

Exploring the Genetic and Genomics Knowledge, Attitudes and Training Needs of Canadian Public Health Nurses and Epidemiologists

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Executive Summary

Healthcare systems around the world are actively working to incorporate products of the current “genomic revolution” that benefit patients and populations. This includes innovations in gene editing, gene/genomic testing and therapies, and genetic epidemiology. While public health systems are also bracing for change due to genomics, the path forward for genomics in public health is less clear. Over the past decade, countries such as the US and UK have begun integrating genomics in public health service delivery. Conversely, Canadian public health systems are still exploring how best to proceed.

This project aimed to investigate an important aspect of this of this issue: the readiness of Canadian public health practitioners to integrate genomics in their work. This was done by administering an online cross-sectional survey with Canadian public health nurses and epidemiologists. The survey was adapted from a study conducted by Marzuillo and colleagues (2014) with an Italian public health workforce sample. All Canadian public health nurses and epidemiologists were invited to participate. Unfortunately, only 18 practitioners responded to the survey (n=14 nurses and n=4 epidemiologists).

Results from this small sample found:

- Inadequate knowledge levels about predictive and susceptibility genetics testing
- Positive attitudes toward genomics
- Perceptions that genomics is potentially important to public health practice
- A desire for more training about genetic testing in public health degree programs and in the professional development of public health practitioners

Results of this exploratory study require validation with further research before they inform policy. Future research in this area should have a higher response rate, and should explore how specific approaches could be integrated in Canadian public health practice. The low response rate also suggests that this topic may be better investigated via other methods, or a survey with enhanced promotion and participant recruitment strategies.

It is recommended that more research be conducted on this topic to guide evidence-based integration of genomics into public health practice.

Table of Contents

Executive Summary	i
Table of Contents	ii
List of Tables	iii
Glossary	iv
1. Introduction.....	1
2. Background.....	3
3. Literature Review.....	5
3.1 Readiness and implementation	5
3.2 Knowledge and attitudes toward genomics	6
4. Methods.....	10
4.1 Ethics review.....	10
4.2 Survey design	10
4.3 Sample selection.....	10
4.4 Pre-testing.....	10
4.5 Survey participation	11
4.6 Consent procedures	11
4.7 Data Analysis	11
5 Limitations	12
6 Results.....	13
6.1 Demographics	13
6.2 Knowledge & Attitudes	14
6.3 Training needs.....	15
6.4 Additional Feedback	16
7 Discussion	17
7.1 Comparison to Italian study results.....	17
7.2 Future research.....	18
8 Conclusion & Recommendation	19
9 References.....	20
Appendix 1: Certificate of Ethics Approval	24
Appendix 2: Marzuillo et al. (2014) Survey	25
Appendix 3: Invitation to Participate (Version 1 of Adapted Survey)	29
Appendix 4: Letter of Information & Consent (Version 1 of Adapted Survey).....	30
Appendix 5: Final Version of Adapted Survey.....	32
Appendix 6: Invitation to Participate (Final Version of Adapted Survey)	35
Appendix 7: Letter of Information & Consent (Final Version of Adapted Survey).....	36

List of Tables

Table 1. Participant demographics.....	13
Table 2. Summary of knowledge and attitude responses.....	14
Table 3. Responses to knowledge questions.....	14
Table 4. Responses to attitude questions	15
Table 5. Responses to training needs questions.....	16
Table 6. Comparison of knowledge level and training need	17

Glossary

Clinical utility refers to the effects a genetic test has on diagnostic or therapeutic management, implications for prognosis, health and psychological benefits to patients, their relatives, populations and the economic impact on a health system (Genetics Home Reference, 2017, para. 1).

Clinical validity refers to the accuracy with which a genetic test can predict the presence or absence of physical characteristics or clinical disease (Genetics Home Reference, 2017, para. 1).

Epigenomics is a related field that examines how chemical compounds interact with the human genome (National Human Genome Research Institute, 2016, para. 1).

Genetic susceptibility testing identifies healthy individuals who may have inherited a genetic predisposition that puts them at increased risk of developing a multifactorial disease, such as heart disease, Alzheimer's disease or cancer, but who, even so, may never develop the disease in question (World Health Organization, 1998, p. 6).

Genome refers to an organism's complete set of DNA, including all of its genes (Genetics Home Reference, 2017a, para. 1).

Genomics is a field of study that examines the genetic material of different organisms. Genomics in health sciences examines human genetics to understand how human genes function, as well as how genes interact with each other, the environment and different interventions (National Human Genome Research Institute, 2015, para. 14).

Genotype refers to the genetic make-up of an organism (Scitable, 2014, para. 1).

Predictive genetic testing is the use of a genetic test in a person showing no symptoms to predict future risk of disease (Evans, Skrzynia & Burke, 2001, p. 1052).

P/S genetic testing is an abbreviation for "predictive or susceptibility genetic testing" (used in this paper).

Public health genomics describes a range of practices that use genome-based knowledge and technologies to benefit population health (Rosenkötter, Vondeling, Blancquaert, Mekel, Kristensen & Brand, 2011, p. 44).

Exploring the Genetic and Genomics Knowledge, Attitudes and Training Needs of Canadian Public Health Nurses and Epidemiologists

1. Introduction

Policymakers, clinicians and academics are currently exploring and debating how novel genomic technologies can be used by public health agencies to improve population health (Boccia & Zimmern, 2015, p. 251-253). This is particularly true for genetic susceptibility testing and predictive genetic testing interventions (Marzuillo et al., 2014, p. 2). In Canada, public health leaders have shown growing interest in genomics, but the optimal role for these interventions remains unclear. It is also unclear if the Canadian public health workforce has adequate knowledge, training and attitudes to support the successful adoption and implementation of genomic interventions.

Genomics is already integrated into some aspects of Canadian public health practice. Little and colleagues (2009) reported most provinces offer prenatal screening, congenital anomalies surveillance and newborn screening (p. 115). There is also national interest in genomics, as evidenced by the Genome Canada centres (2015) and the Public Health Agency of Canada's 2015/16 priority of developing a "genomics roadmap that will support the implementation of genomic technology" to address infectious and food-borne diseases (Ambrose, 2015, p. 9).

Unfortunately, understanding is limited about Canadian public health practitioner views on genomics (Godard & Lévesque, 2012, p. 138). Specifically, little is known about their knowledge and attitudes toward genomics, and their genomics training needs. The aim of this project was to address this knowledge gap by adapting and administering a survey that examined these constructs with an Italian public health workforce sample (Marzuillo et al., 2014). Understanding the knowledge, attitudes and training needs of public health practitioners regarding genetics and genomics is important because these factors influence implementation success (Damschroder, Aron, Keith, Kirsh, Alexander & Lowery, 2009, p. 54). Evidence shows that resources are wasted and Canadians do not optimally benefit when implementation facilitators and barriers, such as practitioner knowledge and attitudes, are ignored (MacDonald, Pauly, Wong, Schick-Makaroff, van Roode, Strosher et al., 2016, p. 2).

All Canadian public health nurses and epidemiologists were invited to participate in this project. Survey results aim to support the evidence-based integration of genomics into Canadian public health practice. Ethical review was required and received for this project (see Appendix 1).

The client in this project was Dr. Laura Arbour, a specialist physician, professor and researcher in the Department of Medical Genetics at the University of British Columbia as well as an Affiliate Professor in the Division of Medical Sciences at the University of Victoria. Her clinical practice and research focuses on northern and Indigenous health issues as they pertain to genetics. Dr. Arbour trained as both pediatrician and clinical geneticist. As a clinician investigator, she integrates maternal-child health issues and the understanding of the genetic component to Aboriginal health of all ages (University of Victoria, 2017, para. 1). The student

approached Dr. Arbour to act as the client for this project given her expertise and experience in this area.

