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ARTICLE

Consulting the community: public expectations and attitudes about genetics research

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Genomic discoveries and technologies promise numerous opportunities for improving health. Key to these potential health improvements, however, are health-care consumers' understanding and acceptance of these new developments. We identified community groups and invited them to a public information-consultation session in order to explore public awareness, perception and expectations about genetics and genomics research. One hundred and four members of seven community groups in Newfoundland, Canada took part in the community sessions. Content analysis of participant comments revealed they were largely hopeful about genetics research in its capacity to improve health; however, they did not accept such research uncritically. Complex issues arose during the community consultations, including the place of genetics in primary care, the value of genetics for personal health, and concerns about access to and uses of genetic information. Participants unequivocally endorsed the value of public engagement with these issues. The rapid pace of discoveries in genomics research offers exciting opportunities to improve population health. However, public support will be crucial to realize health improvements. Our findings suggest that regular, transparent dialog between researchers and the public could allow a greater understanding of the research process, as well as assist in the design of efficient and effective genetic health services, informed by the public that will use them.

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INTRODUCTION

Continued developments in the fields of molecular biology and genomics promise many opportunities for improving health.[1,2] Developments in genomics, in particular, fuel growing rhetoric about personalized medicine, offering unparalleled potential for improving the health of both individuals and populations. Genomic information and technologies do have the potential to improve health. Currently, however, exactly how this information will be integrated into health-care practice remains largely unknown.[3,4]

One important component necessary for the success of genomic medicine is related to health-care consumers' understanding and acceptance. That is, individuals must be willing to gather and use genetic information in their health decisions, to share this information with their health-care providers, and also to self-monitor and manage their health-related behaviors.[4,5]

A second element in realizing the potential of genomic medicine to improve health is the growth of biobanks around the world. These are usually large repositories that contain growing numbers of individuals' genomic DNA, linked with other health, lifestyle, and administrative data.[6,7] Biobanks are acknowledged as important resources for advancing genomics research and improving health; however, a number of participant concerns have been identified, not least including appropriate consent models, ownership and data sharing policies and the return of individual research results.[6–8] In the absence of any legal or empirical consensus on how to resolve these issues, Research Ethics Board's (REB's) decisions about genetics and genomics research is often inconsistent and plagued with uncertainties. In part because of the multiple concerns with biobanking and the fact that there is no general agreement on how best to resolve them, some argue that there is a need for public engagement on the complex issues raised by genetics research.[7,8]

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.[9] 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'.[9]

Understanding how the public perceives genetics and genomics research, what their concerns and expectations are, and their attitude towards using genetic information in health decisions is critically important for the planning and provision of genetic services. In the province of Newfoundland and Labrador (NL), there has been an ongoing program of genetics research for several decades. Research has generally focused on those disorders that are most relevant for the NL population. Ninety percent of NL's 510 000 citizens can trace their family ancestry to 20 000–30 000 immigrants who came from Ireland

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and England in the 18th and 19th centuries.[10] 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, although lower than average incidence of others.[10] NL also has the highest incidence of colorectal cancer (CRC) in Canada and one of the highest rates of familial CRC in the world.[11] A rare inherited heart condition, arrhythmogenic right ventricular cardiomyopathy is also more prevalent in NL; it is a cause of sudden cardiac death, predominantly in young to middle aged males, due to lethal arrhythmias caused by a founder mutation in the gene *TMEM43*.[12]

While these active programs of clinical and molecular research continue, the province lacks a complimentary program of research on public awareness, perception and expectations about genetics research. Our research team shared a general will to make our policy-oriented research production and knowledge transfer processes more democratic (ie, informed by the residents of the province). To that end, and subsequent to pilot work in 2009, we conducted a series of public information-consultation sessions around the province to better understand how the public perceives various aspects of genetics/genomics research. We aimed to provide information about research programs in the province, provide the public with a space for asking questions, and solicit their opinions about genetic testing and research.

MATERIALS AND METHODS

Public recruitment

The project received approval from the REB at the Memorial University. We organized sessions in two communities in the province: St John's (the capital city in Eastern NL) and Grand Falls-Windsor (a smaller center in Central NL) over a 9-month-period in 2010–2011. Pilot work had revealed the difficulty in enlisting members of the public through 'cold' recruiting (eg, ads posted in public locations advertising the sessions). Thus, the research team identified local community groups at both study sites and sent invitations to the sessions. Sessions were open to all members of the group and were held in the evenings at community sites (eg, college campus, church halls) or during groups' regular meeting periods. In all study invitations, individuals were invited to call a toll-free number to express their groups interest in the session; there was no compensation provided to those who attended.

