Privacy risks of direct-to-consumer genetic testing: How do consumers interpret the privacy risks associated with sharing their genetic material with private companies?

Report to the Office of the Privacy Commissioner of Canada

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Emily Christofides and Kieran O'Doherty

University of Guelph

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Executive Summary

The purpose of this study was to explore the way in which Direct-to-Consumer Genetic Testing (DTCGT) companies communicate privacy risk information to customers and how customers understand their risks. We first conducted an analysis of DTCGT company websites to determine what information they provide to consumers regarding the treatment of their personal information and the risks of DTCGT. We conducted a general analysis of all websites and a more detailed analysis on sites offering health-related tests.

Overall we found that:

- In 2013 there were 86 companies offering DTCGT services to Canadians (77 companies in 2015)
- Companies provided a wide range of health-related tests (29 companies), relationship and paternity (46), ancestry and genealogy (28), prenatal (10), traits and talents (6), and other test types (23)
- Up to half the sites (numbers varied by test sub-type) had no privacy policy posted (health 8/29; relationship 20/46; ancestry 13/28, prenatal 5/10, traits 1/6, other 11/23) and many of those that did addressed only aspects related to using the website.

Regarding presentation of privacy information on the health-related sites we found that:

- Eight of 29 companies had little or no privacy-related information at all on their sites

- Five companies that posted privacy policies had only limited information related to visiting the website
- 10 of 21 sites with privacy policies did not provide any information as to what type of personal information they collect
- 20 sites provided no information about what is done with biological samples and genetic information after testing
- Five sites had some information about the potential privacy consequences of DTCGT
- 13 sites provided customers with the opportunity to opt out of secondary uses of their information.

Our analysis of the company websites and review of the academic literature informed the creation of an online survey that sought feedback from DTCGT consumers and people who had considered purchasing genetic testing. We surveyed 415 Canadians about their experiences with DTCGT (180 people who had made the purchase and 235 who considered it).

In summary:

- Cost was the main reason that people chose not to purchase DTCGT
- Learning more about health and family history were the main reasons for purchasing or considering purchasing a genetic test
- Most participants provided their own genetic sample for testing but 35% had ordered a test of someone else’s sample
- Key risks identified were privacy, legitimacy of the test, legitimacy of the company, and apprehension about the results

- Nearly half of participants reported that they had read the company's privacy policy (47%; 64% of those who purchased and 33% of those who considered DTCGT)
- 44% of participants felt they received enough information about how the company treats their information (73% of those who purchased but only 22% of those who considered DTCGT)
- The most common expectation was that the company would only share the results with them and would destroy their sample after testing
- A small percentage (13%) of participants reported having a negative experience as a result of genetic testing.

Introduction

There has been considerable focus on the issue of private data online and recent advances to genetic testing mean that genetic-based ancestry and health risks can now be added to the wealth of online data that needs safeguarding. While much of the research on Direct-to-Consumer Genetic Testing (DTCGT) focuses on the health risks and healthcare burden of such practices, little research has examined the privacy risks associated with entrusting private companies with one’s genetic material. Discussions have only just begun to turn to the additional privacy concerns that arise from private companies having access to, storing, and conducting research with biological samples and genetic information provided by their customers. In order to fill this important gap in the literature regarding knowledge of the privacy risks of engaging with private companies for genetic testing, we first summarize the academic literature, and then report on our study of the way in which DTCGT companies communicate privacy risk information on their websites, conducted in the spring and summer of 2013. We then report on our online survey, conducted in fall 2014 and winter 2015, of what customers understand of the privacy risks and how they perceive DTCGT. Finally, we recommend best practices for DTCGT companies in presenting privacy information to consumers, some considerations for regulation of DTCGT companies, and a guide to consumers in considering the purchase of a DTC genetic test.

Review of the Literature

With scientific advances in health care and technological changes that make accessing health information easier, people are increasingly sidestepping the usual ways of learning about their own health and are taking more ownership over their health-related decisions (Middleton, 2012). One way individuals have gained access to health related information without the aid of a physician is through direct-to-consumer genetic testing (DTCGT). This practice enables people to order genetic tests directly from a company, without involving a medical professional in the process (McGowan et al., 2010). Different DTCGT companies claim to assess anything from the metabolization of specific drugs to the risk of contracting a certain disease, and they vary greatly in quality, utility, and the general testing process. Common tests include paternity tests, tests that determine ancestral background, prenatal genetic testing for diseases such as cystic fibrosis, and a range of tests that determine predisposition for a certain disease (e.g. diabetes), likelihood of developing Parkinson's, and assessment of passing on a certain condition to one's children. While much of the research on DTCGT focuses on the health risks and healthcare burden of such practices, little research has examined the privacy risks associated with entrusting commercial companies with one's genetic material.

Although there is general agreement that there is a strong need for direct-to-consumer genetic testing to be regulated, there is a great deal of disagreement on how this should be done (McGuire et al., 2010). This lack of agreement has resulted in a lack of policy action, despite concerns about a need for stronger oversight of these services (Hogarth, Javitt, & Melzer, 2008). In addition, DTCGT falls under several different overlapping regulatory systems, which has created gaps and variation in the policies that apply within different countries (Hogarth et al., 2008). Norway and Germany, for instance, have elected to ban DTCGT altogether, stating that only professionals should be able to order genetic tests (Beckman, 2004). Some US states also ban direct-to-consumer genetic testing (Hudson et al., 2007). Over the course of this study, 23andMe stopped providing interpretation of its genetic tests to US customers in response to a US Food and Drug Administration order to stop providing medical advice as doing so requires regulatory approval (Green & Farahany, 2014). Most other countries, including Canada, allow DTCGT to continue, despite concerns from clinicians, scientists, consumers, and patient groups alike (Hogarth et al., 2008). An additional issue pertaining to jurisdictions is that most DTCGT is conducted via the web, and therefore difficult to regulate in any one jurisdiction. For example, banning certain DTCGT practices in Canada may not stop individuals from ordering tests from the US.

Little is known about customers' understanding of the privacy risks of providing their genetic material to commercial companies. While much research explores the ethical and privacy implications of biobanks (e.g., Elger, 2013; Heeney et al., 2009; Greely, 2007), and a growing body of literature focuses on lay people's understanding of these issues (O'Doherty, Hawkins, & Burgess, 2012) much of this research focuses on publicly funded biobanks. Discussions have only just begun to turn to the additional privacy concerns that arise from private companies having access to, storing, and conducting research with genetic information provided by their customers. When patients provide samples to their physicians or publicly funded health researchers, it is the researchers who are requesting access to an individual's biospecimens and in turn promise to abide by accepted ethical protocols, including certain privacy protections. Although uncertainty remains with regard to how best to construct ethically sustainable governance for biobanks (O'Doherty et al., 2011), the ethical difficulties are well acknowledged in the academic literature. However, the situation involving DTCGT is different. Here, it is the individual consumer who requests that genetic tests are conducted on a sample that they freely provide to the DTCGT company. To date little attention has focused on the social and ethical implications of DTCGT companies acquiring and storing large numbers of biological samples with associated genetic, health, and other data (for example, Singleton, Erby, Foisie, & Kaphingst, 2012 assess the risks and benefits that DTCGT companies present on their websites but explicitly exclude terms, conditions, and privacy statements from their analysis). In particular, little attention has focused on the privacy implications of consumers providing DTCGT companies with samples of their DNA.

Interestingly, many companies advertise their services as having the benefit of increased privacy (Williams-Jones, 2003). People may access these services because the genetic information they receive will not be part of their medical record, but as previous researchers have pointed out, many of the privacy promises provided by these companies are merely advertising claims and do not necessarily provide better safeguards for people's information (Health Law Institute, 2010). In addition, DTCGT companies vary in their treatment of customer information and the extent to which they keep this information confidential, and DTCGT companies are not necessarily subject to the same privacy laws as population biobanks (Knoppers, 2010). There has also been some concern that companies carefully craft the description of their services in order to avoid oversight or regulation. Additionally, the protections against discrimination based on genetic data that are in place in certain countries (for example, GINA in the United

States) do not apply to all types of insurance (Lewis et al., 2011). While these issues may be less prevalent in Canada because we have a publicly funded healthcare system, there are still issues with privacy and oversight (Williams-Jones, 2003).

As some researchers have rightly pointed out, consumers should be concerned about how companies are storing their data online, as well as how their genetic information will be used in the future (Williams-Jones, 2003). The information that people provide when undergoing genetic testing includes not only their genetic makeup, but in many cases also contains information about family history, their lifestyle, their previous health status, and health-related behaviours. Their results provide information about people’s potential future health, which may not always be accurate depending on the test. Collecting such broad data poses a number of risks, some known, and some unknown. This is especially true because efforts to anonymize data, particularly genetic data, meet a number of challenges since health records can be reidentified surprisingly often (Rothstein, 2010).

The negative personal and societal impacts of the use of genetic and health information can be seen both in history and in our society more recently (Garver & Garver, 1991), and situations involving the misuse of health information have been seminal in the decision to ban the use of genetic information for employment and health insurance purposes (Hampton, 2008). It has been argued that genetic information is different than other information and with new technology, even anonymized and aggregated data could potentially be re-identified (Knoppers, 2010). However, it is not clear that people understand the risks of providing their genetic information to a private company – this issue is one that has not been extensively explored. Past research has shown that the privacy policies of DTCGT services are often unclear or incomplete (Health Law Institute, 2010). It therefore seems reasonable to predict that given unclear information about privacy protections, consumers' understanding of these issues may be inadequate. Indeed, a recent study found that 45% of DTCGT users shared their genetic test results with friends on Facebook, indicating that perhaps people's own disclosures may be a source of problems surrounding privacy (Lee et al., 2013). Issues of understanding may be even more difficult for children (Borry et al., 2010), and it is unclear how privacy protection can be obtained for individuals who are not specifically involved in the purchase of genetic testing services.

DTCGT companies may use customers' genetic information for more than simply providing them with the results of the test they purchased. For example, they may use the information to improve the quality of their tests, to conduct research, or they may share it with other companies for profit. In this case, the social contract can be seen to be more akin to the relationship between Facebook and its users. On Facebook, users freely provide the product that Facebook uses or sells to other companies. That is, Facebook users give up much of their privacy not only by posting personal information on Facebook, but by providing the company with a valuable product that can be sold on for profit. Some research has shown that consumers have relatively high confidence in the companies they engage with for genetic testing, but would nonetheless welcome regulation to ensure their privacy in regards to when their information can be disclosed (Bollinger, Green, & Kaufman, 2013). It is for these reasons that we believe that more research is needed regarding the way in which companies present and consumers understand the privacy implications of DTCGT.

Review of DTCGT Company Websites

The first stage of this project examined what DTCGT companies claim and communicate to customers about the way in which they use the genetic materials they receive. Using the methodology described below, we analysed the websites of primarily health-related DTCGT companies that offer their services to Canadians.

Methods

The first part of this activity was to compile an up-to-date list of all companies that currently offer DTCGT. In completing this activity, many companies were identified for which websites were not functional or had only minimal information in place. Also, some companies that were identified in existing literature or the news media did not appear to be in existence any longer. We excluded companies where the website was unavailable, incomplete (for example, because it was no longer maintained) or marked as under development. This is consistent with the findings of other researchers who searched the literature for DTCGT companies but found that some no longer have an active website or no longer offer genetic testing (Singleton et al., 2012).

Some of the companies we identified are Canadian, but websites can typically be accessed throughout the world. Therefore we included any websites where Canadians could order a test either online (we assessed this by trying to purchase a genetic test from these companies), by phone, or by mail. We also excluded sites that did not offer tests “direct-to–consumer”. This includes sites that were directed towards physicians and researchers, sites that were marketed to consumers but where the services were only available through a physician, and sites that were directed at employers. This last exclusion, while beyond the scope of the current project, is a potentially interesting and important area for the assessment of privacy risks in the use of genetic material if employers are able to require that employees undergo genetic testing or are found to test genetic material covertly.

Once we identified a complete listing of all relevant websites, we divided the websites into categories based on the type of test provided (some websites fell into multiple categories). Categories include: health tests (our primary focus), traits & talents, ancestry & genealogy, relationship & paternity, forensics & infidelity, prenatal testing, and other. We divided the websites in this manner in order to facilitate summarization of the privacy issues for the different types of tests that are available. While we intended to focus only on sites that offered health relevant genetic testing services, we thought it would be useful to include some information on other types of tests since they all involve potential privacy issues as a result of sharing genetic material with a private company. We therefore provide summary information on these additional types of sites.

To evaluate the sites, we devised criteria based on past research (e.g. Health Law Institute, 2010) and the material covered in the most comprehensive privacy policies (e.g. 23andme.com). We tested our evaluation criteria on a subset of sites and refined them before analysing any additional health-related DTCGT websites. If the website included a privacy policy, we focused on the privacy information covered there. However if it did not, we checked other areas of the website (for example, About Us, FAQ’s, Terms of Service) and included relevant privacy information in our evaluation of the site.