2. Background

From 1990 to 2003, the Human Genome Project mapped all the genes of the human genome. Throughout the Project, and since its completion, understanding of the important role of genetics in human health has increased exponentially, and hundreds of new genetic tests and therapies have been introduced (Burton, Jackson & Abubakar, 2014, p. 44; Boccia & Zimmern, 2015, p. 249). More recently, this includes the widespread use of gene editing tools in research and genetic epidemiological modelling (Seyerle & Avery, 2012, p. 507; Petherick, 2015, p. S1). The intense interest in this area is due the fact that the presence of specific genes in an individual's genetic code (a.k.a., genome) influences their risk of developing or contracting certain serious diseases. It also influences the impact of these diseases and the effectiveness of treatment options (such as medication or lifestyle modification) (Boccia & Zimmern, 2015, p. 251-252). For example, at least three Canadian First Nations communities have significantly higher rates of *Congenital Long QT Syndrome*, a genetic predisposition to arrhythmia and sudden cardiac death (Arbour, Asuri, Whittome, Polanco & Hegele, 2015, p. 1094).

Some claim developments in genomics have the potential to transform public health and healthcare service delivery through (a) early diagnosis and intervention, (b) targeted prevention programs, and (c) more precision in disease treatment (Zimmern, 2011, p. 478; Burton, Jackson & Abubakar, 2014, p. 39-40; Boccia & Zimmern, 2015, p. 251). Others suggest genomic testing and data analysis can improve infectious disease control and outbreak responses (Tang & Gardy, 2014, p. 2). However, genomics has received a mixed response from many public health leaders, and the integration of genomics into public health practice has varied internationally (Zimmern, 2011, p. 477). Khoury and Galea (2016) report there are “clear tensions at the intersection of genomics and public health” (p. E2). Part of this tension is that genomics represents a departure from ‘traditional’ public health practices that aim to prevent illness and injury with entire populations (e.g., flu immunization campaigns, restaurant inspections) (Boccia & Zimmern, 2015, p. 250). While some public health interventions focus on target groups within populations, target groups are often determined by socioeconomic or ethno-cultural factors, not genetics (e.g., nurse home visits for low-income single mothers). An additional source of tension for those in public health (and healthcare) is that enthusiasm for genomics in some areas appears to have outpaced the evidence (Khoury & Galea, 2016, p. E2). For example, Caulfield reports that “scant evidence” has not hindered the “unbridled enthusiasm” regarding the potential of genetic and genomic interventions to prevent obesity (2015, p. 321).

While the exact impact of genomics on public health remains unclear, most leaders and scholars agree that enhancing public health practitioner understanding of genomics is worthwhile and should be a priority given the rapid development of genomics and its potential impacts (Zimmern & Khoury, 2012, p. 121). Some even claim that “public health will simply not be able to contribute optimally to improving health in the twenty-first century unless it factors genomic science into its practice” (Sampson, 2011, p. 485).

The US and UK have arguably taken the most strategic approaches to integrate genomic testing into public health practice at the federal, regional and local levels (Hall, Finnegan & Alberg, 2014, p. 30-42; Green, Dotson, Bowen, Kolor & Khoury, 2015, p. 831-833; Yu, Gwinn, Dotson, Green, Clyne, Wulf et al., 2016, p. 2). For example, in the US, the Michigan Public Health

Genomics Program (MPHGP) has collaborated with the Centres for Disease Control (CDC) to successfully integrate genetic testing into regional and national public health practices (Genetic Alliance, 2014, n.p.). The MPHGP and CDC model includes:

- Centralized review and approval of new genomic tests and interventions
- Genomics education of the public health workforce
- Genomic testing teams in regional and local public health agencies
- Increased resources to public health observatories and laboratories
- Ongoing evaluation and research

3. Literature Review

A review of relevant literature was conducted on two questions:

1. Does public health professional readiness influence intervention implementation?
2. What are current knowledge and attitudes of public health professionals toward genomics?

Google Scholar & PubMed databases were reviewed using the following search terms in various combinations: “public health,” “genomics,” “genetic,” “genetics,” “gene,” “personalized medicine,” “precision medicine,” “knowledge,” “attitudes,” “implementation,” and “readiness.” Only article titles were searched. Only English-language articles were reviewed.

3.1 Readiness and implementation

There is consensus in the literature that a public health workforce with high-levels of readiness helps facilitate intervention implementation (e.g., Glanz & Bishop, 2010, p. 404; Brownson Jacobs, Tabak, Hoehner & Stamatakis, 2013, p. e2; MacDonald, Pauly, Wong, Schick-Makaroff, van Roode, Strosher et al., 2016, p. 2). This includes recent evidence from BC (Tomm-Bonde, Schreiber, Allan, MacDonald, Pauly & Hancock, 2013, p. 4). Tomm-Bonde and colleagues interviewed and held focus groups with 56 BC public health leaders about implementation of the provincial public health core functions framework (p. 2). The most common theme identified was summarized as “you’ve told me what, now tell me how” denoting the importance of workforce readiness to facilitate successful implementation (p. 4). Specifically, participants reported that lack of knowledge and poor attitudes among public health professionals toward the intervention were barriers to implementation.

Evidence from other jurisdictions aligns with these findings. This is true to the extent that an online guidebook for US public health professionals reports that successful implementation requires understanding the knowledge, attitudes, beliefs, motivations and behaviors of target audiences and stakeholders (University of Colorado, 2017, Steps 3.2-3.4). The authors report that these factors should be addressed prior to implementation if they suboptimal, such as inadequate knowledge.

More broadly, this evidence is part of the literature on implementation science and it aligns with the field’s most prominent meta-theoretical framework: The Consolidated Framework for Implementation Research (CFIR) (Damschroder, Aron, Keith, Kirsh, Alexander & Lowery, 2009). The CFIR is comprised of 39 domains that have been found to most influence implementation of complex health interventions. CFIR domains are organized into five overarching constructs: Intervention characteristics (8 domains), outer setting (4 domains), inner setting (14 domains), characteristics of individuals (5 domains), and process (8 domains). The following domains are examples of the CFIR’s direct relevant to this evidence reported above:

- Access to knowledge & information: Do those involved have ease of access to digestible information and knowledge about the intervention and how to incorporate it into work tasks?
- Knowledge & beliefs about the intervention: What is individuals’ attitudes toward and value placed on the intervention, as well as their familiarity with facts, truths, and principles related to the intervention?

Canadian public health scholar report that the CFIR is the “the most comprehensive theoretical framework” in the field, and that is widely-used and applicable to public health interventions and settings (MacDonald, Pauly, Wong, Schick-Makaroff, van Roode, Strosher et al., 2016, p. 5).

Similarly, there is also consensus in the literature that ensuring public health professionals have adequate genomics knowledge and positive attitudes toward genomics is important, because these facilitate implementation adoption (Chen, Kwok & Goodson, 2008, p. 1654; Talwar, Tseng, Foster, Xu & Chen, 2016, p. 729). However, the majority of literature supporting this position is reported in commentaries. For example, Beskow and colleagues reported that “present and future health professionals must develop the knowledge base, skills and attitudes needed to effectively integrate advances in genomics into their work” (2001, p. 8). Similar claims are made in the ‘education and training’ sections of public health genetics and genomics textbooks (e.g., Stewart, Brice, Burton, Pharoah, Sanderson & Zimmern, 2007, p. 278). While evidence to support these claims appears to be primarily from the many studies involving healthcare practitioners, there are five studies with public health samples that also support these claims (reported in Section below).