Groups were identified that contained a broad mix of members of the general public. For example, both men's and women's church groups, a youth group, community service organizations (eg, Rotary clubs, Lions' Clubs), municipal town councils and an illness support group. In total, 11 groups were mailed/emailed study invite letters, with seven eventually accepting and taking part in a community group consultation. Reasons for declining were mainly related to time constraints of the groups, although the Director of the youth group felt the topic would not be of interest to her members.

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 (eg, their perceptions of the risks, benefits and harms). We administered a short, anonymous survey following the session to collect demographic information and provide space for participant comments. Community sessions began with a welcome from a team member (HE), followed by a short powerpoint presentation (20–30 min) by a geneticist and project team member (JG). The presentation reviewed some basic genetic concepts (eg, cells, chromosomes, genes, DNA, inheritance patterns) before providing information about specific research projects in our jurisdiction (powerpoint slides available upon request).

Following the presentation, there was a question and answer period with JG and HE 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. We note that participants nearly always chose the latter. Many had specific questions for the geneticist that related to conditions in their own families, and these questions and subsequent discussion normally began the Q and A period. Further, discussion followed from these opening questions; thus, answers to the four questions on the powerpoint slide were not formally collected.

Following the discussion, participants were asked to complete their post-session surveys. The discussion was not audio-taped, but flip charts were used to record key discussion points, and extensive notes were also taken by team members attending the sessions (eg, HE, ED). All sessions were attended by three team members, and two were responsible for recording verbatim as much in detail of the discussion as possible. We believe that participant comments and discussion were adequately captured through this process, and also in the open comments on the short survey. For interested readers, field notes of group discussions are available from the first author uponrequest.

Session facilitation

Both facilitators are project team members and experienced public speakers. 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 (eg, length of time for gene discovery, uncertainty around many genes and their effects, and so on), and both presenters took care not to impose their own views and opinions on the subsequent discussion.

Analysis

Qualitative description[13] was used to explore and summarize participant comments. This is a form of naturalistic inquiry that makes no *a priori* philosophical or theoretical 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.

Field notes and flip charts were typed in a text program (Mircosoft Word) to facilitate analysis. No qualitative software package was used in the analysis. Comments from participants (as recorded on flip charts, field notes and the post-session survey) were read and reread independently by two investigators (HE and ED) in order to identify and index emerging categories and themes.[14] 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 were resolved through discussion and consultation with JG, as well as informed by prior opinion studies (eg,[15,16]) about genetics. Data analysis was ongoing throughout the data collection period and ended when data saturation was reached; that is, the point at which no new ideas, codes or themes were emerging from the data.[14]

RESULTS

Community sessions – session statistics

The seven sessions lasted an average of 1.5 h and included 104 participants (70 males). Four sessions were held in the capital city of St John's ($n=81$), with three in Grand Falls-Windsor ($n=23$). Two sessions were held with Rotary Club members, two with women's groups, one with a men's church group, one with a municipal council committee and an open public session was advertised at a local college (Table 1). Table 2 displays the demographic information of the participants. The mean age of participants was about 58 years, but a variety of ages was represented across the sessions

Table 1 Consultation groups ($N=7$)

Group	*Group number as referenced in results section (participant quotes)*	*Number of members in group*
Women's group, St John's	1	8
Men's group, St John's	2	32
Rotary Club one, St John's	3	27
Rotary Club two, St John's	4	14
Women's group, Grand Falls-Windsor	5	6
Municipal council committee, Grand Falls-Windsor	6	7
Open session, local college, Grand Falls-Windsor	7	10

Table 2 Demographic information of study participants ($N=104$)

Education (%)	
Less than high school	3.8
High school	9.6
Post secondary	33.6
University graduate	51
Age (mean, SD)	58.1 (17.4)
Age range (years)	13–91
Age ranges (years)	
<30	9
30–39	5
40–49	18
50–59	16
60–69	25
70–79	21
⩾80	9
Children (mean, SD)	1.8 (1.3)
Range	0–5
Marital status (%)	
Single	16.3
Married/partner	71.2
Divorced/separated	7.7
Widowed	3.8
Genetic condition in the family? (%)	
Yes	32
No	39
Unsure	29

Totals may not add to 100% due to missing data (~1%).

