (Clarenville Session)

> It is important to engage the public in such an important area of research for the province. Needs to be presented annually for updates on research. (St. John's, Session 2)

> I'm glad that you've taken this initiative on the road to get a cross section of the public's concerns. Certain issues come up at each session, which gives you an idea of what's perceived to be important. (St. John's, Session 2)

Online Survey results

Respondents

In total, 1024 Atlantic Canadians completed the survey items, representing a response rate of 65%. Respondents were comprised of a roughly equal proportion of males (56%) and females. Table 1 displays the remaining demographic information about respondents.

Opinion about genetics

Respondents were split on the importance of genetic testing in the Canadian health-care system, with about a third agreeing it was important, and a third disagreeing that it should be a priority in the system (Table 2). Most respondents (87%) indicated a positive genetic test would affect the decisions they made about their health. Nearly half of respondents were concerned that genetic test results could be used in ways that were harmful to people.

Most survey respondents agreed they had given little to no prior thought about genetics, and a majority (~58%) indicated they would be concerned about the privacy of their genetic information, echoing participants in the community consultations.

Table 1 Demographic information online survey respondents ($N = 1024$)

Age Category (%)		Education (%)	
18–24	3.6	Less than high school	6.7
25–34	8	High school	25.3
35–44	16.8	Post-secondary	50.4
45–54	23.4	University graduate	17.6
55–64	24.2		
Over 65	23.9		
Province (%)		Have children at home	
NL	12.2	Yes	24.9
NB	29.8	No	75.1
NS	52.1		
PEI	5.9		

Differences among groups in opinions on the survey items

There were relatively few differences in opinions among groups on the five survey items (Table 3). However, men were more likely than women to agree that genetic testing was *not* an important priority for the Canadian health-care system (31% and 23%, respectively; $P < 0.05$). Older respondents (35–54 and 55+) were also more likely to agree with this item (29% and 34%, respectively) compared with younger (18–34) respondents (15%; $P < 0.05$). Respondents from Newfoundland were more likely to disagree (48%) than respondents from the other Atlantic provinces ($P < 0.05$). Thus, women, younger respondents and those from NL were more supportive of genetic testing as a priority in our health-care system.

Younger participants were less likely to be worried that genetic test results could be used in ways that were harmful to people (40% agreeing, vs. 48% for older respondents; $P < 0.05$) Respondents with the lowest levels of education were more concerned about this issue (17% disagreeing) than those with higher levels of education (32% of university graduates, $P < 0.05$).

Females were more likely to have thought about the use of genetic information to prevent disease than males (31% and 21%, respectively; $P < 0.05$). Those with the lowest levels of education indicated little to no prior thought about genetic information, and this was significantly different from those with higher levels of education ($P < 0.05$). There were no differences in the amount of prior thought about genetics by province.

Finally, older respondents (35–54 and 55+) were more likely to agree (59% of each group) that they would be concerned about the privacy of their genetic information if they were to have a genetic test than younger respondents (42%, $P < 0.05$). Those with the highest level of education were significantly less likely to agree with this item (48%), indicating lower levels of privacy concerns than those with lower levels of education (e.g. 65% of those

Table 2 Respondent attitude towards genetic issues in online Omnibus survey ($N = 1024$)

Attitude item	Agree and strongly agree (%)	Neither agree, nor disagree (%)	Disagree and strongly disagree (%)
Item 1: How much do you agree or disagree with the following statement? Compared to other public health problems, genetic testing is not an important priority for the Canadian Health care system.	30.9	32.8	36.4
Item 2: If a genetic test showed that you were at increased risk for a disease, it would affect the decisions you make about your health.	87.1	5.1	7.8
Item 3: How much do you agree or disagree with the following statement? I am concerned that genetic test results could be used in way that are harmful to people.	45.6	31.1	23.3
Item 4: Before today, how much had you thought about the use of genetic information to prevent disease?	Not at all/only a little 72.9		Some/A lot 27.1
Item 5: How much do you agree or disagree with the following statement? If I were to have a genetic test, I would be concerned about the privacy of my genetic information.	57.7	19.7	22.6

with less than high school agreeing, $P < 0.05$). Again, there were no differences on this item by province.