Collectively, this evidence provides strong indication that public health professional readiness is important for intervention implementation success.

3.2 Knowledge and attitudes toward genomics

Evidence on public health professionals’ attitudes and knowledge of genomics comes primarily from two sources: three studies conducted by Chen and colleagues with US public health educators, and two studies conducted by Marzuillo and colleagues with European public health professionals.

Chen and colleagues published six papers on three studies that examined the public health genomics knowledge and attitudes of US public health educators. The first study was mixed-methods, involving an online survey (n=1607) and semi-structured interviews (n=24) (Chen & Goodson, 2007; Chen, Kwok & Goodson, 2008; Chen & Goodson, 2009; Chen & Goodson, 2013). Participants were asked a variety of questions about their genomics awareness, attitudes and training needs. They were also asked about barriers to integrating genomics interventions into their practice. Key findings from this research:

- Participants had unfavorable attitudes toward genomics and limited genomic knowledge (Chen & Goodson, 2007, p. 501).
- Participant awareness and attitudes toward genomics significantly affected their likelihood to incorporate genomic competencies into their professional development and practice (Chen, Kwok & Goodson, 2008, p.1654).
- Participants with more genomics training have more positive attitudes toward genomics and were more knowledgeable (Chen & Goodson, 2007, p. 501).
- Participants reported the following as key barriers to integrating genomics into their work: (a) Limited ‘basic and applied’ genomic knowledge, (b) public unawareness of the importance of genomics, (c) limited institutional support for genomics as a priority, (d) limited time and resources, and (e) incompatibility between genomics and their religious and ethical beliefs (Chen & Goodson, 2009, p. 107).

- Participants identified four key training topics: (a) applied genetics/genomics, (b) basic genetics/genomics, and (c) current and future developments in genetics/genomics, and (d) genetic testing and screening (Chen & Goodson, 2013, p. 49).

The second relevant study conducted by Chen and colleagues examined the effectiveness of an online genomics training intervention with public health educators in Texas, US (Chen et al., 2013). The intervention had three training modules and participants were surveyed 3-month post training completion to assess knowledge retention. All training modules were completed by n=137 participants, and at least one module was completed by n=207 participants. They found that participants significantly improved their attitudes and knowledge regarding genomics immediately after the training and that this effect lasted for at least 3-months.

The third relevant study conducted by Chen and colleagues was an online genomics education needs assessment with US public health educators (n=980) (Chen & Kim, 2014, p. 592). Expanding on the four key training topics identified in the 2013 paper, they identified three 'preferred' training topics: (a) knowledge of genomic disorders/diseases (reported by 68% of respondents), (b) how to conduct a family health history and genetic risk assessments (56%), and (c) how to link genomics to health promotion practices (51%) (Chen & Kim, 2014, p. 595).

Marzuillo and colleagues have published two papers on two studies that examined public health genomics knowledge and attitudes with European public health practitioners (Marzuillo, Vito, D'Addario, Santini, D'Andrea, Boccia et al., 2014; Rosso, D'Andrea, Di Marco, Pitini, Unim, De Vito et al., 2017).

In 2014, Marzuillo et al. surveyed 1200 Italian public health practitioners via an anonymous online questionnaire (See Appendix 2). The survey received 797 responses (response rate=67%). Practitioners were asked 34 questions about the following topics:

- Demographic information (9 questions)
- Access to professional development including genomics training (6 questions)
- Genomics knowledge (7 questions)
- Attitude toward genomics (6 questions)
- Genomics training needs (5 questions)

The final questions allowed for open-ended comments. Overall, the authors found participants had "positive" attitudes toward genomics, but self-reported "inadequate" levels of genomics knowledge and limited access to genomics training (p. 3). They found that 80% of respondents felt their knowledge of genomics was inadequate, and 95% of respondents desired more training on genomics (p. 3). The authors concluded there was a high level of attitudinal readiness in the Italian public health workforce for integration of genomics, yet more training was required to support this integration (p. 5).

Marzuillo et al.'s second study was a pilot study using the same survey with a convenience sample of the European Public Health Association (n=34) (Rosso et al., 2017). It was conducted in preparation for a planned survey of the entire Association. Over 60% of survey respondents were physicians. The investigators found respondents had positive attitudes toward genomics and significant training needs. These results aligned with 2014 survey findings.

The results of these five studies support the claims that public health professionals likely do not currently have adequate knowledge about genomics given the novelty and rapid development of this field.

While there have been no studies with Canadian public health practitioners about genomics knowledge and attitudes, six major studies have been conducted on the topic with Canadian healthcare providers (Carroll, Brown, Blaine, Glendon, Pugh & Medved, 2003; Carroll, Cappelli, Miller, Wilson, Grunfeld, Peeters et al., 2008; Winquist Ogle & Muhajarine, 2008; Weir, Morin, Ries & Castle, 2010; Bonter, Desjardins, Currier, Pun & Ashbury, 2011; De Denus, Letarte, Hurlimann, Lambert, Lavoie & Robb, 2013).

In 2003, Carroll and colleagues held focus groups with 40 family physicians in Ontario to explore their experience with testing for genetic susceptibility to cancer. The participants reported that their role was expanding in this area due to increasing public awareness. They reported a need for increased knowledge to appropriately educate patients, assess risk, order tests, and manage treatment (p. 47).

In 2008, Carroll and colleagues conducted a cross-sectional survey with Ontario physicians (family, gynecologists, oncologists, gastroenterologists, general surgeons) regarding their experience with genetic services for hereditary breast/ovarian and colorectal cancers (n=1,427). The investigators found that increased knowledge of cancer genetics services led to increased use of these services. Participants also reported need for more education about hereditary cancers and susceptibility testing (p. 48).

Also in 2008, Winquist and colleagues explored attitudes toward maternal serum screening with Saskatchewan family physicians and obstetricians (n=191). Over 50% of respondents reported a desire for more training in maternal serum screening counselling. Approximately 30% reported they did not have enough knowledge to explain test results or test implications to patients (p. 564).

In 2010, Weir and colleagues held focus groups with 25 healthcare professionals from Toronto and Vancouver (n=9 naturopaths, n=6 pharmacists, n=5 physicians, n=4 dietitians, and n=1 nutritionist). They found the participants had limited knowledge about nutritional genomics, and that they held contradictory attitudes towards genomics:

The reaction of respondents towards genetics and genomics indicated a paradox of being sceptical, yet believing its incorporation into health care is inevitable. With respect to nutritional genomics, health care professionals indicated doubts as to whether it was 'sound science', a clear deterrent to offering nutritional genomic-based recommendations to patients (p. 1116).

In 2011, Bonter and colleagues, surveyed Canadian oncologists, cardiologists and family physicians about their experience with genetics and genomics (n=363). They found that the physician participants recognised the benefits of genetic testing; however, they "lacked the education, information and support needed to practice effectively in this area" (p. 1).

In 2013, De Denus and colleagues surveyed pharmacists from Québec about their attitudes toward pharmacogenomics (n=284). Participants reported positive attitudes. However, while >95% reported a willingness to recommend pharmacogenomic testing, only 8% felt knowledgeable enough to advise patients about pharmacogenomic test results. Nearly all respondents (97%) reported an interest in further education and training related to pharmacogenomics.

Collectively, these studies suggest that Canadian healthcare practitioners also have significant interest and need for training about genetic and genomics interventions relevant to their work.

4. Methods

A 25-question online anonymous self-administered cross-sectional survey was conducted with a Canadian public health nursing and epidemiologist sample.

4.1 Ethics review

This project received approval from the University of Victoria Human Research Ethics Board (protocol # 16-423; see Appendix 1).