(range 13–91 years). Most participants were well educated and married, and roughly a third (32%) reported that either they or someone in their family had been diagnosed with a genetic condition. Participants named a wide variety of conditions such as cancer, cardiac disease, diabetes, hearing loss, vision loss, Factor V Leiden, Down's Syndrome and one noted Von Hippel Lindau disease.

Themes raised during discussion

Many participants noted, they lacked knowledge about genetics and associated research and took the opportunity to ask numerous questions throughout sessions (eg, what is involved in having a test, who is eligible, and so on). They were universal in their endorsement of the value of such community consultations and expressed their gratitude for the opportunity. The following comments from surveys were typical. 'Great that you are engaging the public in the discussion and increasing the awareness of genetic research.' 'Wish we had more time for discussion; the appetite has been whetted.'

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 were raised and discussed during the community consultations. These are captured in the following three themes, and we discuss each in turn: (1) The place and priority of genetics in primary care; (2) The value of genetics for personal health; and (3) Concerns about genetics, at both the personal and societal levels.

The place and priority of genetics in primary care

In some groups, basic questions about genetic testing (eg, where and how to obtain a test) led to a discussion on the place of genetics in our health-care system. The consensus seemed to be that genetics and family history are not often discussed in primary care and even when they are, there is little follow-up, or discussion of what this might mean in practical terms (eg, how the information translates into risk assessment or preventive health behaviors). An exchange in one of the women's groups highlights these concerns:

> I find that when the doctor asks if anyone in your family has that, it isn't followed up. So what happens after that? So I'm asked about things in my family, but no one follows up. (Female, Group 1)

> There is disease in my family, but I'm not sure what the implications would be for me. Knowing it was hereditary, I didn't know what actions could be taken. (Female, Group 1)

Others with a personal experience of genetic illness noted the difficulty of accessing the appropriate tests:

> It's taken a long time to collect family history information. Then it took months to get the testing for me, then months to get testing for my brother. So it takes a long time. (Female, Group 5)

Another suggested there was a disconnect between genetics' focus on prevention and our current system of providing care:

> Our system is geared towards, not so much prevention, but the outcomes. Right now, we deal with disease, not prevention. (Female, Group 5)

While participants recognized the potential value of genetic research and information for health, they suggested it was hard to compete with other health-care priorities:

> Genetics doesn't have that sense of immediacy. Think about waiting lists. How do we prioritize genetic testing over people waiting for surgery? (Female, Group 1)

> Genetics is not an area that's really in the mass media. Wait times, not enough family doctors, that's the stuff that's in the media. So people don't really know how important genetics is. (Male, Group 7)

Value of genetics for personal health

Participants quickly endorsed the potential value of new discoveries in genetics research for personal health and also for the health-care system:

> I feel it is very important in developing cures and treatments for many disorders. (Male, survey response, Group 2)

> Excellent to be able to identify a potential-health risk, steps can be taken to prevent disease and reduce health-care costs. (Male, survey response, Group 3)

> I think it has the potential to revolutionize preventive healthcare. If used properly, it could give people a sense of control over their personal healthcare and preparations for the future, including family planning. (Female, survey response, Group 1)

A member of one group recalled the experience of a fellow member who had genetic testing for a rare disorder:

> She tested positive and was able to take action. It sounded horrible and drastic, but there's an upside too. (Female, Group 4)

Another member agreed, also pointing out:

> Then having her daughters tested and they tested negative. That was a huge thing. (Male, Group 4)

Others also recognized the value of genetic research for future offspring:

> So even if it's too late for that person, may be for their children and grandchildren. (Female, Group 6)

Concerns about genetics – personal and societal

While participants' attitude towards genetics research and applications for improving health were very positive, they also voiced several areas of concern at both the personal and societal levels. At the personal level, participants questioned the psychological impact of genetic risk information and the effect it could have on critical life decisions. For example:

> I was thinking if you were aware of this in the family, a genetic illness, and you find out you are going to contract the disease, but there's no hope or cure, that must be a horrible thing. Sometimes knowledge is not good. (Male, Group 6)

> What is the state of mind when someone finds out they are predisposed to an illness I wonder? How do they deal with that? (Female, Group 5)

> It might cause some people not to have children of their own. Having seen their loved ones die, they choose not to have their own children. (Female, Group 1)

In the open public session, a mother shared her concerns with testing for her daughter:

> I have an inherited condition. I've been tested, but I won't let her get tested. I won't let her life be ruined because it won't hit until she's 30 or so. There's no way I would let her do that. (Female, Group 7)