Companies that provided health related tests were evaluated based on the following criteria:

1. **Accessibility of Policy**
   a. Has the company posted a privacy policy to their website?
   b. Is the privacy policy accessible from the company's homepage?
   c. If not, is there a statement about the company's privacy practices elsewhere on the site?

2. **Completeness of the Privacy Information**
   a. Does the information address the privacy aspects of visiting the website (e.g. use of cookies)?
   b. How will personal information be used?
   c. What is meant by "personal information"?
   d. How will genetic samples be handled?
   e. Does the site discuss confidentiality regarding results of testing?

3. **Content of the Privacy Information: Access**
   a. Who will have access to customers' personal information, including lifestyle, medical history?
   b. Who will have access to the genetic sample?
   c. Who will have access to test results?
   d. What security is in place to protect these data?

4. **Content of the Privacy Information: Disposal**
   a. How long is electronic data retained?
   b. What will happen to the genetic sample once testing is complete?

5. **Content of the Privacy Information: Consequences**
   a. Does the site discuss the potential for employment and insurance discrimination?
   b. The potential impact on other family members?
   c. Compliance with specific privacy legislation?

6. **Content of the Privacy Information: Secondary Use**
   a. Do they use samples and/or information for secondary purposes (e.g. research)?
   b. What happens with banks of genetic samples and personal information if the company ceases to exist?
   c. Can consumers consent to some but not all uses of genetic samples and personal information?

7. **Content of the Privacy Information: Recourse**
   a. What procedures are in place for obtaining additional information, making complaints, or reporting a privacy breach?

Sites that provided information in all of these categories were ranked as "excellent", those that provided partial information spanning several categories were categorized as “good”, those that provided minimal or vague information or those that provided little information but encouraged customers to contact the company with any questions were categorized as “fair”, and those with little or no information were categorized as “poor”.

Findings

Overall, we found that there were many sites that offered tests using genetic material, though few sites provided all or even most of the information that would be expected to fully inform customers about the potential privacy issues or risks associated with direct-to-consumer genetic testing. We provide more detailed information and rankings for the health-related companies, as well as brief summary information for sites that offered the other categories of tests. For a complete listing of all the sites we analysed including their country of origin, their URL, types of tests offered, and sample type required, please see Appendix A. Knowing that the mix of companies has tended to change quite frequently, we conducted a brief review to determine what companies remain available to consumers in 2015 at the time of our customer survey, and provide this updated information in Appendices B and C.

Health Tests

Health tests, the main focus of this report, refer to any test that diagnoses, estimates the risk of, or determines carrier status (whether someone might pass on to their children the risk of a particular health condition) using genetic material. We excluded sites that assess health based on other types of information, even though these sites may sometimes require a biological sample. Included in the ‘health’ category are tests that determine a person’s response to different medications (also called drug response), for example, tests that estimate one’s risk of having severe side effects to Statins. Other health tests assess issues such as someone’s predisposition to diabetes, whether or not they will develop Parkinson’s, or if they carry a copy of the gene mutation known to cause cystic fibrosis (a recessive genetic disorder that could be passed on to future generations). We also included telomere length tests in this category, even though telomeres are not technically part of one’s genetic makeup. These are the end portions of chromosomes that can be lost during cell division and have therefore been used as an indicator of expected lifespan or chromosomal age. A final sub-category within our health category includes diet and nutritional tests, which provide information and advice concerning weight loss, diet, and nutrition based on genetic information. Many genetic testing companies offer health tests, two of the largest being 23andMe and Geneplanet.

Of those sites included in our analysis, 29 companies were found to offer health-related direct-to-consumer genetic tests, and some of these companies offered a large selection of these types of tests. For example, 23andMe advertises that it offers over 240 tests of health conditions (e.g. predisposition to celiac disease) and over 40 tests for inherited conditions (e.g. carrier status for cystic fibrosis). Generally, the type of sample required for these tests was saliva (21 companies required a saliva sample), though some companies required a blood (7) or stool (1) sample and an additional two did not specify. Of the companies whose websites we were able to access, 21 had posted their privacy policy, though some of these policies (5) were limited, or discussed only privacy aspects related to visiting the website, such as how they use cookies. Other companies lacked a formal policy, but included privacy-related information in other areas of their website, including the homepage or FAQ section. Notably, eight of the companies had little to no privacy information at all, giving them a ranking of *poor* on our rating scheme. Of the companies with privacy policies, five included additional privacy information such as a HIPAA page or forum. In total, four sites ranked as *excellent* in terms of the privacy information they provided, six ranked as *good*, and 11 were *fair* (see Table 1 for the overall ratings of the privacy information the companies provided).

Table 1. Health Tests Offered and Overall Ratings.

Name	**Health Test Type**	**Overall Rating**	**Notes**
23 and Me	Disease Risk, Carrier Status, Drug Response	Excellent	Addresses all categories and provides further information and contact person
Acu-Metrics	Disease Risk	Poor	Extremely brief
Cygene Direct	Disease Risk	Good	Many aspects addressed but still missing some
DNA Dimensions	Diet / Nutrition, Disease Risk	Poor	No information
DNA Testing Centres of Canada	Drug Response, Carrier Status, Diet / Nutrition, Disease Risk	Poor	No information
EnteroLab	Disease Risk	Poor	Limited information, no contact
Executive Health Centre	Telomere	Poor	No information
Genelex	Drug Response	Good	Many aspects addressed and privacy contact listed
Geneplanet	Drug Response	Fair	Limited information
Graceful Earth	Disease Risk	Poor	No information
Health Check U.S.A.	Disease Risk	Excellent	Addresses all categories and provides further information and contact person

Hemochromatosis DNA Test	Disease Risk	Fair	Limited information but encourages contacting privacy person
Inherent Health	Disease Risk, Diet / Nutrition	Excellent	Addresses all categories and provides contact
Life Genetics	Diet / Nutrition	Fair	Includes some information but it is generally brief and vague
Map My Genome	Drug Response	Fair	Some information listed, but no contact
Market America/Gene SNP	Disease Risk, Diet / Nutrition	Fair	Limited information but encourages contacting privacy person
Matrix Genomics	Drug Response	Good	Many aspect addressed but brief and no contact person
Medcan Clinic	Disease Risk, Drug Response	Good	Many aspects addressed and privacy contact listed
Natural Care Solution	Telomere	Fair	Limited information
Spectra Cell Laboratories	Telomere	Good	Most aspects addressed
TeloMe	Telomere	Fair	Many aspects addressed but still missing some
Terraternal	Telomere	Fair	Limited information but encourages contacting privacy person
Test Country	Disease Risk	Fair	Limited information
The Genetic Testing Laboratories	Disease Risk	Fair	Limited information but encourages contacting privacy person
True Health Labs	Telomere	Good	Most aspects addressed
Unikey Health Systems	Telomere	Fair	Limited information but encourages contacting privacy person
Vitamin Mineral Testing	Telomere	Poor	No information
vuGene	Disease Risk, Diet / Nutrition	Excellent	Almost all aspects covered; provides a contact
Youology	Diet / Nutrition	Poor	Brief/vague

For each assessment criterion we provide a summary of the findings followed by a table that details the site-by-site findings from our assessment:

- **Accessibility**. 21 sites had posted a privacy policy (see Table 2), and of these, 20 sites had a link to the policy on their homepage. The remaining sites linked to the policy through their ‘About Us’ page, 2 clicks from their homepage. Four sites did not have a privacy policy, but did list some privacy information in their About Us, FAQ page, or homepage. The remaining four sites did not have any privacy information accessible, including one site that provided a privacy policy link that was non-functioning.

Table 2. Site-by-Site Ratings of Accessibility of Privacy Information.

Name	**(1a) Privacy Policy**	**Notes**	**(1b) Accessibility of Policy**	**(1c) Additional Information If No Policy**
23 and Me	Yes	Additional information	Homepage	n/a
Acu-Metrics	No	Brief statement without specific information	Homepage (difficult to find)	Yes
Cygene Direct	Yes	Additional information	About us page (2 clicks from home page)	n/a
DNA Dimensions	No	The term privacy is mentioned without any description of their practices	n/a	No

DNA Testing Centres of Canada	No	Broken link	Homepage	No
EnteroLab	No	Brief statement without specific information	Homepage	Yes
Executive Health Centre	No		n/a	No
Genelex	Yes	Additional information	Homepage	n/a
Geneplanet	Yes		Homepage	n/a
Graceful Earth	No	Brief statement without specific information	About us page (1 clicks from home page)	Yes
Health Check U.S.A.	Yes	Additional information	Homepage	n/a
Hemochromatosis DNA Test	Yes		Homepage	n/a
Inherent Health	Yes		Homepage	n/a
Life Genetics	Yes	Additional information	Homepage	n/a
Map My Genome	Yes		Homepage	n/a
Market America/Gene SNP	Yes	Personal information via website only	Homepage	n/a
Matrix Genomics	Yes		Homepage	n/a

Medcan Clinic	Yes	Additional information	Homepage	n/a
Natural Care Solution	Yes		Homepage	n/a
Spectra Cell Laboratories	Yes		Homepage	n/a
TeloMe	Yes		Homepage	n/a
Terraternal	Yes	Personal information via website only	Homepage	n/a
Test Country	Yes		Homepage - privacy policy is part of a larger document of store policies	n/a
The Genetic Testing Laboratories	Yes	Limited	Homepage	n/a
True Health Labs	Yes	Additional information	Homepage; 2 clicks	n/a
Unikey Health Systems	Yes	Personal information via website only	Homepage	n/a
Vitamin Mineral Testing	No		n/a	No
vuGene	Yes	Additional information	Homepage	n/a
Youology	No	Limited info in FAQ page	FAQ page (1 click from homepage)	Yes

- **Completeness.** Of the 29 sites, 21 had privacy policies of varying completeness (see Table 3). Five policies were limited, and discussed only privacy aspects related to visiting the website, such as how they use cookies. Five policies included additional privacy information such as a HIPAA page or forum, and the remaining policies had a moderate amount of information. Other companies lacked a formal policy, but included privacy-related information, and the remaining sites had little or no information. Of the companies with privacy policies, nine sites had well-defined, thorough descriptions of what types of personal information they collect, 10 did not define any type of information in relation to privacy, and the remaining sites had limited descriptions. The description of how personal information would be used varied greatly from policy to policy, but a great number of policies (10) indicated the customer's personal information would be used for normal business practices and the provision of services. Ten sites indicated they also use personal information for research or marketing purposes, in addition to service provision. Of the remaining two sites, one indicated that they do not collect any personal information whatsoever and even encouraged the use of a false name, while the last site did not include any information on how personal information would be used.

Table 3. Site-by-Site Ratings of Completeness of Privacy Information

Name	**(2a) Privacy of Website**	**(2b) How will information be used**	**(2c) Definition of Personal Information**	**(2d) Sample handling**	**(2e) Confidentiality is discussed**
23 and Me	Yes	Research, service provision	Yes - comprehensive description of PI and PHI	Yes	Yes
Acu-Metrics	No	No	No	No	No

Cygene Direct	Yes	Service provision; research	Yes - description of personal information they collect	No	Yes
DNA Dimensions	No	No	No	No	No
DNA Testing Centres of Canada	No	No	No	No	No
EnteroLab	No	Service provision only	No	No	Yes
Executive Health Centre	No	No	No	No	No
Genelex	Yes	Service provision; research	Yes - description of PI and PHI	No	No
Geneplanet	Yes	Service provision only	Yes	Vague	Yes
Graceful Earth	No	No	No	No	No
Health Check U.S.A.	Yes	Service provision; marketing; research	Yes - description of personal information they collect	No	Yes
Hemochromatosis DNA Test	No	Service provision only	Yes - PI	No	Yes
Inherent Health	Yes	Service provision only	Yes - description of personal information they collect	Yes	Yes
Life Genetics	Yes	Service provision only	Very limited description	Yes	Yes
Map My Genome	No	Service provision; research	Limited description	Yes	No
Market America/Gene SNP	Yes	Service provision; marketing	Yes - description of personal	No	Yes

			information they collect		
Matrix Genomics	No	None required (encourages use of false name)	No	Yes	Yes
Medcan Clinic	No	Service provision; research	Yes - description of PI and PHI	No	Yes
Natural Care Solution	Yes	Service provision; marketing	Yes - description of PI	No	No
Spectra Cell Laboratories	No	Service provision; research	Yes - PHI	No	No
TeloMe	Yes	No	Yes	Vague	No
Terraternal	Yes	No	Limited description	No	No
Test Country	Yes	Service provision only	Yes - description of PI and PHI	No	Yes
The Genetic Testing Laboratories	No	Service provision only	No	No	No
True Health Labs	Yes	Service provision; research	Limited description	No	Yes
Unikey Health Systems	No	Service provision only	Yes - PI	No	No
Vitamin Mineral Testing	No	No	No	No	No
vuGene		Service provision only	Yes - PI		
Youology	No	No	No	No	No

- **Access.** The 21 sites that provided privacy policies varied greatly in their descriptions of who would have access to the information (see Table 4). Ten sites indicated staff members would have access to customer's information in order to provide services. Of these, four went on to specify that they may need to disclose personal information if required by law, and an additional site also indicated it may need to share information with family members. Eight policies indicated a third party would have access to the information in addition to staff, one site specified a client's consent would be required, and that information might be shared with family members. The remaining seven websites did not specify whether they would require consent before sharing information with third parties. Of the 21 sites with privacy policies, 14 also included privacy practices specific to genetic information and/or test results. Eight sites indicated they do not share genetic or other personal information with anyone, or use this only for typical business practices. Of these, two sites indicated they may disclose this information if required by law. Two companies indicated they may disclose this information for billing or insurance purposes, two companies may disclose this information to health care providers, and five may disclose it for research purposes. Of the sites with privacy policies, six companies did not provide any information on how the personal information or sample is protected, and five had very brief or vague information. Six sites mentioned their methods for protecting personal information online (e.g. SSL, encryption), and one mentioned briefly their method for protecting the sample. The remaining three sites had more thorough descriptions both of how privacy is protected online, and how the sample is protected.