4.2 Survey design

Marzuillo granted permission to use and adapt their survey in this project (see Marzuillo et al., 2014 for information on the survey's development and validation). For this study, their survey was first reviewed and revised by the Study Team (i.e., the student, client and academic supervisor) to ensure that the questions were relevant to the Canadian context, and accurately assessed the desired constructs. This created version one of the adapted survey. All revisions and their rationale were recorded. Only minor revisions were made and the rationale was most often due to contextual differences. For example, Marzuillo et al. asked their participants whether they had internet access in their workplace. The Study Team removed this question because it can safely be assumed that all public health practitioners in Canada have internet access at work. The Study Team also removed questions about (a) whether a library was present in the participant's workplace, and (b) the amount of time spent weekly on professional development. This was done to shorten the survey and to ensure the final survey questions focused on desired areas of interest: knowledge, attitudes, and training needs.

4.3 Sample selection

The target participant population was public health physicians, nurses and epidemiologists. These professions were chosen by the client because the nature of their work was most related to genomics, when compared to other professions in the public health workforce, such as health promoters, community health workers or health inspectors. The target participant population size (N) was estimated at approximately 2,172 (488 physicians, 874 nurses and 810 epidemiologists). This estimate was based on recent certification reports from the Canadian Medical Association (2016, p. 6) and the Canadian Nursing Association (2017, p. 1), as well as a population-adjusted estimate using membership data from the Association of Public Health Epidemiologists in Ontario (2016, p. 3). The exact size of the Canadian epidemiologist workforce is difficult to determine because the profession is unregulated and membership to epidemiologist associations is optional. Furthermore, unlike nurses and physicians, individuals can work as epidemiologists with training in related fields (e.g., statistics) and no epidemiology training.

4.4 Pre-testing

A convenience sample was then invited to review and pre-test the adapted survey (version one) for face validity, grammar, and feasibility (see Appendices 3 and 4). The inclusion criterion for the convenience sample was ≥ 5 years of experience leading or working in public health in one of the target professions. Four individuals consented to participate (one public health physician, one public health nurse and two public health epidemiologists). The convenience sample only recommended minor changes regarding grammar, survey layout and additional definitions. Their suggested revisions were reviewed by the Study Team. All suggested revisions were accepted

creating version two of the adapted survey. The convenience sample was then sent version two of the survey for final review. Minor further revisions were suggested to enhance survey feasibility. These revisions were also accepted by the Study Team, creating the third and final version of the survey (see Appendix 5).

4.5 Survey participation

National associations representing the target participant populations were contacted with a request for assistance inviting their members: (a) Public Health Physicians of Canada, (b) Community Health Nurses of Canada, and (c) the Canadian Society for Epidemiology and Biostatistics (see Appendix 6). The nursing and epidemiology associations agreed to invite their members to participate. The physician association did not respond to inquiries and therefore did not agree to participate. This adjusted the N to 1,684; however, the associations indicated that not all public health nurses and epidemiologist were members of their associations. The associations indicated that approximately 1,230 individuals would be invited. The public health nursing and epidemiology associations were sent messaging to invite their members, including the survey hyperlink. Participants were invited via email from their association.

The inclusion criteria for survey participants was ≥ 1 year of experience providing or leading public health service delivery in Canada at the local, provincial, federal or international level. Retired practitioners could also participate. The target sample was practitioners and leaders who were part of the ‘governmental public health enterprise’ performing one ‘essential public health functions’ (British Columbia Ministry of Health, 2005, p. 12). Those who contribute to population health via a community nonprofit or social housing, for example, were not the target sample. The final survey was hosted online via Fluid Survey©. Due to resource limitations, only an English-language version of the survey was offered. The survey was open for two months and no reminders were sent due to the project’s completion timeline.

4.6 Consent procedures

Individuals who participated in the pre-testing were required to sign consent forms (see Appendices 4). Survey respondents consented to participate via the survey. The survey cover page was the information letter and consent form. Participants had to click “agree” to access the survey (See Appendix 7).

4.7 Data Analysis

The initial plan was to analyze response data using identical methods to Marzuillo et al. This would have entailed descriptive statistical analysis as well as multiple logistic regressions models to identify predictors of (a) knowledge and (b) positive attitudes. Unfortunately, this was impossible due to the low response rate (n=18; response rate: 1.1%). Marzuillo et al. followed the analysis strategy of Hosmer and Lemeshow (1980) which required a sample of >400 (p. 1055). Instead, descriptive statistical analysis was conducted on all response data. Calculations were made using Microsoft Excel © version 14. Results of this study are compared to the Marzuillo study in the Discussion section.

5 Limitations

The low response rate limited the study analysis and the project's ability to draw conclusions and make recommendations. A larger sample would have provided more representative information and would have allowed the analysis to draw more robust conclusions, determine correlations between variables, and to compare differences in the target public health professions.

Chief issues that limited participation in this study were due to (a) language, (b) promotion, (c) reminders and (d) scope. First, resource limitations caused the survey to be English-language only. This likely created a barrier for French-speaking participants and reduced the probability that individuals from Québec, Ontario and Atlantic Canada would participate. Second, the survey was only promoted via one strategy: inclusion in online newsletters from professional associations. This was a limitation because not all members of the target populations are members of these associations, and not all members may read newsletters. Becoming aware of the study relied on potential participants reviewing the contents of the association's newsletter, which was likely inferior to direct contact from the Study Team. Third, lack of reminders likely contributed to the low response rate. Unfortunately, reminders were not feasible given the project's completion timeline and the frequency of the association newsletters. Fourth, the survey's narrow focus on genetic susceptibility testing and predictive genetic testing was an additional limitation and may have discouraged participation. Focus on other aspects of genomics, such as cascade genetic screening, might have yielded different results.

6 Results

6.1 Demographics

Table 1 shows participant demographics. Twenty individuals responded to the survey. However, two were students and did not meet the inclusion criteria resulting in n=18. Three-quarters of participants were nurses (n=14). The rest were epidemiologists (n=4). Based on the target sample size (n=1684), the response rate was 1.1% (or 1.5% using n of 1230). Nurse participants had an average of 10 years of work experience more than the epidemiologists. Nearly all participants worked at the regional / municipal level, also known as ‘local public health.’ While the participants were spread across six provinces, the sample was not representative of the assumed distribution of the Canadian public health workforce, with oversampling in Prince Edward Island and the absence of any participants from British Columbia, Québec, Saskatchewan and New Brunswick being notable issues.

Table 1. Participant demographics

	Nurses	Epidemiologists
Years of experience		
<i>Mean (SD)</i>	14.3 (11.3)	4.5 (2.4)
Work scope		
<i>Regional / Municipal</i>	86%	100%
<i>Provincial / Territorial</i>	14%	0%
Primary work location		
<i>Alberta</i>	14%	0%
<i>Manitoba</i>	7%	0%
<i>Newfoundland & Labrador</i>	7%	0%
<i>Nova Scotia</i>	0%	25%
<i>Ontario</i>	43%	50%
<i>Prince Edward Island</i>	28%	0%
Educated about genetics during university		
<i>Yes</i>	43%	75%
<i>No</i>	57%	25%
Self-rated knowledge level about P/S genetic testing		
<i>Insufficient</i>	93%	100%
<i>Sufficient</i>	7%	0%
Received any information or materials on genetic in past year		
<i>No</i>	86%	100%
<i>Yes¹</i>	14%	0%
Received any advertising materials on P/S genetic testing from a company in past year		
<i>No</i>	79%	100%
<i>Yes²</i>	21%	0%

*SD = Standard Deviation; P/S = Predictive/Susceptibility; 1) Scientific articles; 2) 23andMe

While nine participants reported being educated about genetics during university, all but one participant reported insufficient knowledge about predictive/susceptibility (P/S) genetic testing. Two nursing participants reported receiving information about genetics via scientific journal

articles in the past year, and one nurse reported receiving materials from the US personal genomic testing company 23andMe ©.