Beyond these personal concerns, participants also raised broader societal concerns that tended to focus on the uses of, and access to, genetic information. Some were concerned about promoting a climate of social discrimination:

> Sometimes I wonder about it from an ethical point of view – eg, manipulation to have people with some desired characteristics. (Male, survey response, Group 2)

> The disability community is very concerned about genetic testing. If a disease is identified, women may want to have abortions, so almost like discriminating against the fetus. (Female, Group 1)

Other concerns revolved around access to genetic information. An exchange from one of the women's groups is revealing:

> What about if you have genetic information in a database, can the police or law enforcement access this information? What is to stop other organizations from accessing the information? (Female, Group 1)

> Who owns this information? The medical community? The people who gave it? Or society at large? (Female, Group 1)

> Can we see down the road what the implications of this information will be? How do we know who will want access? (Female, Group 1)

In the men's church group, there was recognition that compilations of genetic information (eg, biobanks) had great potential, but acknowledgment that access could be an issue:

> Is there a simple registry or database where all this is compiled so that other researchers can have access? That really accelerates the discovery process, and if that wasn't made public, that would kill this area of research. (Male, Group 2)

> But insurance companies would be all over this. They would love to find people at risk for these conditions so they don't have to insure them. (Male, Group 2)

> Concerned that genetic testing may be used to stop persons from acquiring life, critical illness and health insurance if information was made available to requestors. (Female, survey response, Group 3)

DISCUSSION

Growing genomic advances offer the potential for personalized medicine and subsequent health improvement. We undertook a consultation process to better understand what the public currently know about genetics research and what their concerns are in this area. Consultations also provided a knowledge translation opportunity to inform the public about research programs in our jurisdiction. Such transparency is important in order to foster public participation and trust in genetics research, as well as to provide information for health-care professionals who are faced with increasing numbers of patients seeking knowledge about their genetic health risks.[17]

The majority of session participants (>95%) endorsed the potential for genetics research to improve health and potentially offer health-care savings by allowing early prevention of disease. This optimism is consistent with the generally positive attitude related to the application of genetic advances to health reported by others.[5,15,18,19] While participants quickly saw the potential, they also identified challenges with the place of genetics in primary care. While championing the importance of genetics for health, some questioned the broader social perception of the relevance of genetics when compared with competing priorities in primary care (eg, wait lists, doctor shortages).

Others remarked on the lack of discussion about genetics with their primary care providers (PCPs). Notably, there was little discussion about their family history of disease and little followup as to what that history might mean in practical terms (eg, preventive health behaviors, disease risk assessment, and so on). These findings suggest that there may be a disconnect between what the public expects of their PCPs and what they find in practice. Indeed, research confirms the public expects their PCPs to know something about genetics,[20,21]

but that PCPs are ill-equipped to help them due to lack of education, confidence and other factors.[20,22,23] As the first point of contact in the Canadian health-care system, primary care has a central role for individuals with questions about their genetic risk. Information about genetic tests is increasingly available to patients via the internet, popular media and direct-to-consumer marketing, and patients are likely to turn to their PCPs for advice in making informed decisions about genetics.

Primary care will have an essential role in integrating genomic medicine into chronic disease management, providing the care that families require and playing a gatekeeper role, offering genetic and genomic tests and referrals when appropriate and limiting them when inappropriate or of little benefit. Educating PCPs on how to identify and manage families affected by genetic illness is essential, not only to use limited health-care system resources wisely, but also to promote positive health outcomes. This is an important area for future research, along with evaluation research that measures patient and family outcomes following such educational interventions.

Findings from the community sessions revealed several areas of public concern, including the potential misuse of genetic research to promote social discrimination, particularly in the prenatal period, the storage and protection of genetic information, as well as the issue of access to this information by third parties (eg, insurers, police). These findings are in line with the growing literature on public attitudes towards genetics and biobank research[6–8] and point to areas of concern that must be addressed in order to foster public trust and participation in research. While no consensus currently exists regarding how best to protect participants' privacy, how to ensure fair and equitable access to genetic information to foster continued research, and a number of other ethical, legal and social issues related to genetic and biobank research, we and others[8] suggest public engagement be at least one factor to be considered in resolving these problems. Such concerns 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 ($>90\%$) explicitly commented on the value of public input to identify areas of concern in the local area and to promote feelings of inclusion in the research process. It has been suggested that if the potential health benefits arising from genomic science and technologies are to be realized, 'it is crucial that they are incorporated in ways that promote acceptance – something that will only be achieved if the various groups feel they have been fully informed throughout, facilitated in contributing their own expertise and viewpoints, and engaged in the process of determining policy.'[24,p.12] Our findings also point to the need to consider the local context when determining the type and format of public engagement processes, a caution raised by others.[25] In our jurisdiction, pilot work had revealed low levels of knowledge about genetics, but a high level of interest and engagement with the issues once raised. Thus, we designed our consultations as hybrid information-consultation sessions, allowing the opportunity for knowledge provision, but also an assessment of the public's attitudes and perceptions on key issues. This initial public engagement exercise provided valuable insights into areas of public concern and a unique opportunity for members of the public to interact with and ask questions of local researchers. We recognize, however, that future public engagement efforts may require different approaches, depending on the research goals and stakeholders involved.