Table 4. Site-by-Site Findings Regarding Access

Name	**(3a) Access to information**	**(3b) Access to sample**	**(3c) Access to test results**	**(3d) Protection of PI**
23 and Me	3rd parties, service provider	Lab staff	Researchers, 3rd parties, other site members (with consent)	SSL, encryption, physical, technical, and administrative measures
Acu-Metrics	Not disclosed	No	Not disclosed	Vague
Cygene Direct	Service provider	No	Not disclosed	Limited access, physical, electronic, and procedural safeguards; describes patented method that will not allow matching someone's identity with their DNA and ensures anonymity from the point of sale through access to results
DNA Dimensions	No	No	No	No
DNA Testing Centres of Canada	No	No	No	No
EnteroLab	Service provider only	No	Not disclosed	Vague
Executive Health Centre	No	No	No	No
Genelex	Service provider; legal; insurance provider; health care provider	No	Service provider; legal; insurance provider; health care provider	SSL
Geneplanet	Service provider	No	Service provider	Sample is coded
Graceful Earth	No	No	No	SSL
Health Check U.S.A.	Service provider; 3rd parties	No	Service provider; legal; for payment (e.g. Billing a health plan); for safety of the public if necessary (with examples); to	Encryption

			family involved in medical care	
Hemochromatosis DNA Test	Service provider only	No	Service provider; legal	Vague
Inherent Health	Service provider; 3rd parties; legal	Lab staff	Service provider	Barcodes, encryption, SSL, firewall, samples are coded, employees and 3rd parties have limited access
Life Genetics	Not disclosed	Lab staff	Not disclosed	Sample is coded
Map My Genome	Service provider; legal	Lab staff	Not disclosed	Sample is coded
Market America/Gene SNP	3rd parties; service provider; legal	No	No	Encryption
Matrix Genomics	Service provider	Lab staff	No	Vague
Medcan Clinic	Service provider	No	Service provider; researchers; health information custodian	Vague
Natural Care Solution	Service provider; 3rd parties; legal	No	No	Vague
Spectra Cell Laboratories	Service provision, legal (examples); researchers (with consent); family (if they are involved in care); emergencies, public health	No	Service provision; when required by law (examples); research (with consent); family if they are involved in care; emergencies, public health;	No
TeloMe	Service provider; legal; health care provider	No	Service provider; legal; health care provider; research	No
Terraternal	Service provider; legal	No	No	No

Test Country	3rd parties can access "group profiles"; legal	No	Service provider; legal	SSL, encryption
The Genetic Testing Laboratories	Legal; service provider	No	Service provider; legal	SSL
True Health Labs	Service provider	No	Service provision, family, legal; research; health care provider	Vague
Unikey Health Systems	Service provider	No	No	SSL, encryption
Vitamin Mineral Testing	No	No	No	No
vuGene	Not disclosed		Does not store, copy or share this information	Vague (although they do not keep this information)
Youology	No	No	No	No

- **Disposal.** Most websites (20) did not include any information on how they dispose of samples once testing is complete or what happens to user information (see Table 5). Only four websites explained that samples are destroyed after testing. Five sites mentioned that they keep test results, and three companies indicated that they destroy this information.

Table 5. Site-by-Site Findings Regarding Disposal

Name	**(4a) Data Retention**	**(4b) Sample Retention**
23 and Me	Retained	Destroyed after testing
Acu-Metrics	No information	No information
Cygene Direct	No information	No information
DNA Dimensions	No information	No information
DNA Testing Centres of Canada	No information	No information
EnteroLab	No information	No information
Executive Health Centre	No information	No information

Genelex	No information	No information
Geneplanet	No information	No information
Graceful Earth	No information	No information
Health Check U.S.A.	Retained for 3 years	No information
Hemochromatosis DNA Test	No information	No information
Inherent Health	Retained for 7 years	Destroyed within 10 days of testing
Life Genetics	No information	Destroyed after analysis
Map My Genome	No information	No information
Market America/Gene SNP	No information	No information
Matrix Genomics	No information	Destroyed after testing
Medcan Clinic	No information	No information
Natural Care Solution	No information	No information
Spectra Cell Laboratories	No information	No information
TeloMe	No information	No information
Terraternal	No information	No information
Test Country	Retained	Retained
The Genetic Testing Laboratories	No information	No information
True Health Labs	Retained for 3 years	No information
Unikey Health Systems	No information	No information
Vitamin Mineral Testing	No information	No information
vuGene	Destroyed after delivery of results	Destroyed after delivery of results
Youology	No information	No information

- **Consequences.** Seven sites referenced a law such as GINA or HIPAA (see Table 6). Five explicitly described a negative privacy consequence.

Table 6. Site-by-Site Findings Regarding Consequences

Name	**(5a) Consequences (employment / insurance)**	**(5b) Consequences (family member)**	**(5c) Consequences (specific legislation)**
23 and Me	No	No	GINA
Acu-Metrics	Vague	No	No
Cygene Direct	Yes (employment, insurance)	No	HIPAA
DNA Dimensions	No	No	No
DNA Testing Centres of Canada	No	No	No
EnteroLab	Yes (employment, insurance)	Yes	No
Executive Health Centre	No	No	No
Genelex	No	No	No
Geneplanet	No	No	No
Graceful Earth	No	No	No
Health Check U.S.A.	No	No	HIPAA
Hemochromatosis DNA Test	No	No	No
Inherent Health	Yes (employment, insurance)	Yes	GINA
Life Genetics	No	No	Personal Data Protection Act of the Republic of Slovenia
Map My Genome	No	No	No
Market America/Gene SNP	No	No	No
Matrix Genomics	Yes (employment, insurance)	No	Public Law #110-233
Medcan Clinic	No	No	PHIPA; PIPEDA
Natural Care Solution	No	No	No
Spectra Cell Laboratories	No	No	No
TeloMe	No	No	No
Terraternal	No	No	No
Test Country	No	No	No

The Genetic Testing Laboratories	No	No	No
True Health Labs	No	No	HIPAA
Unikey Health Systems	No	No	No
Vitamin Mineral Testing	No	No	No
vuGene	No	No	GINA
Youology	No	No	No

- **Secondary Use.** Ten companies stated that they use information for secondary purposes (see Table 7). Five companies declared that they use customer information for research (two use it only with consent and one uses unidentifiable information). Six sites explained that they would share personal information with another company in the event of a merger or acquisition, of these only two stated that they would require the new company to comply with the current policy. 13 sites provided customers with the ability to opt out of data collection, data use, and/or research.

Table 7. Site-by-Site Findings Regarding Secondary Use

Name	**(6a) Secondary Use**	**(6b) If company closes**	**(6c) Consent - different options?**
23 and Me	Research (with consent)	Company will comply with this policy	Yes
Acu-Metrics	Not used	No	No
Cygene Direct	Research	No	Yes
DNA Dimensions	No	No	No
DNA Testing Centres of Canada	No	No	No
EnteroLab	Not used	No	Yes

Executive Health Centre	No	No	No
Genelex	Research (unidentifiable information)	No	Yes (can refuse)
Geneplanet	No	No	Can opt out of accepting cookies
Graceful Earth	No	No	No
Health Check U.S.A.	Research	Disclosed if a merger occurs with another company	Yes (opt out of emails from 3rd parties); can revoke consent to disclose PHI in writing
Hemochromatosis DNA Test	Not used	No	No
Inherent Health	No	Company will comply with this policy	No
Life Genetics	Not used	No	No
Map My Genome	Research (with consent)	Information will be transferred as a business asset	Yes
Market America/Gene SNP	No	No	No
Matrix Genomics	No	No	No
Medcan Clinic	Research	No	Yes
Natural Care Solution	No	Information will be transferred as a business asset	Yes (can opt out of emails)
Spectra Cell Laboratories	Research	No	Yes (can refuse)
TeloMe	Research	Information will be transferred as a business asset	Yes
Terraternal	No	No	No
Test Country	No	No	Yes (can opt out of emails)
The Genetic Testing Laboratories	No	No	No
True Health Labs	Research	Information will be transferred as a business asset	Yes
Unikey Health Systems	Not used	No	Yes
Vitamin Mineral Testing	No	No	No

vuGene	Not used	Personal information will be transferred as a business asset	Yes
Youology	No	No	No

- **Recourse.** Many websites provided some sort of contact information (except for 12 which did not provide contact information directly in their privacy section or did not have a privacy section; see Table 8). 5 provided an email address specifically for privacy concerns, a privacy officer, or a privacy administrator.

Table 8. Site-by-Site Findings Regarding Recourse

Name	**(7a) Recourse**	**Notes**
23 and Me	Yes	Privacy administrator
Acu-Metrics	Yes	General email
Cygene Direct	Yes	Phone number (privacy specific)
DNA Dimensions	No contact listed in privacy section	
DNA Testing Centres of Canada	No contact listed in privacy section	
EnteroLab	No contact listed in privacy section	
Executive Health Centre	No contact listed in privacy section	
Genelex	Yes	General email (encourages contact)
Geneplanet	Yes	General email
Graceful Earth	No contact listed in privacy section	
Health Check U.S.A.	Yes	General email
Hemochromatosis DNA Test	Yes	General email (encourages contact)
Inherent Health	Yes	Privacy email (encourages contact)
Life Genetics	Yes	General email (encourages contact)
Map My Genome	No contact listed in privacy section	
Market America/Gene SNP	Yes	Privacy email (encourages contact)
Matrix Genomics	No contact listed in privacy section	
Medcan Clinic	Yes	Privacy officer

Natural Care Solution	No contact listed in privacy section	
Spectra Cell Laboratories	Yes	Privacy officer
TeloMe	Yes	General email (not easily accessible)
Terraternal	Yes	General email (encourages contact)
Test Country	No contact listed in privacy section	
The Genetic Testing Laboratories	Yes	Complaints email
True Health Labs	No contact listed in privacy section	
Unikey Health Systems	Yes	General email (encourages contact)
Vitamin Mineral Testing	No contact listed in privacy section	
vuGene	Yes	General email (encourages contact)
Youology	No contact listed in privacy section	

Relationship & Paternity

Relationship tests, and most often paternity tests, which we have categorized with relationship tests, determine how two people are related (please see Table 9 for our brief site-by-site analysis). Most commonly companies who offer these tests provide court-admissible tests that establish paternity for legal reasons, but many companies also offer the tests direct-to-the consumer for their own purposes allowing for the determination of the relationship between different individuals, such as twin zygosity (whether twins are identical or not), identifying adopted children’s biological parents, or grandparents. Examples of companies offering these tests include easyDNA and Who’z the Daddy? Relationship tests were extremely common, with 46 companies offering them. To establish a relationship, users must provide a sample from each person potentially involved in the biological relationship in question. For example, if the purpose is to determine which of two men fathered a child, a sample is required from the child and each man. Samples required were primarily saliva (43), though 6 companies required a blood sample, 1 did not indicate what kind of sample would be needed, and 6 indicated they accept other “discrete” samples such as hair, gum, or semen. This point is interesting because it implies that customers might provide samples without the explicit knowledge or consent of the party being tested. Of these 46 companies, 20 had not posted any privacy policy. Of the 26 policies, 19 discussed only aspects related to visiting the website (e.g. cookie use).