6.2 Knowledge & Attitudes

Table 2 reports the average number of correct knowledge responses and positive attitude responses. Three participants (17%) got all knowledge questions correct and four participants (22%) had a positive attitude about genomics on all questions. Only one participant got all the knowledge questions correct and had positive attitude on all questions. While nurses and epidemiologists had similar knowledge levels, the epidemiologists had more positive attitudes, on average.

Table 2. Summary of knowledge and attitude responses

	<u>Nurses</u> <i>Mean (SD)</i>	<u>Epidemiologists</u> <i>Mean (SD)</i>
# of correct knowledge responses*	4.1 (1.7)	4.0 (1.4)
# of positive attitude responses*	4.3 (1.0)	5.3 (1.0)

*On a scale of 0 to 6, 6 = all questions correct/positive

Responses to knowledge questions are reported in Table 3; correct answers are bolded. With one exception, the majority of knowledge questions were answered correctly. Where the correct answer was not provided, a response of “unsure” was most common.

Table 3. Responses to knowledge questions*

	Profession	Agree	Unsure	Disagree
a) P/S genetic tests are able to identify genotypes, which themselves do not cause the disease, but modify the risk of developing disease	Nurse	64%	29%	7%
	Epi	75%	25%	0%
b) Lifestyles, socioeconomic factors and pollution exposure cannot modify or influence the risk of disease due to a genetic predisposition	Nurse	21%	0%	79%
	Epi	0%	0%	100%
c) The clinical validity of a P/S genetic test is related to the power of the test to quantify the risk of developing the disease	Nurse	53%	33%	13%
	Epi	75%	25%	0%
d) The clinical utility of a P/S genetic test is related to the power of the test to improve the health status of the subject	Nurse	64%	21%	14%
	Epi	50%	50%	0%
e) Performing P/S genetic tests should not necessarily be associated with genetic counselling that includes information, informed consent, and discussion of the results	Nurse	7%	7%	86%
	Epi	25%	0%	75%
f) Recommendations/guidelines produced by national/international organizations already exist about the use of some P/S genetic tests	Nurse	53%	47%	0%
	Epi	25%	75%	0%

*Bold responses indicate correct responses; P/S = Predictive/Susceptibility

For example, 75% of epidemiologist participants indicated being unsure about recommendations/guidelines, which aligns with (a) the current state of genomics having limited involvement in their work, and (b) their reported insufficient knowledge level. The question answered correctly most often was about lifestyles, socioeconomic factors and pollution exposure. This is perhaps not surprising given the in-depth knowledge of public health practitioners about the social determinants of health (SDOH) and the interaction between the SDOH and genetics.

Responses to attitude questions are reported in Table 4; answers denoting a positive attitude toward genomics (according to Marzuillo et al. 2014) are bolded. With one exception, the majority of attitude questions were answered positively. Similar to the knowledge questions, when the participants did not report a positive response, they often indicated being “unsure.” The most common negative responses were to the question about the role of economic evaluation. Eight participants (44%) felt that favourable economic evaluation results should not be required prior to introducing a new P/S genetic test. Two questions received unanimously positive responses: the importance of evidence-based guidelines and the need for consideration of ethical, legal and social implications.

Table 4. Responses to attitude questions

	Profession	Agree	Unsure	Disagree
a) P/S genetic tests can increase prevention opportunities for chronic diseases	Nurse	93%	7%	0%
	Epi	100%	0%	0%
b) P/S genetic tests able to identify an increased risk of developing a disease should be introduced into clinical and public health practice even without health interventions with proven efficacy	Nurse	21%	21%	57%
	Epi	0%	25%	75%
c) P/S genetic tests should be introduced into clinical and public health practice only if economic evaluations show the tests are preferred to alternative interventions	Nurse	14%	43%	43%
	Epi	50%	0%	50%
d) Evidence based guidelines are needed for the appropriate use of P/S genetic tests	Nurse	100%	0%	0%
	Epi	100%	0%	0%
e) P/S genetic tests can contribute to effective health promotion and disease prevention only if included in wider strategies taking into account the other available interventions	Nurse	71%	21%	7%
	Epi	100%	0%	0%
f) The implementation of P/S genetic testing in clinical and public health practice should not take into account ethical, legal and social implications	Nurse	0%	0%	100%
	Epi	0%	0%	100%

**Bold responses indicate position attitude responses; P/S = Predictive/Susceptibility*

6.3 Training needs

Table 5 shows participant responses regarding training needs. The majority of participants reported the need for more genomics training for themselves, public health university students,

and for working public health professionals. Nurses reported higher levels of support for training in these areas, particularly regarding the need to improve their own knowledge. This may reflect the study’s focus on P/S genetic testing, which is more closely linked to clinical nursing practice, versus the analytic and planning work done by public health epidemiologists.

Table 5. Responses to training needs questions

	Nurses	Epidemiologists
Important to improve your knowledge about P/S genetic testing in public health practice?		
Yes	93%	50%
No	7%	50%
Public health programs at Canadian universities should have more content on P/S genetic testing		
Yes	93%	75%
No	7%	25%
More professional development required for public health practitioners on P/S genetic testing		
Yes	100%	100%
No	0%	0%

*P/S = Predictive/Susceptibility

6.4 Additional Feedback

Participants were invited to provide any additional comments at the end of the survey. Six participants (33%) reported a comment. Four comments reinforced the need for more information and training on genomics for public health students and professionals. For example:

- *“I think more information should be available if this testing is going to be used in [public health] practice.”*
- *“If this testing is going to become more available and/or prescribed, public health practitioners should be fully informed.”*
- *“Don’t know about this and sounds like an important area for future development.”*

One participant suggested genomics appeared to be more applicable to primary care than to public health.

- *“There is no Canadian or Ontario mandate to force the use of genetic testing in the public health system. It may be more appropriately integrated into the family medicine / primary care stream. Many local (municipal) health units lack the capacity and resources to incorporate genetics into their public health programs and strategies.”*

The other comment was about the ethics of private companies offering genomics testing without accompanying counselling or formal linkages to the publicly-funded healthcare system.

- *[Private DNA testing] “...seems a bit unethical in the absence of genetic counselling. I picture people ordering these tests, getting results that may be questionable, then accessing health services that they might not even need. Not very efficient for a publicly funded health care system, in my opinion.”*

7 Discussion

This project aimed to assess the genomics knowledge, attitudes and training needs of Canadian public health physicians, nurses and epidemiologist. Unfortunately, due to low participation rates, the result was more of an initial exploration into the subject with a small sample of public health nurses and epidemiologists. Furthermore, the small sample limited the ability to draw any significant conclusions about relationships between variables. Nonetheless, this study represents the first investigation into the important topic of the Canadian public health workforce's readiness to incorporate genomic technologies that can improve population health into their practice.