Discussion

As research in genetics and genomics continues to advance, we undertook a pilot consultation process to better understand what the public currently knows about genetics/genomics research and what their concerns are in this area. The sessions were a knowledge translation opportunity to inform the public about current research programmes in our jurisdiction. Such transparency and accountability is important to foster trust and participation in genetics research, as well as to provide information for general practitioners and other allied health professionals who are faced with increasing numbers of patients seeking knowledge about their genes and any associated health risks.[28]

The majority of session participants and survey respondents reported little prior thought about the use of genetic information to prevent disease. However, the potential for genetics research was expressed by most participants, and a large majority of survey respondents indicated they would use genetic information in decisions about their health. This optimism is consistent with the generally positive attitude related to the application of genetic advances to health reported by others.[5,26,29] In our survey, females, younger respondents and those from Newfoundland (NL) were more likely to agree that genetic testing was an important priority for the Canadian health-care system. It has been suggested that human genetics research might be more salient to women, particularly younger women of reproductive age, as much of the public discourse about genetics revolves around reproduction and prenatal tests.[30] In addition, women are traditionally the 'genetic housekeepers' of the family,[31] taking responsibility for their family's health. As NL has a strong history of genetics research and a higher incidence of several genetic disorders, it is not surprising these respondents would assign genetic advances a higher priority than other respondents.

Participants also conveyed a strong interest in learning more about genetics/genomics research, particularly research being carried out provincially. Many suggested that information sessions be held regularly to keep the public up

Table 3 Percentage responses among demographic groups on the five survey items

Survey item	Sex		Age			Education				Province			
	Male	Female	18–34	35–54	55+	<HS	HS	Post-secondary	University Graduate	NL	NS	NB	PEI
Percentage of respondents who agreed with each survey item (responses to 'strongly agree' and 'agree' added to form percentages in table):													
Genetic testing not an important priority	31	23*	15	29	34*	20	27	26	32	20*	30	29	22
Affect the decisions you make about your health	86	86	82	86	91	83	87	86	85	91	88	82	83
Tests can be used in ways that are harmful to people	41	47	40*	48	44	17*	20	23	32	48	46	38	56
Thought about genetic information to prevent disease	23	31*	33	24	27	21*	34	28	36	33	28	24	21
Concerned about the privacy of my information	57	52	42*	59	59	65*	51	59	48	57	56	51	50

*Indicates significant difference in subgroup response, $P < 0.05$, among levels of that demographic variable.

to date on research advances. Participants in the community sessions were self-selected, so it is impossible to determine if the same level of interest exists in the general population, but this response was consistent across all sessions and with prior research (e.g.[5,14]).

The type of information desired by the general public in this study included not only information on specific and particularly local programmes of research and their findings, but also more basic information such as eligibility requirements for genetic testing, how to get a referral to genetics services and whether participants have the right to refuse test results in a research study. These informational elements are critically important in the recruitment of the general public to large-scale population genetics research and to the design of informed consent documents (for any genetics research). These findings also highlight the importance of being explicit and realistic about the types of results that may be available (if any) to research participants and to be honest that useful test results cannot be guaranteed, in that, the outcome of a research project is not necessarily predictable[7,14].

Findings from the community sessions revealed several areas of public concern, including the potential misuse of genetic research to promote eugenics, the possibility of insurance difficulties, the privacy and protection of genetic information, as well as the return of individual research results. These findings are in line with the growing literature on public attitudes towards genetics and biobank research[6–8,11,13] and point to areas of concern that must be addressed to foster public trust and participation in research. While no consensus currently exists regarding how best to protect participants' privacy, where and how to return individual research results and a number of other ethical, legal and social issues related to genetic and biobank research, we and others[11] suggest public engagement be at least one factor to be considered in resolving these problems.

The online survey results supplement the concerns raised in community consultations.

Almost half of respondents were worried that genetic test results could be used in ways that were harmful to people, particularly older respondents and those with lower levels of education. A similar pattern emerged regarding privacy concerns: older respondents and those with lower levels of education had higher levels of concerns. Regarding age, it may be that older respondents have simply had more time to experience the adverse privacy effects of compromised personal health information and therefore show higher levels of concern. Prior research has also revealed risk perception differences between lower- and higher-education respondents.[32,33] The explanation for such difference is unclear, although it has been suggested that education and income effects might be explained in terms of lower power and control over health risk policy in respondents with lower levels of education or income.[32] It is also possible that respondents with lower levels of education have more difficulty understanding informed consent documents that should ideally explain what action(s) will be taken to protect their participation in research studies. This study was not designed to test these explanations and they should be regarded as tentative. Future research, specifically designed to explore the effect of age or education on genetic risk perception, would allow firmer conclusions to be drawn. We suggest, however, these demographic differences in risk perception may be important in the design of health and research communication that attempts to present a balanced picture of the role of genetics in disease and inform the public on the legitimate uses of genetic information.