Table 9. Privacy Policies for Relationship Tests

Name	**Privacy Policy**	**Notes**
Acu-Metrics	No	Brief statement only
Advanced Healthcare	No	Limited info in FAQ's
Canadian DNA Services	Yes	Privacy policy includes only personal information via website
Consumer Genetics	Yes	Privacy policy includes only personal information via website
DNA Diagnostics Center	Yes	Privacy statement
DNA Dimensions	No	Privacy mentioned without reference to their practices
DNA Findings	Yes	Privacy policy has limited information
DNA Force	Yes	Privacy policy includes only personal information via website
DNA ID Check	No	Brief statement without specific information
DNA LAB CENTER	Yes	Privacy policy includes primarily personal information via website
DNA Labs India	No	Link to the privacy policy does not work
DNA People Diagnostics	No	Limited info in FAQ's
DNA PLUS	Yes	Privacy policy includes only personal information via website
DNA Solutions	No	Limited info in FAQ's

DNA Testing Centres of Canada	No	Link to the privacy policy does not work
DNA Worldwide	Yes	
dnaCanada	No	Limited info in FAQ's
DNAplus	Yes	Privacy policy includes only personal information via website
Dynamic Testing Solutions	No	Brief statement without specific information
easyDNA	Yes	Privacy policy includes only personal information via website
Fairfax Identity Laboratories	Yes	Privacy policy includes only personal information via website
Forensic Genetics Center	No	
Genetrack Biolabs	Yes	Privacy policy includes only personal information via website
GFI Lab	Yes	
Home DNA Direct	Yes	Privacy policy includes only personal information via website
Home DNA test Ghana	No	
Identigene	Yes	Privacy policy has limited information
Identigene (DNA Testing)	Yes	Notice of privacy practices
Interior Workplace Compliance Testing	No	Brief statement without specific information
International Biosciences	Yes	Privacy policy includes only personal information via website
Life Labs	Yes	Privacy statement and other publications
Maxxam Analytics	Yes	Privacy policy includes only personal information via website
Nimble Diagnostics	No	Limited info in FAQ's
Orchid PRO-DNA	Yes	Confidentiality policy includes primarily personal information via website
Paleo-DNA	No	
Paternity Test Canada	Yes	Privacy policy includes only personal information via website
Paternity Testing Centres of Canada	No	Brief statement without specific information
Prenatal Genetics	No	Limited info in FAQ's
RPC Genetics	No	Brief statement on confidentiality with contact
Serotech Laboratories LTD	No	Link to privacy policy does not work
Swab Test	Yes	Privacy policy includes primarily personal information via website
Test Country	Yes	Store policies with privacy section

The Genetic Testing Laboratories	Yes	Privacy policy has limited information; refers to "Privacy Policy Details" but we were unable to find the link
TNB Laboratories	No	Privacy mentioned without reference to their practices
Universal Genetics	Yes	Privacy statement
Who'z the Daddy?	Yes	Privacy policy includes only personal information via website

Ancestry & Genealogy

Ancestry and Genealogy tests trace a person's roots back to their distant ancestors or their not-so-distant family members, depending on the company (see Table 10). Some of these companies offer to trace mitochondrial DNA in addition to chromosomal DNA. Some of these tests indicate a person's membership of certain groups including First Nations and African ancestry. Twenty-eight companies offered these tests, including Oxford Ancestors and The Genographic project. All of these tests required a saliva sample. Typically people have to provide their own sample, though women may also choose to provide their father's or brother's sample to trace their paternal line (since women do not have a Y chromosome). Of these sites, 15 had posted a privacy policy and 13 had not. Of the 15 policies, 8 discussed only aspects related to visiting the website.

Table 10. Privacy Policies for Ancestry and Genealogy Tests

Name	**Privacy Policy**	**Notes**
23 and Me	Yes	Privacy statement and policy; cookie policy; policy forum; additional links and resources (not analyzed)
Acu-Metrics	No	Brief statement only
Advanced Healthcare	No	Limited info in FAQ's
African Ancestry	Yes	Privacy policy includes only personal information via website

African DNA	Yes	Privacy policy has limited information
Ancestry by DNA	No	
Britains DNA	Yes	Privacy policy includes primarily personal information via website
Canadian DNA Services	Yes	Privacy policy includes only personal information via website
DNA Consultants	Yes	Privacy policy includes primarily personal information via website
DNA Dimensions	No	Privacy mentioned without reference to their practices
DNA Force	Yes	Privacy policy includes only personal information via website
DNA People Diagnostics	No	Limited info in FAQ's
DNA Solutions	No	Limited info in FAQ's
DNA Testing Centres of Canada	No	Link to privacy policy does not work
DNA Tribes	Yes	
DNA Worldwide	Yes	
Family Tree DNA	Yes	Privacy policy and other statements and documents
Genetic Genealogy	No	
Genographic Project	Yes	Privacy policy includes only personal information via website
iGENEA	No	Limited information in security section and terms page
Indigenous DNA	No	
MyHeritage	Yes	Privacy policy includes primarily personal information via website; separate privacy policy for FTDNA (applicable for those who have done DNA testing) which links to Safe Harbor Privacy Statement
Nimble Diagnostics	No	Limited info in FAQ's
Oxford Ancestors	Yes	Privacy policy includes only personal information via website
Paleo-DNA	No	
Roots for Real	Yes	Privacy statement includes only personal information via website
The Genetic Testing Laboratories	Yes	Privacy policy contains limited information; refers to "Privacy Policy Details" but we were unable to find a link
Warrior Roots	No	Brief statement only

Prenatal Testing

Prenatal tests, with which we have included fetal sex tests, refer to any test conducted on a fetus (see Table 11). These tests are typically health-related as described above, but can also be used to indicate the biological sex of the fetus, as is the case with fetal sex tests, and are offered by companies such as Prenatal Genetics and Home DNA Direct. 10 companies provide prenatal or fetal sex tests and required a saliva sample (8), a blood sample (1), or both (1). For prenatal testing, it is mothers who provide their own blood or saliva sample. This is sufficient for testing since the mothers' samples also contain DNA from the fetus. Of these companies, five had posted a privacy policy and five had not. Of the five sites that had policies, four discussed only aspects related to visiting the website.

Table 11. Privacy Policies for Prenatal Tests

Name	**Privacy Policy**	**Notes**
Consumer Genetics	Yes	Privacy policy includes only personal information via website
DNA ID Check	No	Brief statement without specific information
DNA People Diagnostics	No	Limited info in FAQ's
DNA PLUS	Yes	Privacy policy includes only personal information via website
DNA Testing Centres of Canada	No	Link to privacy policy does not work
DNAplus	Yes	Privacy policy includes only personal information via website
Home DNA Direct	Yes	Privacy policy includes only personal information via website
Medcan Clinic	Yes	Privacy policy and notice (for personal info vs. genetic info)
Nimble Diagnostics	No	Limited info in FAQ's
Prenatal Genetics	No	Limited info in FAQ's

Traits & Talents

Our traits/talents category (also called inherited traits) refers to tests that indicate phenotypic characteristics or characteristics that are not necessarily health-related (see Table 12). This category is broad and can include anything from athletic ability, to freckling, to bitter taste perception. Six companies offer these types of tests, including Map My Genome and Atlas Sports Genetics. These tests require a saliva sample from users. Five of the six companies had privacy policies posted on their websites. Of these six companies, two discussed only aspects related to visiting the website.

Table 12. Privacy Policies for Traits & Talents Tests

Name	**Privacy Policy**	**Notes**
Atlas Sports Genetics	Yes	Privacy policy includes only personal information via website
Britains DNA	Yes	Privacy policy includes primarily personal information via website
Cygene Direct	Yes	Privacy policy and security policy
Geneplanet	Yes	Privacy statement
Map My Genome	Yes	Privacy statement
Warrior Roots	No	Brief statement only

Other Types of Genetic Tests

Any tests that did not fit into the categories above were labelled as ‘other’ (see Table 13). Tests belonging to this category include ID profile tests, which retain an individual’s DNA on file in case their body needs to be identified, child safety identification (an ID profile for children), artwork made from DNA, testing for immigration purposes, or post mortem viability testing where it is determined whether a deceased person’s DNA is still viable for genetic testing. Forensic and infidelity tests are also included in this category. Forensic tests can provide clues about many different issues ranging from estate settlements to threatening mail. Infidelity tests, such as the CheckMate test offered by DNA Plus, indicate whether or not someone’s partner has been unfaithful based on the presence of genetic material. Both of these tests accept many different kinds of samples, including “discreet” samples such as gum, hair, or a toothbrush. While no companies offer services only within this category, 23 companies offer some tests of this type (for example, Advanced Healthcare and Maxxam Analytics).

As with the other types of tests, the most common sample required by companies for testing is a saliva sample (22), three companies require blood samples, and three indicate that they accept “discrete” samples. As with relationship tests, in the case of forensic and infidelity tests, there remains the concern that people can provide biological samples and genetic material without the consent of another individual. In addition, services that keep genetic material on file for future identification may provide their own set of risks, particularly in the case of children, who may not be able to provide their own consent. Of these 23 companies, 12 posted a privacy policy and 11 did not. Of the companies providing policies, eight discussed only aspects related to visiting the website.

Table 13. Privacy Policies for “Other” Test Types.

Name	**"Other" Test Types**	**Privacy Policy**	**Notes**
Acu-Metrics	Immigration, Infidelity, ID	No	Brief statement only
Advanced Healthcare	Immigration, Infidelity, ID	No	Limited info in FAQ's
Canadian DNA Services	Infidelity, Forensic, Immigration, Child Safety	Yes	Privacy policy includes only personal information via website

DNA Diagnostics Center	Forensic, Immigration	Yes	Privacy statement
DNA Dimensions	Forensics	No	Privacy mentioned without reference to their practices
DNA Findings	Immigration	Yes	Privacy policy has limited information
DNA LAB CENTER	Immigration	Yes	Privacy policy includes primarily personal information via website
DNA Labs India	Immigration, Forensic	No	Link to privacy policy does not work
DNA People Diagnostics	Infidelity	No	Limited info in FAQ's
DNA PLUS	Immigration, Infidelity	Yes	Privacy policy includes only personal information via website
DNA Worldwide	Immigration	Yes	
DNAplus	Infidelity	Yes	Privacy policy includes only personal information via website
Dynamic Testing Solutions	Infidelity, ID	No	Brief statement without specific information
Forensic Genetics Center	Infidelity, Forensic	No	
Genetrack Biolabs	Immigration	Yes	Privacy policy includes only personal information via website
GFI Lab	Infidelity	Yes	
Home DNA test Ghana	Infidelity	No	
International Biosciences	Infidelity	Yes	Privacy policy includes only personal information via website
Maxxam Analytics	Forensic, Immigration	Yes	Privacy policy includes only personal information via website
Nimble Diagnostics	Art	No	Limited info in FAQ's
Orchid PRO-DNA	Forensic, Immigration	Yes	Confidentiality policy includes primarily personal information via website
Paternity Testing Centres of Canada	Forensic, Infidelity	No	Brief statement without specific information
RPC Genetics	Forensic, Infidelity	No	Brief statement on confidentiality with contact

Survey of DTCGT Consumers

Based on the key issues that have emerged from the literature regarding DTCGT, as well as our review of websites offering DTCGT to Canadians, we designed a survey to examine what customers understand about the way DTCGT companies use their genetic material and information. Through the survey, we aimed to learn about the following issues relating to individuals' use of DTCGT services:

- Reasons for pursuing this type of testing
- The way individuals interpret the privacy-related information provided by the companies
- Any privacy concerns individuals may have about providing their genetic material for testing
- Beliefs about what might happen to their DNA after the DTCGT company has provided them with their test results
- The extent to which individuals share that information with others (physicians, family, etc.)
- Any negative experiences individuals may have had as a result of their use of DTCGT
- Feelings about the types of negative consequences that could occur as a result of the genetic testing
- How individuals assess the differences in potential risks of genetic testing done through a private company as opposed to the health care system.

We also surveyed individuals who had considered DTCGT but then decided not to make the purchase to better understand their motivations, their concerns, and to what extent privacy was a factor in their decision not to make the purchase. Please consult Appendix D for the survey questions. Note that we asked some questions about participants' understanding of the genetic risk information and their use of the results but for the purpose of this report we will confine our discussion to issues related to privacy.

Participant Recruitment

After developing the survey and obtaining ethics approval from the University of Guelph Research Ethics Board, we distributed the survey using three main recruitment methods (see Table 14): First, we advertised the survey as a volunteer research opportunity on free websites such as Kijiji, Craigslist, the University of Guelph Research website, and sites that are specific to groups that may have a particular interest in DTCGT. Second, we used paid recruitment methods such as Google Adwords to advertise our survey as an opportunity to share one's experiences with DTCGT. As a participation incentive, we offered entry into a draw for one of two ipads. These recruitment methods were more successful at recruiting participants who had considered but not purchased DTCGT so we enlisted the help of a recruiting firm that uses a survey panel to increase the sample of people who had purchased DTCGT.

Table 14. Participants per Recruitment Source.