Surveying the public health workforce is a noted challenge (Leider, Shah, Rider, Beck, Castrucci, Harris et al., 2016, p. 1968-1969). This may be particularly true in Canada, since the field of public health human resources is still somewhat in its infancy, often lacking basic elements such as reliable workforce estimates (Regan, MacDonald, Allan, Martin, Peroff-Johnston, 2014, p. 2). Specific to the issue of response rate when surveying public health professionals, Leider et al. (2016) report that studies often face difficulty (a) gaining buy-in from the workforce being surveyed, (b) ensuring survey questions are relevant to respondents, and (c) reducing the respondent burden (p. 1969). They recommend that investigators (a) include practitioners in survey development and implementation, (b) create incentives for participation, (c) obtain endorsement from those who will encourage others to participate, and (d) tailor questionnaire to respondents (p. 1969). This study included practitioners in survey development, but lacked in the other areas Leider et al. recommend. These gaps coupled the limitations reported above likely resulted in the low response rate.

7.1 Comparison to Italian study results

In comparison to this study, the Marzuillo et al., 2014 study sample (n=797) was comprised of 80% physicians and reported less training about genomics during university. They also reported higher knowledge levels about genomics and more need for training, compared to the Canadian sample in this study (see Table 6). That said, the Canadian sample and the Italian sample had comparable responses to the knowledge, attitude and training need questions. Following Marzuillo et al.'s interpretation of these results, both samples appeared to have "inadequate" levels of genomics knowledge, "positive" attitudes toward genomics, and both recognized the need for more genomics training.

Table 6. Comparison of knowledge level and training need

	Italian Sample	Canadian Sample
Inadequate/insufficient self-report genomics knowledge	80%	94%
Desire for more training on genomics	95%	83%

As mentioned above, Marzuillo et al. concluded from their results that there was a high level of readiness in the Italian public health workforce for integration of genomics, yet more training was required to support this integration. In comparison, the results of this small exploratory study appear to draw similar conclusions about the Canadian public health workforce. However, these results should be validated by further research.

7.2 Future research

Future research on this topic should aim to have a higher response rate and align with the recommendations of Leider et al. (2016, p. 1969). It would also be worthwhile to investigate the selected public health professions' readiness to integrate specific genomics interventions into their practice. For example, surveying the readiness of public health epidemiologists to integrate genetic epidemiology techniques into their practice would yield more specific information for decision-makers about the enablers and challenges that would influence the integration of specific approaches into their practice. There is a pressing need for this information as evidenced by two pre-conferences workforce on the subject at the 2017 National Conference of the Canadian Society for Epidemiology and Biostatistics: "Novel methods in genetic epidemiology" and "SAS for genome-wide association and prediction" (p. 6).

8 Conclusion & Recommendation

The results of this study suggest that the Canadian public health workforce may have a similar level of attitudinal readiness for genomics as the Italian public health workforce, based on self-reported levels of knowledge and attitudes toward genomics. The Canadian public health workforce likely also has significant training needs that may be addressed by increasing the amount of genomics training in public health degree programs and in the professional development of public health practitioners. However, these results should be considered exploratory and should not be used to inform policy at present.

Recommendations:

It is recommended that more research be conducted on this topic. Specifically, I recommend that this survey be re-administered using the recommendations of Leider et al. (2016, p. 1969) in attempt to achieve a higher response rate. This work should include:

1. Involving more practitioners in survey development and implementation,
2. Creating incentives for participation,
3. Obtaining endorsement from those who will encourage others to participate, and
4. Tailoring questions to respondent settings and practices.

It may also be worthwhile to conduct a stakeholder analysis prior to survey administration to optimize communication and promotion strategies, perhaps including use of social media. Coordination of survey administration with public health conferences may also promote a higher response rate.

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Appendix 1: Certificate of Ethics Approval

		Office of Research Services Human Research Ethics Board Administrative Services Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada T 250-472-4545 F 250-721-8960 uvic.ca/research ethics@uvic.ca	
<h2>Certificate of Approval</h2>			
PRINCIPAL INVESTIGATOR: James Ross Graham		ETHICS PROTOCOL NUMBER 16-423 <small>Minimal Risk Review - Delegated</small>	
UVic STATUS: Master's Student		ORIGINAL APPROVAL DATE: 19-Dec-16	
UVic DEPARTMENT: PADM		APPROVED ON: 19-Dec-16	
SUPERVISOR: Rebecca Warburton		APPROVAL EXPIRY DATE: 18-Dec-17	
PROJECT TITLE: An Assessment of the Genomics Readiness of Canadian Public Health Physicians, Public Health Nurses and Public Health Epidemiologists			
RESEARCH TEAM MEMBER Ross Graham (PI, UVic), Dr. Laura Arbour (Clien, UVic), Ross Graham (PI, UVic), Dr. Laura Arbour (Client, UVic)			
DECLARED PROJECT FUNDING: None			
CONDITIONS OF APPROVAL			
<p>This Certificate of Approval is valid for the above term provided there is no change in the protocol.</p> <p>Modifications To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.</p> <p>Renewals Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.</p> <p>Project Closures When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.</p>			
<h2>Certification</h2>			
<p>This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.</p>			
 <hr/> Dr. Rachael Scarth Associate Vice-President Research Operations			
Certificate Issued On: 20-Dec-16			

16-423 Graham, James Ross

Appendix 2: Marzuillo et al. (2014) Survey

SURVEY ON KNOWLEDGE, ATTITUDES AND TRAINING NEEDS OF PUBLIC HEALTH PROFESSIONALS ON THE USE OF PREDICTIVE GENETIC TESTS

*Make an X or respond briefly when instructed;
tick one box only, unless otherwise specified.*

A. PERSONAL DETAILS

A1. BIRTH YEAR _____ GENDER M F

B. PROFESSIONAL ACTIVITY

B1. YEAR OF DEGREE _____

B2. TYPE OF DEGREE _____

B3. POSTGRADUATE TRAINING (MULTIPLE ANSWERS ARE ALLOWED):

- a) Postgraduate School Type: _____
- b) Ph. D. Type: _____
- c) Master Type: _____
- d) Advanced postgraduate training courses Type: _____
- e) Other Please, specify: _____

B4. CURRENT SETTING OF PROFESSIONAL ACTIVITY

Please, specify _____

B5. HOW MANY YEARS DO YOU HELD YOUR CURRENT PROFESSIONAL ACTIVITY? _____

B6. IN WHICH CITY DO YOU CONDUCT YOUR PROFESSIONAL ACTIVITY? _____

B7. HAVE PREDICTIVE GENETIC TESTING BEEN TREATED DURING YOUR UNDERGRADUATE TRAINING?

NO YES

B8. HAVE PREDICTIVE GENETIC TESTING BEEN TREATED DURING YOUR POSTGRADUATE TRAINING?

NO YES

C. ACCESS TO CONTINUING MEDICAL EDUCATION

C1. HOW WOULD YOU RATE YOUR LEVEL OF ENGLISH LANGUAGE KNOWLEDGE?

very low low intermediate good excellent

C2. IS THERE AN INTERNET ACCESS AVAILABLE IN YOUR WORKPLACE?

NO YES

C3. IS THERE A SCIENTIFIC LIBRARY AVAILABLE IN YOUR WORKPLACE?

NO YES

C4. HOW MANY HOURS PER WEEK DO YOU SPEND IN CONTINUING MEDICAL EDUCATION?

<1 hour per week 1-5 hours per week 6-10 hours per week >10 hours per week

C5. DURING THE LAST YEAR DID YOU RECEIVED INFORMATION MATERIAL ON PREDICTIVE GENETIC TESTING BY THE FOLLOWING AUTHORITIES?

MINISTRY OF HEALTH	NO <input type="checkbox"/>	YES <input type="checkbox"/>
REGION	NO <input type="checkbox"/>	YES <input type="checkbox"/>
LOCAL HEALTH AUTHORITY	NO <input type="checkbox"/>	YES <input type="checkbox"/>
BOARD OF PHYSICIANS	NO <input type="checkbox"/>	YES <input type="checkbox"/>
SCIENTIFIC ASSOCIATIONS	NO <input type="checkbox"/>	YES <input type="checkbox"/>
OTHER	NO <input type="checkbox"/>	YES <input type="checkbox"/> (Please, specify) _____

C6. DURING THE LAST YEAR DID YOU RECEIVED ADVERTISING MATERIAL ON PREDICTIVE GENETIC TESTING?