Session participants explicitly commented on the value of public input to identify areas of concern in the local area. One notable area of concern for both session participants and survey respondents was the protection of their genetic information, in line with other studies.[5,7,14] While the United States has introduced federal legislation to protect its citizens against genetic discrimination with regard to employment and health insurance, the Genetic Information Non-discrimination Act (GINA), no comparable legislation exists in Canada. Unlike the USA, in which the majority of citizens receive their private health insurance through their employers, Canadians are covered under the universal health-care system that provides basic coverage to all residents. Hence, it has been argued that Canada does not require genetic non-discrimination legislation.[34] Nevertheless, Canada has two data protection laws: the *Privacy Act*, adopted more than 25 years ago to regulate the collection, use and disclosure of personal information by federal government institutions and the more recent *Personal Information Protection and Electronic Documents Act* (PIPEDA) in 2000, which applies to private sector organizations and their data-related activities in most parts of the country. Organizations covered by very similar provincial laws are exempted from PIPEDA. Our findings suggest that educational campaigns and informed consent documents related to genetics research must be explicit about what safeguards will be in place to protect participant research data and what the limits of that protection might be. These informational elements should be tailored to the local context, taking into account data protection laws, as well as resident concerns.

Study limitations

Participants in the community sessions were self-selected, and there were relatively low turnouts for the sessions. We do not have information on members of the general public who did not accept the invitation to attend a session, so we do not know whether they would differ from the current session participants in ways that might affect the results. Participants were recruited from only one province, although we did attempt to reach different areas of the province, including rural and urban centres. However, we cannot generalize the perceptions of our community session participants to other communities. We note also that recruitment to the online panel was achieved largely through electronic means.

Thus, it is likely that certain segments of the population were less likely than others to participate (e.g. participants with lower education or income levels or limited experience with internet technology), further limiting the generalizability of our survey findings. We note, however, that results from both the community sessions and online survey are quite similar to a growing body of research on public expectations and attitudes about genetics research and testing, which provides some confidence in the results obtained.

Conclusions

The public reports relatively low knowledge about genetics research, but fairly high levels of support. Many participants reported interest in attending regular information–consultation sessions and suggested that such regularity might increase awareness and interest in genetic research. With the proliferation of biobanks and the rapid pace of discoveries in genomics research, public support will be crucial to realize health improvements. If researchers can engage the public in regular, transparent dialogue, areas of public (and researcher) concern could be identified and discussed. Such two-way communication could help open the way for greater understanding of the research process and the design of efficient and effective genetic health services, informed by the public that will use them.

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Conflict of interest

The authors declare that they have no conflict of interests.

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References

1 Burke W, Burton H, Hall A *et al.* Extending the reach of public health genomics: what should be the agenda for public health in an era of genome-based and "personalized" medicine? *Genetics in Medicine*, 2010; **12**: 785–791.
2 Snyderman R, Dinan M. Improving health by taking it personally. *Journal of the American Medical Association*, 2010; **303**: 363–364.
3 Khoury M. Genetics and genomics in practice: the continuum from genetic disease to genetic information in health and disease. *Genetics in Medicine*, 2003; **5**: 261–268.
4 McBride C, Bowen D, Brody L *et al.* Future health applications of genomics: priorities for communication, behavioral and social sciences research. *American Journal of Preventive Medicine*, 2010; **38**: 556–565.
5 Hahn S, Letvak S, Powell K *et al.* A community's awareness and perceptions of genomic medicine. *Public Health Genomics*, 2010; **13**: 63–71.
6 Caufield T, Knoppers B. Consent, privacy and research biobanks. Policy Brief No. 1 Genome Canada. Available at: http://www.genomecanada.ca/medias/pdf/en/GPS-Policy-Directions-Brief.pdf, accessed 15 January 2012.
7 Lemke A, Wolf W, Herbert-Beirne J, Smith M. Public and biobank participant attitudes toward genetic research participation and data sharing. *Public Health Genomics*, 2010; **13**: 368–377.
8 Kaufman D, Murphy J, Erby L *et al.* Veterans' attitudes regarding a database for genomic research. *Genetics in Medicine*, 2009; **11**: 329–337.
9 Manolio T, Chisholm R, Ozenberger B *et al.* Implementing genomic medicine in the clinic: the future is here. *Genetics in Medicine*, 2013; **15**: 258–267.
10 Scheuner M, Sieverding P, Shekelle P. Delivery of genomic medicine for common chronic adult disease: a systematic review. *Journal of the American Medical Association*, 2008; **299**: 1320–1334.
11 O'Doherty K, Hawkins A. Structuring public engagement for effective input in policy development on human tissue biobanking. *Public Health Genomics*, 2010; **13**: 197–206.
12 Daudelin G, Lehoux P, Abelson J *et al.* The integration of citizens into a science/policy network in genetics: governance arrangements and