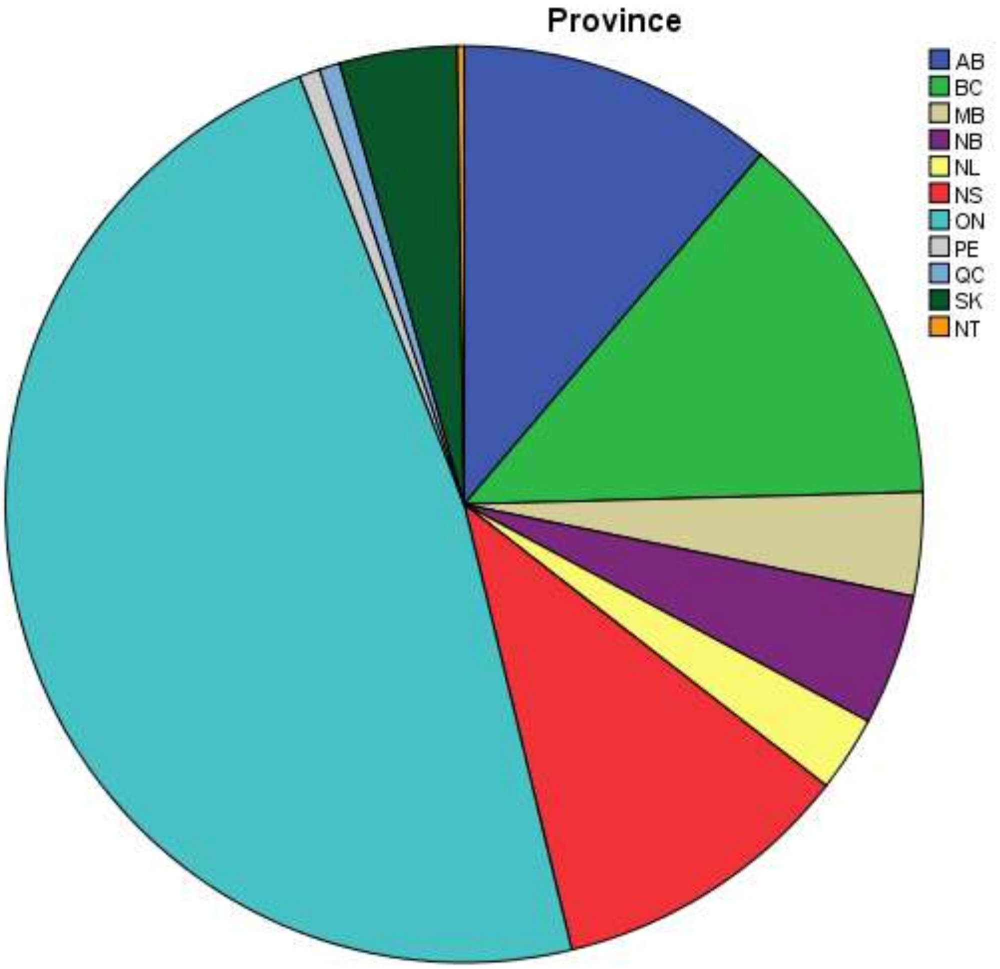
Source		**Frequency**
Free Sites:	Kijiji	166
	University of Guelph	35
	Craigslist	13
	Interest Sites	10
Paid Sites:	Google	6
	Research Panel	185
	Total	415

Interested participants were directed to the online survey where they answered some demographic questions and then responded to questions about reasons for or against purchasing DTCGT, the type of test they purchased, and questions regarding their understanding of the way the DTCGT company treats their data.

Participant Characteristics

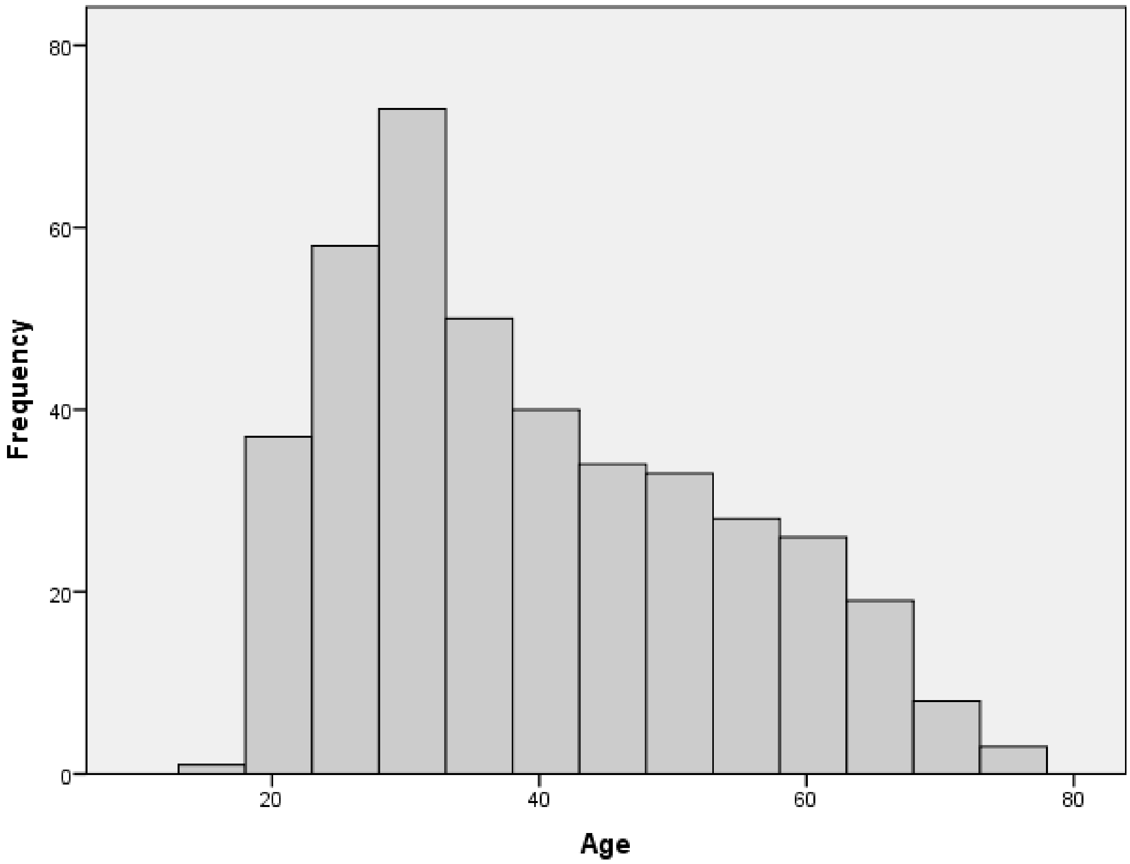
Overall, 415 people participated in our survey. Of these, 235 had considered but decided not to purchase DTCGT and 180 had purchased DTCGT. These numbers do not reflect the relative rates of purchase and consideration in the general population as we specifically over-recruited people who had made a purchase to have sufficient numbers of this group for meaningful analysis. However, our recruitment through the survey panel, where 3,425 people viewed the survey screening question asking about their use of DTCGT, leads us to conclude that the rate of purchase of DTCGT, and of considering but not purchasing DTCGT among English-speaking Canadians is approximately 4% and 13% of the population, respectively. Survey participants were recruited from across the provinces and territories, with nearly half (48%) of all participants from Ontario and the rest distributed across the remaining provinces and territories (see Figure 1).

Figure 1. Geographic Distribution of Survey Participants.



Participants ranged in age from 18 (the minimum to participate) to 77 years old (mean age was 39 years), with a mix of males (156), females (257), and one participant identifying as trans female.

Figure 2. Age Distribution of Survey Participants.



The majority of participants were married (176) or in a serious relationship (112), with the remainder casually dating one or more partners (27) or not dating anyone (95). Participants were split between those who had children (216) and those who did not (195), with the average number of children equalling two. Participants identified primarily as White/Caucasian (80%), East Asian (8%), Aboriginal/Native/Indigenous (6%), South Asian (3%), Black/African Canadian (3%), Middle Eastern/Arabic (2%), Hispanic (2%), Southeast Asian (1%), or other (3%), including participants identifying as biracial. Note that participants could select all categories that apply, meaning that percentages do not total 100%.

DTC Companies

For those who had purchased a genetic test (180), we asked a series of questions about the companies, biological samples required, and types of tests purchased. Participants had experiences with a range of companies, the most common of which were 23andMe (39), National Geographic's Genographic Project (19), DNA Plus (18), Family Tree DNA (12), Home DNA Direct (10), easyDNA (9), Genelex (9), Cygene Direct (8), True Health Labs (6) and others (all below 5 participants each). Thirteen participants did not remember what company they used for their genetic test. Even though all participants lived in Canada, there were some cases where participants reported using companies that do not (or no longer) provide their services to Canadians, as is the case with Ancestry.ca's genetic testing service, which is available in the US but not in Canada.

Tests and Samples

Participants had purchased a variety of DTC genetic tests, with the most common being ancestry and genealogy testing (111), health-related tests (75), paternity or relationship tests (44), prenatal genetic testing (12), and other categories of tests (5). Tests that participants listed as “other” included pet DNA testing (3) which we will not discuss further in this report, a test of physical characteristics (which we have previously referred to as *Traits and Talents* tests), and a test to determine STEM cell or bone marrow match. One person also reported that while they purchased an ancestry test, they used it as a paternity test. No participants reported having used DTCGT services to determine infidelity, for forensic identification, or other more covert uses. In most cases (112) participants provided a cheek swab, but they also reported giving blood (46), hair (17), urine (10), or stool (2) samples.

Other People's Samples

When asked if they had ordered a test about someone else, 35% said they had done so (65% had not). While most of the participants had provided their own biological sample for testing (133 people), 30 had provided their child's sample, 26 had provided their partner's, and 16 provided another family members' biological sample. Additionally, 4 had provided a sample from their partner's child, 3 from a past partner, 3 from a potential parent/child and 3 from some other individual (note that participants may have provided more than one person's sample). When asked if they had obtained permission to provide such a sample, 62% reported that they had and 38% reported that they did not get permission to do so. Indeed, 13 of the company sites we visited specifically advertised the ability to test using "discrete" samples (e.g. gum, toothbrush). Although no participant specifically reported providing such samples, hair samples in particular could be easily obtained without another person's knowledge. That said, not obtaining permission does not necessarily imply a covert use of genetic material as participants may not have believed it was necessary or appropriate to obtain permission from a child.

Reasons For and Against Purchasing DTCGT

Participants offered a variety of reasons for purchasing or considering DTCGT, most of which involved wanting to know more about their family connections or history, their health, or just curiosity. Other participants mentioned the ease and convenience of online genetic testing, the privacy afforded online, and the reasonable cost. See Table 15 for a full list of reasons participants provided as well as the frequencies for each reason. While previous research has suggested that the privacy available online may be a presented as an advantage of DTCGT (Williams-Jones, 2003), this did not appear to be a primary motivator in our sample.

Table 15. Reasons for Considering or Purchasing DTCGT.

Reasons	**Considered**	**Purchased**
To learn more about their health	105	24
To learn more about their family history	66	40
General curiosity	47	20
Convenience of DTCGT	6	17
Privacy afforded online	3	8
Reasonable cost	2	13
Legitimacy of test	0	5
Desire to be part of research	0	5
No other option available	0	3
Asked by someone to do it	0	2

Of those who chose not to purchase DTCGT, cost was described as the main factor in this decision (see Table 16). Specifically, participants felt that the tests were expensive or expensive for what they offer. Tied to this is the issue of legitimacy – many participants questioned the legitimacy of the test, meaning its ability to do what it says it does or its ability to do what the participant wants it to do. Some participants were concerned about maintaining their privacy and the security of their data, while others commented on a general sense of uncertainty or discomfort without specifying or perhaps knowing the cause of their uncertainty. Others were apprehensive about getting their results and were not sure if they wanted to know what a genetic test might tell them. Some were also concerned about the legitimacy of the company itself. Legitimacy of the company seemed to be tied to both privacy concerns and cost in that participants wanted to ensure that their data was safe from being inappropriately used or revealed, and that their purchase met their needs and expectations. Perhaps not surprisingly, some participants explained that they simply did not have enough information to make their decision, be it about the company or the tests. Others indicated that genetic testing is not a priority at this time, perhaps because of the factors described above.

Table 16. Reasons for Choosing Not to Purchase DTCGT.

Reasons	**Frequency**
Cost is prohibitive	114
Legitimacy of test	60
Privacy concerns	21
Genetic testing is not a priority	19
Unspecified discomfort	18
Apprehension about the results	14
Legitimacy of company	12
Insufficient information available to decide	10

Risks of DTCGT

When asked whether they perceived there to be any risks associated with DTCGT, 38% of people thought there are risks to DTCGT and 56% did not (not all participants answered the question). However, when comparing those who ended up purchasing DTCGT against those who did not, only 29% of people who had purchased tests online considered it to be risky, whereas 46% of those who had only considered DTCGT perceived it that way ($\chi 2$ (1, n=392) = 14.17, p<.00). The types of risks that participants reported were similar to the reasons cited for not pursuing DTCGT. For both groups, privacy concerns were the most commonly cited, followed by questions about the legitimacy of the company, legitimacy or accuracy of the test itself, and apprehension about the results (see Table 17). Participants also were concerned about potential insurance implications to genetic testing.

Table 17. Perceptions of Risks Involved with DTCGT.