NO YES

IF YES, FROM WHICH SOURCES?: _____

D. KNOWLEDGE	Agree	Uncertain	Disagree
<i>D1.</i> Predictive genetic tests are able to identify genotypes which themselves do not cause the disease but modify the risk of developing it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>D2.</i> Lifestyles, socioeconomic factors and pollution exposure cannot modify or influence the risk of disease due to a genetic predisposition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>D3.</i> The analytic validity of a predictive genetic test is related to the accuracy of the laboratory test in identifying a specific genetic characteristic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>D4.</i> The clinical validity of a predictive genetic test is related to the power of the test to quantify the risk of developing the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>D5.</i> The clinical utility of a predictive genetic test is related to the power of the test to improve the health status of the subject	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>D6.</i> Performing predictive genetic tests should not necessarily be associated with genetic counseling that includes information, informed consent, and discussion of the results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>D7.</i> Recommendations/guidelines produced by national/international organizations about the use of some predictive genetic tests already exist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. ATTITUDES	Agree	Uncertain	Disagree
<i>E1.</i> Predictive genetic tests increase prevention opportunities for chronic diseases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>E2.</i> Predictive genetic tests able to identify an increased risk of developing a disease should be introduced in the clinical and public health practice even without health interventions with proven efficacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>E3.</i> Predictive genetic tests should be introduced in the clinical and public health practice only if economic evaluations show cost-effectiveness ratios favorable compared with alternative health interventions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>E4.</i> Authoritative and evidence based guidelines are needed for the appropriate use of predictive genetic tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>E5.</i> Predictive genetic tests can contribute efficaciously to health promotion and disease prevention only if included in wider strategies taking into account the other available health interventions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>E6.</i> The implementation of predictive genetic testing in the clinical and public health practice, being a medical matter, should not take into account ethical, legal and social implications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

F. TRAINING NEEDS

F1. How would you rate your level of knowledge about the use of predictive genetic tests (features, eligibility criteria for testing, benefits, risks and non-medical implications)?

Not sufficient Sufficient Good Excellent

F2. Do you think it is important to improve your knowledge on the use of predictive genetic tests in clinical and public health practice?

NO YES

F3. Do you think that the teaching of the use of predictive genetic tests should be increased within the undergraduate course that you attended?

NO YES

F4. Do you think that the teaching of the use of predictive genetic tests should be increased within the postgraduate School in Hygiene and Preventive Medicine?

NO YES

F5. Do you think that specific postgraduate courses in predictive genetic testing for chronic diseases should be implemented?

NO YES

The questionnaire is finished. However, if you believe that there is something to add, please use the space below

Appendix 3: Invitation to Participate (Version 1 of Adapted Survey)

Dear [name]

You are invited to participate in the pre-testing of a national online survey that will be conducted to assess the knowledge, attitudes and training needs regarding genomics¹ of Canadian public health physicians, nurses and epidemiologists.

You are being asked to participate because of your public health expertise and >5 years of experience. Participation should take 30 minutes, and will involve reviewing a brief survey and providing feedback and suggestions to me via email or telephone. See attached for more information and the consent form.

Please let me know if you would be interested in participating. For more information, please contact me at irgraham@uvic.ca or 1-250-370-8462.

Thank you,

Ross Graham
Graduate Student, Public Administration, University of Victoria

¹Genomics is a field of study that examines the genetic material of different organisms. Genomics in health sciences examines human genetic material to understand how human genes function, and how genes interact with each other, the environment and different interventions. A related field is Epigenomics, which examines how chemical compounds interact with the human genome (NHGRI, 2015).

Appendix 4: Letter of Information & Consent (Version 1 of Adapted Survey)



University of Victoria
PO Box 1700 STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Tel (250) 721 8055 Fax (250) 721 8849
<http://web.uvic.ca/padm/>

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Appendix 4 – Group 1 Consent/Information Letter

Signed Participant Consent Form

You are invited to participate in a study entitled *An Assessment of the Genomics¹ Readiness of Canadian Public Health Physicians, Nurses and Epidemiologists* that is being conducted by Ross Graham, a Graduate Student in the School of Public Administration of the department of Human and Social Development at the University of Victoria.

As a Graduate student, Ross Graham is required to conduct research as part of the requirements for the degree entitled Master's of Public Administration. It is being conducted under the supervision of Dr. Rebecca Warburton. You may contact Dr. Warburton at mwarbur@uvic.ca. You may also contact the director of the School of Public Administration, Dr. Lindsay Tedds, if you have further questions by emailing padirect@uvic.ca.

Purpose and Objectives

This study will assess Canadian public health physicians, nurses and epidemiologists' knowledge, attitudes and training needs regarding genomics using a cross-sectional online survey. The survey is being adapted from a 2014 survey conducted with the Italian public health workforce sample:

Marzuillo et al. (2014). Are public health professionals prepared for public health genomics? A cross-sectional survey in Italy. *BMC Health Services Research*,14(1).

Importance of this Research

This research will provide important information for leaders and policymakers to support planning and public health workforce development regarding genomics.

Participant Selection

You are being asked to participate in this study because of your experience in public health service delivery and/or leadership.

What is Involved

If you consent to voluntarily participate in this research, participation involves

- Reviewing the survey questions
- Recommending any revisions to enhance the survey's intelligibility, grammar, relevance to the public health workforce, and/or feasibility

Risks, Benefits and Inconveniences

There are no major or anticipated risks, benefits or inconveniences to you by participating in this research

¹Genomics is a field of study that examines the genetic material of different organisms. Genomics in health sciences examines human genetic material to understand how human genes function, and how genes interact with each other, the environment and different interventions. A related field is Epigenomics, which examines how chemical compounds interact with the human genome (NHGRI, 2015).

Compensation

There is no compensation for participation in this study.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your feedback will be excluded from the study and securely deleted.

Anonymity & Confidentiality

Your participation is 100% anonymous and you will not be directly quoted in the analysis, publications or presentations. Your confidentiality and the confidentiality of the data will be protected by storing data on password protected computers in locked offices.

Dissemination of Results

It is anticipated that the results of this study will be published in a peer-reviewed journal and presented at a public health conference.

Disposal of Data

Data from this study will be securely archived once the study is complete, and then disposed in accordance with organizational policy.