Groups and institutions worldwide continue to endorse the value of community engagement in health research and policy initiatives,[26] a position also endorsed by our research team. A growing literature reveals a wide variety of community engagement methods and practices from which to choose,[25–29] although no gold standard exists as approaches are dependent on goals, research questions and local decision-making contexts.[25] Thus, community engagement methods will need to be diverse, taking into account both the research goals and the unique characteristics of the local community to be engaged. 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.[26–29] All have their challenges, and the literature reveals valuable lessons learned from these experiences.[26] In particular, it is apparent that community engagement requires an ongoing commitment of time and resources, and that a one-size-fits-all approach will not succeed. Researchers will need to spend some time determining the goals and intended outcomes of their community engagement approaches to reap the benefits of public participation, namely an improvement in both the quality and impact of their research. Engagement with the public may not be easy for researchers,[25] but can ultimately improve communication with participants and foster truly inclusive discussions so the potential health benefits of genomics research can be realized.

Study limitations

Participants in the community consultations were self-selected and members of particular social, community service and church groups. We cannot know if such group members possess certain characteristics (eg, altruistic attitudes, sense of community belonging, particular beliefs about spirituality or religion, and so on) that may affect their views of genetic research and testing. Further, a third of participants reported having a genetic condition in their families. This may in part account for the largely positive attitude of participants towards genetics, given the relevance for their own lives and the lives of family members. Participants were recruited from only one province, although we did attempt to reach different areas of the province. Further, our sample was highly educated and older, with only 14 participants below the age of 40. In contrast, roughly 30% of Newfoundland residents were between the age of 20 and 44 in 2011 (www.stats.gov.nl.ca). The education level of this sample was also quite high. According to 2006 Census data, however, only 11% of Newfoundland residents reported a Bachelor's degree or higher, and about 34% did not have a high school diploma (http://nl.communityaccounts.ca/). For all of these reasons, we cannot generalize the perceptions of our community session participants to other communities. However, we note that our findings are similar to other studies with varied public populations and also to those with high risk families. Our sessions were often held during groups' regular meeting periods, thus limiting the time for discussion. While data saturation was reached with the data collected, we do not know if different ideas/themes would have arisen if more time was available for discussion. Finally, we note that the very nature of our recruiting methods necessarily determined who attended the sessions. Excepting one public session, only members of community groups to whom we sent study invitations could have attended. We do not know which members of the general public would have turned out for the sessions and whether they would differ in ways from the current session participants that might affect the results. We note, however, that our results 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 expresses fairly high levels of support for the potential health applications of genomics research and technologies. Many (>90%) participants reported interest in attending regular information-consultation sessions and suggested that such regularity might increase awareness and interest in genetics research. With the proliferation of biobanks and the rapid pace of discovery in genomics research, public support will be crucial to realize health improvements.

The results of this project will assist our project team with both knowledge transfer and future research activities. For example, summaries of the community consultations are being prepared and will be distributed to community group leaders, with an invitation to distribute findings to their other branches across the province. We have retained a list of the groups who expressly asked that we contact them again should we plan follow-up sessions. Memorial University has recently created an Office of Public Engagement, and two members of our team (HE, PP) have been interviewed about these community consultations for a web article to be released in early 2013. Further, the team is actively discussing how to begin an annual community consultation process (eg, identifying funding opportunities, key community contacts, and so on). In all of our research applications, we now include a request for funding for knowledge translation that will allow us to engage with the public either to assess their opinion on the relevant topic or to allow us to distribute findings via personal visits at the end of the project.

If researchers can engage the public in regular, transparent dialog, 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. Ultimately, community engagement is an important step in ensuring genetic and genomic research is carried out in an ethical, context-appropriate manner.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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