Reasons	**Considered**	**Purchased**
Privacy concerns	56	22
Legitimacy of company	44	12
Legitimacy of test	45	7
Apprehension about the results	16	5
Insurance implications	8	6

Participants were mixed as to whether they felt they had better control over their privacy by accessing a genetic test online instead of through their doctor. The mean response was 4.4, where 1 indicated they felt they had better control over their privacy online and 7 indicated they had better control over their privacy with a doctor. Again, there were differences between those who had and those who had not made the purchase. We found that those who made the purchase were more likely to feel they had better control over their privacy online (M=4.31, SD=1.92) than those who only considered DTCGT (M=5.17, SD=1.79; t(381)=-4.51, p<.00). When asked whether privacy was a motivating factor in their decision to pursue DTCGT, 51% of those who purchased DTCGT said that it was not a motivating factor and 47% said that it was (the remainder were undecided). When examining responses for those who did not purchase DTCGT, 47% said that privacy was not a motivating factor and 52% said that it was.

Only 12% of our participants had actually had a genetic test through their doctor (83% had not and 5% were unsure). Again, differences were seen between the two groups. Those who had purchased DTC genetic testing were also more likely to have had a genetic test through their doctor (21% compared to 5% of those who considered DTCGT, $\chi 2$ (1, n=371) = 22.08, p<.00). We also asked whether participants had health concerns that contributed to their decision to consider or pursue genetic testing.

Interestingly, more of the participants who considered DTCGT reported health concerns than those who actually purchased DTCGT (42% and 26% respectively, $\chi2$ (1, n=390) = 11.10, p<.00).

Understanding of Privacy Information

In assessing participants' understanding of the privacy information provided by DTCGT companies, we first asked whether they had read the privacy policy provided by the company they used or considered. 47% of participants indicated that they had read the company's privacy policy, 39% said they did not, 3% reported that the company did not have a privacy policy, and 11% did not recall. Perhaps not surprisingly, more of the participants who purchased DTCGT read the policy than those who only considered it (64% and 33% respectively, $\chi2$ (1, n=325) = 37.88, p<.00). It should be emphasised here that in our assessment of company websites (see above), we found that 8 of 29 health-related sites had no privacy policy and little or no privacy-related information and 11 provided only limited information.

When we asked participants whether they felt they received enough information about how companies treat their information, 44% felt they did, 26% felt they did not, and 30% were unsure (see Table 18).

Table 18. Did Participants Feel They Received Enough Privacy Information?

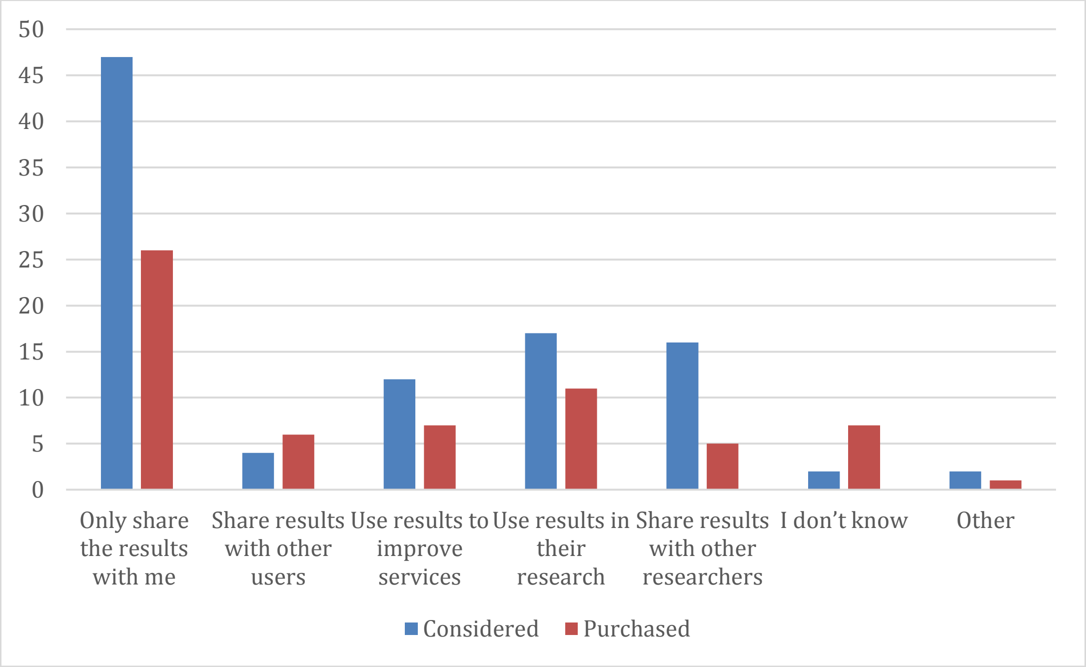
Enough Information	Considered	Purchased	Total
Yes	46	122	168
No	75	23	98
Unsure	91	23	114
Totals	212	168	380

If respondents who were unsure were treated as not receiving enough information, a clear difference emerges between those who went ahead with DTCGT and those who did not. Specifically, 22% of those who considered purchasing DTCGT felt they had enough information, whereas 73% of those who made the purchase felt they did (χ2 (1, n=380) = 98.53, p<.00).

Expected Use of Information and Samples

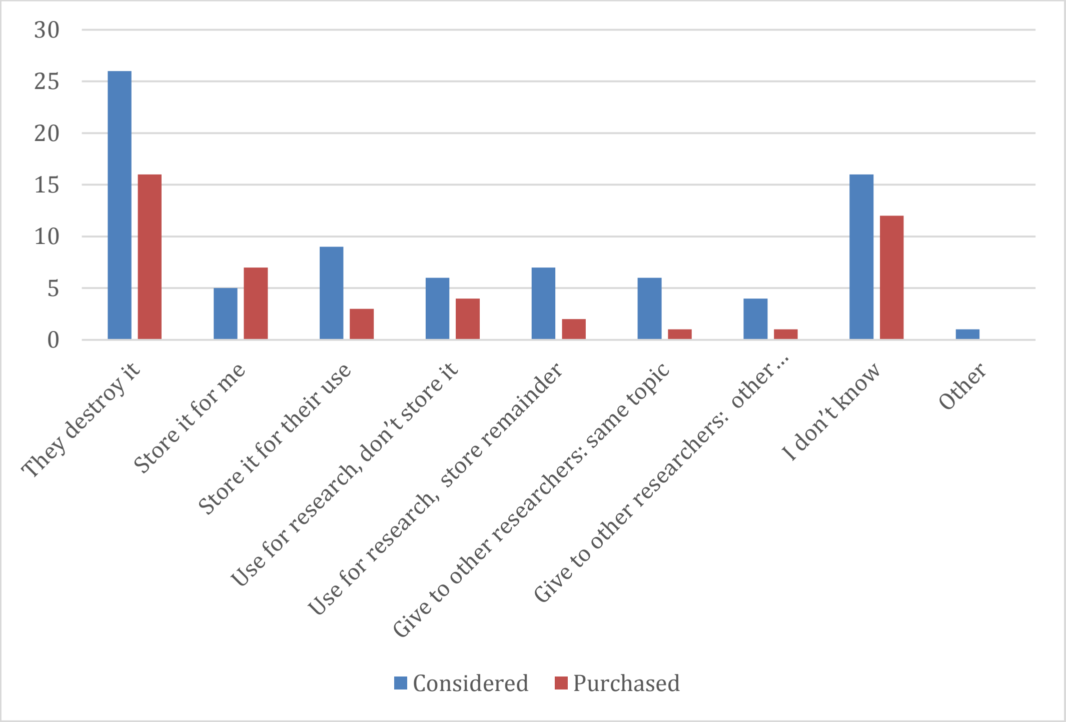
The most common expectation was that the company would only share their results with the customer (47% for those who considered and 26% for those who purchased DTCGT). Using the results for research purposes was another common expectation, especially for those who considered but did not purchase DTCGT (see Figure 3).

Figure 3. Expectations for Use of Genetic Test Results (Percentages).



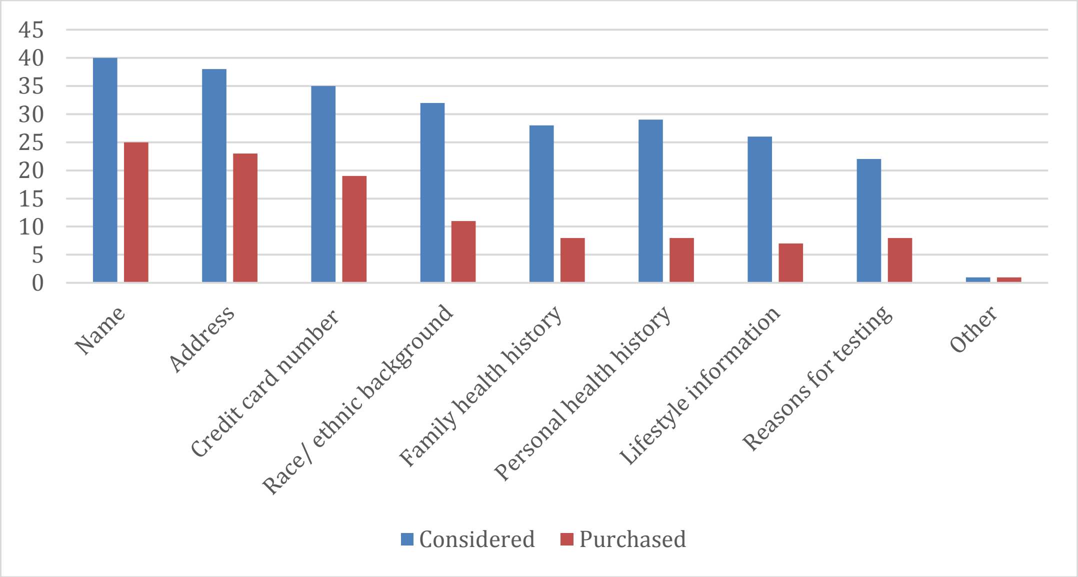
When it came to their sample, the most common response was that participants expected it to be destroyed after testing (26% of those who considered DTCGT and 16% of those who purchased it). However a sizeable minority (16% who considered and 12% who purchased) did not know what would be done with their sample (see Figure 4). This finding is perhaps not surprising in light of the fact that our website assessment showed that most websites (20 of the 29 health websites we reviewed) provide no information about what they do with the sample or results following testing.

Figure 4. What Participants Expect to be Done With Their Sample (Percentages).



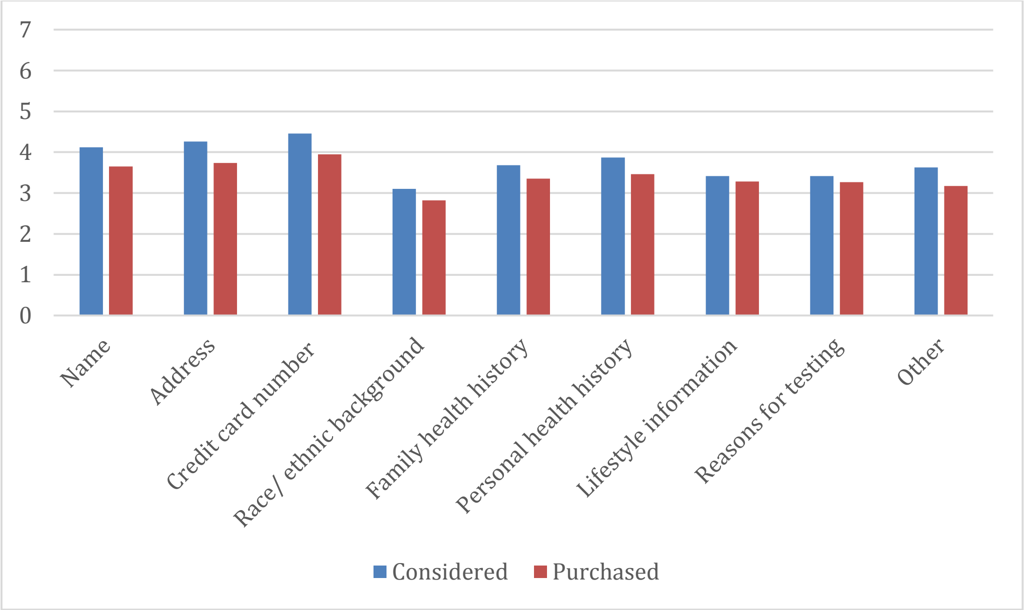
Participants who only considered DTCGT were more likely than those who purchased DTCGT to believe that they would have to provide extensive personal information. Over 25% of this group expected they would have to give their name, address, credit card number, racial or ethnic background, family health history, personal health history, and lifestyle information. 22% also believed they would have to provide their reasons for testing (see Figure 5). Participants who purchased DTCGT were less likely to believe that they would have to provide any of the above information, with most common being those associated with the transaction itself: name (25%), address (23%), and credit card number (19%).

Figure 5. What Information Participants Would Have to Provide.



Keeping these pieces of information private was of average importance for participants in both groups. We asked them to rate the importance of each item from 1 (not at all important) to 7 (very important) and all responses were in the middle range or below (see Figure 6).

Figure 6. Importance of Keeping Their Information Private (Means).