Signature

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

Name of Participant

Signature

Date

Contacts

Individuals that may be contacted regarding this study include Ross Graham at jrgraham@uvic.ca, and Dr. Rebecca Warburton at rnwarbur@uvic.ca.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix 5: Final Version of Adapted Survey

Participant Information

1. Select your profession:
 - a. Public health nursing
 - b. Public health / community health medicine
 - c. Public health epidemiology
 - d. Other, please specify:
2. How many years of public health experience do you have in this profession?
 - a. WHOLE NUMBER
3. At what geographic scope / level of government do you primarily work?
 - a. Municipal / local / regional
 - b. Provincial / territorial
 - c. Federal
 - d. International

If A or B selected, the following question appears

4. Please select your location:
 - a. Alberta
 - b. British Columbia
 - c. Manitoba
 - d. New Brunswick
 - e. Newfoundland and Labrador
 - f. Northwest Territories
 - g. Nova Scotia
 - h. Nunavut
 - i. Ontario
 - j. Prince Edward Island
 - k. Quebec
 - l. Saskatchewan
 - m. Yukon
5. Were you educated about genetics or predictive/susceptibility genetic testing during your university education?
 - a. Yes
 - b. No

Knowledge Section

Please answer these questions about your knowledge of genetic testing. Click “unsure” for any that you do not know:

	Agree	Unsure	Disagree
6. Predictive/susceptibility genetic tests are able to identify genotypes, which themselves do not cause the disease, but modify the risk of developing disease			
7. Lifestyles, socioeconomic factors and pollution exposure cannot modify or influence the risk of disease due to a genetic predisposition			
8. The clinical validity of a predictive/susceptibility genetic test is related to the power of the test to quantify the risk of developing the disease			
9. The clinical utility of a predictive/susceptibility genetic test is related to the power of the test to improve the health status of the subject			
10. Performing predictive/susceptibility genetic tests should not necessarily be associated with genetic counselling that includes information, informed consent, and discussion of the results			
11. Recommendations/guidelines produced by national/international organizations already exist about the use of some predictive/susceptibility genetic tests			

Attitudes Section

Please answer the follow questions about your attitudes toward genetic testing:

	Agree	Unsure	Disagree
12. Predictive/susceptibility genetic tests can increase prevention opportunities for chronic diseases			
13. Predictive/susceptibility genetic tests able to identify an increased risk of developing a disease should be introduced into clinical and public health practice even without health interventions with proven efficacy			
14. Predictive/susceptibility genetic tests should be introduced into clinical and public health practice only if economic evaluations show the tests are preferred to alternative interventions			
15. Evidence based guidelines are needed for the appropriate use of predictive/susceptibility genetic tests			
16. Predictive/susceptibility genetic tests can contribute to effective health promotion and disease prevention only if included in wider strategies taking into account the other available interventions			
17. The implementation of predictive/susceptibility genetic testing in clinical and public health practice should not take into account ethical, legal and social implications			

Training Needs

18. How would you rate your level of knowledge about the use of predictive/susceptibility genetic tests (e.g., eligibility criteria for testing, benefits, risks, non-medical implications)?
- Insufficient
 - Sufficient
 - Expert
19. Do you think it is important to improve your knowledge on the use of predictive/susceptibility genetic tests in public health practice?
- No
 - Yes
20. During the past year, have you received any **information or training materials** on predictive/susceptibility genetic testing from: (*check all that apply*)
- Ministry of Health
 - Health authority
 - Board of physicians
 - Scientific association
 - Other, please specify:
21. During the past year have you received any advertising materials on predictive/susceptibility genetic testing from a private company?
- Yes
 - No

If YES selected, the following question appears

22. If yes, what was the company?
- TEXT BOX
23. Do you think public health degree programs at Canadian universities should include more content on predictive/susceptibility genetic testing?
- No
 - Yes
24. Do you think more continuing professional development should be available for public health practitioners on predictive/susceptibility genetic testing?
- No
 - Yes
25. Please provide any additional comments:
- TEXT BOX

Thank for participating!

Appendix 6: Invitation to Participate (Final Version of Adapted Survey)

Dear [organizational contact from website]

We are inviting [organization name] [members] to participate in a national survey on the knowledge, attitudes and training needs regarding genomics¹ of Canadian public health physicians, nurses and epidemiologists. Input from [profession] is important to this study.

The anonymous online survey is [#] questions long and takes approximately 10 minutes to complete. We would like to have broad participation; we are hoping to have a survey response of 200 professionals from across Canada.

Would you be able to assist us by distributing this email or survey link to your [members]? This could involve:

- Forwarding this email invitation to your [members OR staff], or
- Adding the survey link to your organization's newsletter, if it will be sent before February 1, or
- Posting the survey link & invitation in the member section of your website (if you have one).

The survey link is: [TBD]

Please follow the survey link for more information. For more information please contact me at irgraham@uvic.ca or 1-250-370-8462.

Thank you,

Ross Graham MSc, School of Public Administration, University of Victoria
Rebecca Warburton PhD, School of Public Administration, University of Victoria
Laura Arbour MD MSc FRCPC FCCMG, Department of Medical Genetics, University of British Columbia & Division of Medical Sciences, University of Victoria



**University
of Victoria**

¹Genomics is a field of study that examines the genetic material of different organisms. Genomics in health sciences examines human genetic material to understand how human genes function, and how genes interact with each other, the environment and different interventions. A related field is Epigenomics, which examines how chemical compounds interact with the human genome (NHGRI, 2015).

Appendix 7: Letter of Information & Consent (Final Version of Adapted Survey)

An Assessment of the Genomics Readiness of Canadian Public Health Physicians, Nurses, and Epidemiologists

Study & Consent Information – Please Read Carefully

You are invited to participate in a study entitled *An Assessment of the Genomics Readiness of Canadian Public Health Physicians, Nurses, and Epidemiologists* that is being conducted by Ross Graham, a Graduate Student in the School of Public Administration of the department of Human and Social Development at the University of Victoria.

As a Graduate student, Ross Graham is required to conduct research as part of the requirements for the degree entitled Master's of Public Administration. It is being conducted under the supervision of Dr. Rebecca Warburton. You may contact Dr. Warburton at rwarbur@uvic. You may also contact the director of the School of Public Administration, Dr. Lindsay Tedds, if you have further questions by emailing padiirect@uvic.ca.

Purpose and Objectives

This anonymous online survey aims to assess Canadian public health physicians, nurses and epidemiologists knowledge, attitudes and training needs regarding genomics¹. Survey questions are adapted from a similar survey conducted with the Italian public health workforce (Marzuillo et al., 2014). This research will provide important information for leaders and policymakers to support planning and public health workforce development regarding genomics.

Participants Selection

All Canadian public health physicians, public health nurses and public health epidemiologists with >1 year of experience in public health service delivery and/or leadership at the local/regional, provincial/territorial or federal levels are invited to participate. Canadian-based practitioners involved in international activities and recently retired public health practitioners can also participate.

What is involved?

The survey is [#] questions long and takes approximately 10 minutes to complete.

Risks, Benefits, Inconveniences

There are no major or anticipated risks, benefits or inconveniences to you by participating in this research.

¹*Genomics is a field of study that examines the genetic material of different organisms. Genomics in health sciences examines human genetic material to understand how human genes function, and how genes interact with each other, the environment and different interventions. A related field is Epigenomics, which examines how chemical compounds interact with the human genome (NHGRI, 2015).*

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may exit the survey at any time without any consequences or any explanation.

Anonymity & Confidentiality

Your participation is 100% anonymous. Your confidentiality and the confidentiality of the data will be protected by storing data on password protected computers in locked offices.

Dissemination of Results

It is anticipated that the results of this study will be published in a peer-reviewed journal and presented at a public health conference.

Disposal of Data

Data from this study will be securely archived once the study is complete, and then disposed in accordance with University of Victoria policy.

Contacts

You are free to ask any questions. Ross Graham is a graduate student at the University of Victoria. You can contact him if you have further questions at jrgraham@uvic.ca or 1-250-370-8462. This research is being conducted under the supervision of Prof. Rebecca Warburton. You may contact her at 1-250-598-5865. You may also contact study team member Dr. Laura Arbour regarding this study at 1-250-853-3262.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (1-250-472-4545 or ethics@uvic.ca).

Statement of Consent

I have read this information and consent form. I have had the opportunity to discuss this research study with Ross Graham. Any questions I had were answered in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that my participation in this study is voluntary. I freely agree to participate in this research study.

I understand that my responses will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the University of Victoria Research Ethics Boards for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Agree to Participate

(The above will be a button on the survey website that must be clicked to access the survey)