asymmetry in expertise. *Health Expectations*, 2010; **14**: 261–271.
13 Kaufman D, Murphy J, Scott J *et al*. Subjects matter: a survey of public opinions about a large genetic cohort study. *Genetics in Medicine*, 2008; **10**: 831–839.
14 Godard B, Marshall J, Laberge C. Community engagement in genetics research: results of the first public consultation for the Quebec CARGaGENE project. *Community Genetics*, 2007; **10**: 147–158.
15 Hoeyer K, Olofsson B, Mjorndal T *et al*. Informed consent and biobanks: a population-based study of attitudes towards tissue donation for genetic research. *Scandinavian Journal of Public Health*, 2004; **32**: 224–229.
16 National Human Genome Research Institute. Com-f munity Genetics Forum. Available at: http://www.genome.gov/19518473, accessed 4 February 2013.
17 Rahman P, Jones A, Curtis J *et al*. The Newfoundland population: a unique resource for genetic investigation of complex diseases. *Human Molecular Genetics*, 2007; **12**: R67–R172.
18 Green R, Green J, Buehler S *et al*. Very high incidence of familial colorectal cancer in Newfoundland: a comparison with Ontario and 13 other population-based studies. *Familial Cancer*, 2007; **6**: 53–62.
19 Merner N, Hodgkinson K, Haywood A *et al*. Arrhythmogenic right ventricular cardiomyopathy type 5 (ARVD5) is a fully penetrant, lethal arrhythmic disorder caused by a missense mutation in the *TMEM43* gene. *American Journal of Human Genetics*, 2008; **82**: 80–821.
20 Lemke A, Wu J, Waudby C *et al*. Community engagement in biobanking: experiences from the eMERGE network. *Genomics Society and Policy*, 2010; **6**: 35–52.
21 Anderson C, Stackhouse R, Shaw A *et al*. The National DNA database on trial: engaging young people in South Wales with genetics. *Public Understanding of Science*, 2011; **20**: 146–162.
22 Dove E, Joly Y, Knopper B. Power to the people: a wiki-governance model for biobanks. *Genome Biology*, 2012; **13**: 158–172.
23 O'Daniel J, Rosanbalm R, Boles L *et al*. Enhancing geneticists' perspectives of the public through community engagement. *Genetics in Medicine*, 2012; **14**: 243–249.
24 Sandelowski M. Whatever happened to qualitative description? *Research in Nursing and Health*, 2000; **23**: 334–340.
25 Pope C, Ziebland S, Mays N. Analysing qualitative data. *British Medical Journal*, 2000; **320**: 114–116.
26 Etchegary H, Cappelli M, Potter B *et al*. Attitude and knowledge about genetics and genetic testing. *Public Health Genomics*, 2010; **13**: 80–88.
27 Jallinoja P, Aro A. Does knowledge make a difference? The association between knowledge about genes and attitude towards gene tests *Journal of Health Communication*, 2000; **5**: 29–39.
28 Cunningham-Burley S. Public knowledge and public trust. *Community Genetics*, 2006; **9**: 204–210.
29 Henneman L, Timmermans D, van der Wal G. Public experience, knowledge and expectations about medical genetics and the use of genetic information. *Community Genetics*, 2004; **7**: 33–43.
30 Parrott R, Silk K, Condit C. Diversity in lay perceptions of the sources of human traits: genes, environments and personal behaviors. *Social Science and Medicine*, 2003; **56**: 1099–1109.
31 Richards M. Families, kinship and genetics. In: Marteau T, Richards M (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*. Cambridge: Cambridge University Press, 1996: 249–273.
32 Lemyre L, Lee J, Mercier P *et al*. The factor structure of health risk perceptions in Canadians: environmental, therapeutic and social health risks. *Health, Risk & Society*, 2005; **8**: 185–195.
33 Palmer C. Risk perception: another look at the "white male" effect. *Health, Risk & Society*, 2003; **5**: 71–83.
34 Pullman D, Lemmens T. Keeping the GINA in the bottle: assessing the current need for genetic non-discrimination legislation in Canada. *Open Medicine*, 2010; **4**: e95–e97.