When asked if participants were concerned with the company passing on their information to others, 48% said that they were. Participants who only considered DTCGT were especially concerned, at 67%, compared to 29% of those who made the purchase ($\chi 2$ (1, n=366) = 52.76, p<.00). Those who they did not want their information shared with included other family members, their employers, the general public, the government, other countries, law enforcement, insurance companies, credit agencies, financial companies, drug companies, telemarketers, advertising agencies, and anyone else who might profit from the information. Some participants specifically said they would not want the information shared with anyone other than them.

On the issue of research, some participants said that their data could be used for research, as long as they were anonymous. Others specified that they were comfortable with research uses if their personal information was not included. Participants sometimes elaborated on their use of the words “personal information” to indicate identifying information such as name, address, and credit card information. Some participants only wanted their data used for research with their explicit consent, and others did not want any of their information used in research, particularly in the case of for-profit companies.

Who They Told

When we asked participants who they had spoken to about the results of their test, most mentioned members of their family (73% of those who reported speaking to anyone), including their partner (15 people), parents (5), or children (2). They also talked to friends (25) and other acquaintances (7) and in a few cases their physician (4). There were also cases where genetic testing was done in order to determine relationships, in which case the participant reported sharing the information with the affected parties (3).

Bad Experiences

We asked participants whether they had any negative experiences as a result of the test they purchased or the results from it. 13% of participants reported that they had some negative experiences, though only a few participants elaborated on the nature of these experiences. The explanations participants gave included being personally upset by the results, family members being upset, finding the results confusing or inconclusive, and feeling their money was wasted.

Recommendations

When we embarked on this project we expected we would find that companies presented privacy risk information in a manner that could be improved in order to increase consumers' understanding of the potential risks. However, we found that many companies provided little or none of the information required for customers to make informed decisions about their privacy. When they did include privacy related information it was most often about aspects of privacy related to the financial transaction or the web interface, rather than privacy implications of genetic testing, disclosing health information, and third parties gaining access to an individual's genetic information. As such, we first present recommendations for best practices regarding what information should be included and how it should be presented. We then offer some implications for regulation, and finally provide a list of questions that consumers should ask themselves and DTCGT companies before purchasing their services.

Best Practices for DTCGT Companies

First, we recommend that DTCGT companies provide a clear definition of all the personal information they collect. While some types of information are clearly personal and sensitive in nature, other types, such as genetic information contained in biological samples (e.g., saliva), may not be evident to customers as a source of identifying information. It is therefore important for the companies themselves, as the experts in genetic testing, to serve as proactive information sources for consumers.

Personal information includes:

- Financial transaction information: name, address, credit card information
- Health information: personal and family health history

- Genetic material: the biological sample provided by consumers
- Genetic testing results: genetic sequence, genetic test results as well as any interpretations
- Online profile and communications: login information as well as the communications between users (if applicable) or users and the company.

While it is incumbent on companies to treat personal data in accordance with PIPEDA, there are a number of considerations that should be made explicit. DTCGT companies should post privacy policies that give clear and complete information about how customers' personal information is treated from collection, to storage, use, access, disposal, and any secondary uses. While a few companies are already doing so, most do not. Providing a privacy policy should be the minimum standard as consumers cannot be expected to anticipate all of the potential implications of genetic testing for their privacy.

Most participants in this study expected that their results and sample would be shared with only them and would be destroyed after use. Consumers should therefore be able to consent to any uses of their sample or data beyond those involved in delivering the service they purchased. These potential secondary uses include the improvement of services, internal and external research, and data sharing between companies and other organizations. Participants were especially concerned with the possibility that their data could be shared with insurance companies, financial companies, credit agencies, law enforcement, the government, and anyone who could profit from it. DTCGT companies must therefore be explicit about the circumstances under which their data could be shared.

If someone consents to participate in research, the company should disclose what information is to be used in that research. While some participants did not want their information shared with anyone else, those who were willing to have it used in research generally indicated that they would be comfortable doing so as long as their identifying information (e.g. name, address, and credit card) was not included. However, genetic information is inherently identifiable and thus anonymity cannot be absolutely guaranteed. In addition, biological samples such as saliva may contain the consumers' genetic information as well as bacteria and drug residue, which would provide different information than the genetic material that was the basis for the initial test (Hawkins & O'Doherty, 2011). Companies must therefore be clear about whether they are sharing people's samples or their information. It should also be noted that the type of research being conducted was important to participants and when they indicated they were willing to have their data shared for research purposes, they were distinguishing this use from uses that led to profit for a company. For this reason, it is important to indicate what type of research might be performed with their data, given that some research does lead to profit.

DTCGT companies should also make clear all of the potential implications of genetic testing. The information gathered from genetic testing may have an impact on people directly in terms of their own wellbeing, contribute to anxiety over potential health outcomes, lead to behaviour change, or simply be a source of uncertainty, especially in the case of inconclusive results. Genetic testing may also affect family relationships. Our participants reported learning about family connections and confirming or disconfirming paternal relationships and some also received health information potentially relevant to other family members. Companies should also disclose any insurance implications for their customers, both current and potential, should the situation in Canada change.

Given the fluid nature of the corporate world and in particular the DTCGT field, it is also important for companies to have a plan in place for what would happen to consumer data and samples if the company dissolves, merges, or is acquired. This plan should be proactively disclosed to consumers so that they are aware of how their personal information could change hands in the future. Companies should also consider and disclose the implications of international mergers and acquisitions as rules to protect consumer data are likely to vary across jurisdictions.

While considerable research has shown that consumers do not often read privacy policies, our sample reported being remarkably likely to do so. 47% overall reported reading the company's privacy policy (64% of those who purchased DTCGT and 33% of those who considered it), and of course not all companies posted a privacy policy. This finding may be an indication that consumers are willing to read privacy policies for certain types of purchases, but more research is needed on this issue. We have indicated that companies should provide privacy policies as not all companies currently do so. However, we also urge DTCGT companies to consider more creative approaches to providing the necessary information for consumers to make meaningful purchase decisions.

When individuals encounter genetic testing through the health care system, they receive genetic counselling before actually making the decision to undergo the test. The purpose of this counselling is to ensure that patients understand the risks and limitations of the decision to undergo testing, and the implications should they test positive for a particular genetic mutation. Moreover, genetic testing through the health care system usually only pertains to a small number of health risks, or even just a single condition. In contrast, the services offered by DTCGT companies cover a large number of health conditions. If testing for even a single genetic condition warrants genetic counselling of the client, it stand to reason that testing for multiple conditions should require at least the same degree of counselling, if not more. Given the expense associated with individualised genetic counselling, at a minimum DTCGT companies could provide tutorials both before and after receipt of genetic testing results to help customers understand the implications and limitations of genetic testing.

Considerations for Regulation

We will not discuss implications for regulation extensively, but do want to draw attention to one issue we encountered when analysing the company websites. Some companies indicate that they will process samples from other people, and in particular, samples that were obtained surreptitiously. Given that biological samples contain a great deal of information about people, and given that this information is personal, it should also be considered private. As such, it should not be left to companies or to consumers to make the decision as to whether or not it is appropriate to submit someone else's biological sample for genetic testing. Doing so is unlikely to result in practices that respect the best interests of the individual. Instead there should be clear laws around whose biological sample one can analyse. Allowances perhaps should be made for parents or guardians who want to test their children's genetic material (though of course this situation has other important implications that deserve further attention but are beyond the scope of this report), but it should not be legally allowable to submit another person's biological sample for genetic testing without that person's express permission. In this case, we believe that regulation is the only way to ensure that privacy is protected.

Guide to Consumers

We also recommend that DTCGT companies and consumer advocates assist customers in becoming more informed about DTCGT before purchasing these services. To encourage more informed decisions, we provide the following question guide for consumers to consider. We hope that it will be useful for stimulating discussion and assisting consumers.

If you are considering genetic testing here are some questions you should be asking:

1. *What happens to my sample after I've sent it to you (how do you process, store, use, share, protect, and dispose of it)?*
2. *Who gets my personal information (name, address, credit card information, personal and family health history, my sample, my genetic sequence, my test results, test interpretation, profile information) and what happens to it once I get my results?*
3. *What are the implications of genetic testing to me and any members of my family?*
4. *What implications are there for my insurance if I get a genetic test?*
5. *Is there anyone I would have to disclose my results to and how might that affect me?*
6. *What resources do you have to help me interpret or cope with my results?*

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Appendix A. Companies Included in Analysis (2013)

Name	Country	Link	Tests Available	Sample	Notes
23 and Me	USA	https://www.23andme.com/you/health/	Health, Ancestry/ Genealogy	Saliva	
Acu-Metrics	Canada	http://www.accu-metrics.com/	Relationship, Health, Ancestry/ Genealogy, Other	Saliva or other discrete samples	
Advanced Healthcare	USA	http://www.advanceddna.in/	Relationship, Ancestry, Other	Saliva	
African Ancestry	USA	http://www.africanancestry.com/	Ancestry/ Genealogy	Saliva	
African DNA	USA	http://www.africandna.com/	Ancestry/ Genealogy	Saliva	
Ancestry by DNA	USA	http://www.ancestrybydna.com/	Ancestry/ Genealogy	Saliva	
Atlas Sports Genetics	USA	http://www.atlasgene.com/	Trait/talent	Saliva	
Britains DNA	Scotland	http://www.britainsdna.com/	Ancestry/ Genealogy, Trait/talent	Saliva	Same content and policies as http://www.scotlandsdna.com/ and http://www.irelandsdna.com/ and http://www.yorkshiresdna.com/
Canadian	Canada	http://www.canadiandnas	Ancestry/	Saliva	

DNA Services		ervices.ca/	Genealogy, Other, Relationship		
Consumer Genetics	USA	http://www.consumergenetics.com/	Relationship, Fetal sex/Prenatal	Blood	
Cygene Direct	USA	http://cygene.infinityarts.com/	Health	Saliva	
DNA Consultants	USA	http://dnaconsultants.com/	Ancestry/ Genealogy	Saliva	
DNA Diagnostics Center	USA	http://www.dnacenter.com/	Relationship, Other	Saliva	
DNA Dimensions	USA	http://www.detroitdna.com/	Relationship, Other, Ancestry/ Genealogy, Health	Saliva	
DNA Findings	USA	https://www.dnafindings.com/	Relationship, Other	Saliva	
DNA Force	Canada	http://www.dnatest.ca/	Relationship, Ancestry/ Genealogy		
DNA ID Check	USA	http://www.dnaidcheck.com/	Relationship, Fetal Sex/Prenatal	Saliva	
DNA LAB CENTER	Un-specified	http://www.dnalabcenter.com/	Relationship, Other	Saliva, blood, other	
DNA Labs India	India	http://www.dnalabsindia.com/	Relationship, Other	Saliva, blood	
DNA People Diagnostics	USA	http://www.dnapaternitytestingcenter.com/	Relationship, Ancestry/ Genealogy, Other, Fetal	Saliva	

			sex/ Prenatal		
DNA PLUS	USA	http://www.dnaplus.com/order.htm	Relationship, Fetal Sex/ Prenatal, Other	Saliva	
DNA Solutions	USA	http://www.dnanow.com/	Relationship, Ancestry/ Genealogy	Saliva or other discrete samples	
DNA Testing Centres of Canada	Canada	http://dnatestingcanada.com/	Relationship, Fetal sex/ Prenatal, Ancestry/ Genealogy, Health		
DNA Tribes	USA	http://www.dnatribes.com/index.html	Ancestry/ Genealogy	Saliva	
DNA Worldwide	UK	http://www.dna-worldwide.com/	Relationship, Ancestry/ Genealogy, Other	Saliva	
DnaCanada	Canada	http://dnacanada.ca/	Relationship	Saliva	
DNAplus	USA	http://www.dnaplus.com/	Relationship, Fetal Sex/ Prenatal, Other	Saliva	
Dynamic Testing Solutions	Canada	http://dynamictesting.ca/?Gclid=CKCq8eyloLgCFao-MgodpnUAEw	Relationship, Other	Saliva or other discrete samples	
EasyDNA	Canada	http://www.easydna.ca/paternity-test.html	Relationship	Saliva or other discrete samples	
EnteroLab	USA	https://www.enterolab.com/StaticPages/TestToOr	Health	Saliva, stool	

		der.aspx			
Executive Health Centre	Canada	http://www.executivehealthcentre.com/shop.php	Health		
Fairfax Identity Laboratories	USA	http://www.fairfaxidlab.com//	Relationship	Saliva	
Family Tree DNA	USA	http://www.familytreedna.com/	Ancestry/ Genealogy	Saliva	Related to World Families
Forensic Genetics Center	Canada	http://www.forensicgeneticscenter.com/	Relationship, Other	Saliva	
Genelex	USA	http://www.genelex.com/	Relationship, Other	Saliva	
Geneplanet	Slovenia	http://www.geneplanet.com/personal-genetic-analysis.html/	Health, Traits/talents	Saliva	
Genetic Genealogy	Canada	http://www.dnaancestryproject.com/index.php?&L=n&__atoken=__NONE__	Ancestry/ Genealogy	Saliva	
Genetrack Biolabs	Canada	http://www.genetrackcanada.com/	Relationship, Other	Saliva	Other Services: www.dnacalculator.org; www.dnareunion.org; www.dnahaplogroups.org; www.indigenousdna.org; www.genebase.com
Geno-graphic	USA	https://genographic.nationalgeographic.com/	Ancestry/ Genealogy	Saliva	

Project					
GFI Lab	USA	http://www.gfilab.com/	Relationship, Other	Saliva	
Graceful Earth	USA	http://gracefulearth.com/	Health	Saliva	
Health Check U.S.A.	USA	https://secure.healthcheckusa.com/resultsinfo.asp	Health	Blood	
Hemo-chromatosis DNA Test	Canada	http://www.hemochromatosisdna.com/dna-testing	Health	Saliva	A service of Genetrack Biolabs
Home DNA Direct	Canada	http://www.homednadirect.ca/	Relationship, Fetal sex/ Prenatal	Saliva	
Home DNA test Ghana	Ghana	http://www.homednatestghana.com/	Relationship, Other	Saliva	
Identigene	USA	http://www.identigene.com/	Relationship	Saliva	Related to http://www.dnatesting.com/
Identigene (DNA testing)	USA	http://www.dnatesting.com/	Relationship	Saliva	
IGENEA	Switzer-land	http://www.igenea.com/en/home	Ancestry/ Genealogy	Saliva	
Indigenous DNA	Canada	http://www.indigenousdna.org/article.php?Type=start&page=2&l=n&__atoken=__NONE	Ancestry/ Genealogy	Saliva	A service of Genetrack Biolabs
Inherent Health	USA	http://www.inherenthealth.com/home.aspx	Health	Saliva	
Interior Workplace Compliance Testing	Canada	http://www.iwct-testing.com/dna-testing.html	Relationship	Un-specified	

Inter-national Biosciences	UK	http://www.ibdna.com/regions/ca/en/?Source=google_canada	Relationship, Other	Saliva	
Life Genetics	Slovenia	http://lifegenetics.net/?Gclid=CNnr3MDLmbgCFZE-MgodWDAAQA	Health	Saliva	
Life Labs	Canada	http://www.lifelabs.com/Lifelabs_ON/default.asp#	Relationship	Saliva, blood	
Map My Genome	India	http://www.mapmygenome.in/	Health, Traits/talent	Saliva	
Market America/Gene SNP	USA	http://yourgenesnp.marketamerica.com/	Health	Saliva	
Matrix Genomics	USA	http://www.matrixgenomics.com/testinterpret.php	Health	Saliva	
Maxxam Analytics	Canada	http://www.thednalab.com/	Relationship, Other	Saliva	
Medcan Clinic	Canada	http://www.medcan.com/services/genetics/	Health	Saliva	
MyHeritage	USA	http://www.myheritage.com/	Ancestry/ Genealogy	Saliva	Family Tree DNA
Natural Care Solution	USA	http://www.naturalcaresolution.com/Telomere-Length-Testing.html	Health	Blood	Connected with Spectra-Cell
Nimble Diagnostics	Un-specified	http://www.nimblediagnostics.com/	Relationship, Ancestry/ Genealogy, Fetal sex/ Prenatal, Other	Saliva or other discrete samples	
Orchid PRO-DNA	Canada	http://www.pro-adn.com/en/index.php	Relationship, Other	Saliva	Related to http://www.orchidcellmark.ca

Oxford Ancestors	UK	http://www.oxfordancestors.com/content/view/22/40/#collection	Ancestry/ Genealogy	Saliva	
Paleo-DNA	Canada	http://www.ancientdna.com/paternity.html	Relationship, Ancestry/ Genealogy	Saliva	
Paternity Test Canada	Canada	http://www.paternitytestcanada.ca/	Relationship	Saliva	http://www.easydna.ca/paternity-test.html
Paternity Testing Centres of Canada	Canada	http://www.paternitydnatesting.ca/	Relationship, Other	Saliva	
Prenatal Genetics	Canada	http://www.prenatalgeneticscenter.com/services/	Relationship, Fetal Sex/ Prenatal		
Roots for Real	England	http://www.rootsforreal.com/service_en.php	Ancestry/ Genealogy	Saliva	
RPC Genetics	Canada	http://www.rpcgenetics.com/welcome	Relationship, Other	Saliva	
Serotech Laboratories LTD	Canada	http://serotech.com/index.php	Relationship	Saliva	
Spectra Cell Laboratories	USA	http://www.spectracell.com/clinicians/products/telomere-testing/	Health	Unspecified	
Swab Test	USA	http://www.swabtest.com/	Relationship	Saliva	
TeloMe	USA	http://www.telome.com	Health	Saliva	
Terraternal	USA	http://www.terraternal.com/Products/ProductDetails/cx/Basic-Telomere-Length-Test/428/102.aspx	Health	Blood	

Test Country	USA	http://www.testcountry.com/	Relationship, Health	Saliva	
The Genetic Testing Laboratories	USA	http://www.gtldna.com/	Health, Relationship, Ancestry/ Genealogy	Saliva, blood	
TNB Laboratories	Canada	http://www.mun.ca/seabright/tnb/paternity.html	Relationship	Blood	
True Health Labs	USA	http://www.truehealthlabs.com/telomere-testing/	Health	Blood, saliva	
Unikey Health Systems	USA	http://www.unikeyhealth.com/product/Telomere_Test/Parasite_Testing	Health	Blood	
Universal Genetics	USA	http://www.dnatestingforpaternity.com/index.html	Relationship	Saliva	
Vitamin Mineral Testing	USA	http://www.vitaminmineraltest.com/telomere-testing/	Health	Blood	
VuGene	USA	http://www.mygenesdirect.com/orders.html	Health	Saliva	
Warrior Roots	USA	http://www.warriorroots.com/	Ancestry/ Genealogy, Trait/talent	Saliva	
Who'z the Daddy?	UK	http://www.whozthedaddy.com/regions/CA/EN/help.asp	Relationship	Saliva	
Youology	Canada/ USA	http://www.youology.com/	Health	Saliva	

Appendix B. Updated List of DTCGT Sites (2015)

Consistent with the findings of other researchers (Singleton et al., 2012), and with our own findings in 2013, there was indeed some mobility in terms of the available companies. Whereas there were 86 companies offering services to Canadians in 2013 (and 27 operating from Canada), in 2015 there are 77 (25 based in Canada). Fourteen sites are no longer available due to expired company websites, their merging with other sites, or recently amended policies that prevent Canadians from accessing genetic tests. Ten sites have been added to the list, 5 of which seem to be new operations.

Name	**Country**	**Link**	**Tests Available**	**Sample**	**Notes**
23 and Me	USA	https://www.23andme.com/	Health, Ancestry/ Genealogy	Saliva	
Acu-Metrics	Canada	http://www.accu-metrics.com/	Health, Relationship, Ancestry/ Genealogy, Other	Saliva or other discrete samples	
Advanced Healthcare	USA	http://www.advanceddna.in/	Relationship, Ancestry/Genealogy, Other	Saliva	
African Ancestry	USA	http://www.africanancestry.com/	Ancestry/ Genealogy	Saliva	
African DNA	USA	http://www.africandna.com/	Relationship, Ancestry/ Genealogy	Saliva	
Ancestry by DNA	USA	http://www.ancestrybydna.com/	Relationship, Ancestry/ Genealogy	Saliva	

Atlas Sports Genetics	USA	http://www.atlasgene.com/	Trait/talent	Saliva	
*Biogene DNA	USA	https://dna-paternity-testing.com/	Health, Relationship, Fetal sex/Prenatal, Ancestry/Genealogy, Other	Saliva or other discrete options	
*BodyStrong	Canada	http://www.bodystrongdna.com/	Health	Saliva	Service also accessible through C2DNA (http://www.c2dna.com/)
Britains DNA	Scotland	http://www.britainsdna.com/	Relationship, Ancestry/ Genealogy, Trait/talent	Saliva	Same content and policies as: http://www.scotlandsdna.com/; http://www.irelandsdna.com/; http://www.yorkshiresdna.com/
Canadian DNA Services	Canada	http://www.canadiandnaservices.ca/	Relationship, Ancestry/ Genealogy, Other	Saliva	
*Check Mate	USA	https://www.getcheckmate.com/	Other	Semen	
Consumer Genetics	USA	http://www.consumergenetics.com/	Relationship, Fetal sex/Prenatal	Saliva, Blood	
*DNA Center Ghana	Ghana	http://www.dnacenterghana.com/	Relationship, Other	Saliva	
DNA	USA	http://dnaconsultants.co	Ancestry/	Saliva or	

Consultants		m/	Genealogy	other discrete samples	
DNA Diagnostics Center	USA	http://www.dnacenter.com/	Relationship, Other	Saliva	
DNA Findings	USA	https://www.dnafindings.com/	Relationship, Other	Saliva	
DNA Force	Canada	http://www.dnatest.ca/	Relationship, Ancestry/ Genealogy	Saliva	Domain name has changed. Old name: http://www.dnatest.ca/
DNA Lab Center	USA	http://www.dnalabcenter.com/	Relationship, Other	Saliva, blood, other	
DNA Labs India	India	http://www.dnalabsindia.com/	Health, Relationship, Other	Saliva, blood	
DNA People Diagnostics	USA	http://www.dnapaternitytestingcenter.com/	Relationship, Ancestry/ Genealogy, Fetal sex/ Prenatal, Other	Saliva	
DNA Plus	USA	http://www.dnaplus.com/	Relationship, Fetal Sex/ Prenatal, Other	Saliva	
DNA Solutions	USA	http://www.dnanow.com/	Relationship, Ancestry/ Genealogy	Saliva or other discrete samples	DNA Canada (http://www.dnacanada.com/) is the Canadian portion of the website; identical information

					and services
DNA Testing Centres of Canada	Canada	http://dnatestingcanada.com/	Health, Relationship, Fetal sex/ Prenatal, Ancestry/ Genealogy	Saliva	
DNA Tribes	USA	http://www.dnatribes.com/	Ancestry/ Genealogy	Saliva	
DNA Worldwide	UK	http://www.dna-worldwide.com/	Relationship, Ancestry/ Genealogy, Other	Saliva or other discrete samples	
Dynamic Testing Solutions	Canada	http://dynamictesting.ca/	Relationship, Other	Saliva or other discrete samples	
EasyDNA	Canada	http://www.easydna.ca/	Health, Relationship, Ancestry/Genealogy, Fetal sex/Prenatal	Saliva or other discrete samples	Service also accessible through Paternity Test Canada (http://www.paternitytestcanada.ca/)
EnteroLab	USA	https://www.enterolab.com/	Health	Saliva, stool	
Fairfax Identity Laboratories	USA	http://www.fairfaxidlab.com/	Relationship, Other	Saliva	
Family Tree DNA	USA	http://www.familytreedna.com/	Ancestry/ Genealogy	Saliva	World Families (http://www.worldfamilies.net/) provides information on DTCGT and links to

					this site for all orders; Affiliated with Gene by Gene (https://www.genebygene.com/)
Forensic Genetics Center	Canada	http://www.forensicgeneticscenter.com/	Relationship, Fetal sex/Prenatal, Other	Saliva or other discrete samples	Prenatal testing orders are routed to Prenatal Genetics Center (http://www.prenatalgeneticscenter.com/)
*Genebase	USA	http://www.genebase.com/	Relationship, Ancestry/Genealogy	Saliva	A service of Genetrack Biolabs
*Gene by Gene	USA	https://www.genebygene.com/	Ancestry/Geneology, Other	Saliva, Blood	
Genelex	USA	http://www.genelex.com/	Health	Saliva	
Geneplanet	Slovenia	http://www.geneplanet.com/	Health, Traits/talents	Saliva	
Genetic Genealogy	USA	http://www.dnaancestryproject.com/	Ancestry/ Genealogy	Saliva	
Genetrack Biolabs	Canada	http://www.genetrackcanada.com/	Relationship, Ancestry/Genealogy, Other	Saliva	Genebase (www.genebase.com/) and Hemo-chromatosis DNA Test (http://www.hemochromatosisdna.com/) are affiliated

					sites
Geno-graphic Project	USA	https://genographic.nationalgeographic.com/	Ancestry/ Genealogy	Saliva	
GFI Lab	USA	http://www.gfilab.com/	Relationship, Other	Saliva	
Graceful Earth	USA	http://gracefulearth.com/	Health	Saliva	
*Health in a Box	Canada	http://healthinabox.ca/	Health, Other	Saliva and other discrete samples	Service also accessible through Executive Heath Centre (http://www.executivehealthcentre.com/)
Hemo-chromatosis DNA Test	Canada	http://www.hemochromatosisdna.com/	Health	Saliva	A service of Genetrack Biolabs
Home DNA Direct	Canada	http://www.homednadirect.ca/	Relationship, Fetal sex/ Prenatal	Saliva	
Identigene	USA	http://www.identigene.com/	Relationship	Saliva	Routes to http://www.dnatesting.com/ upon ordering, an Identigene domain
IGENEA	Switzer-land	http://www.igenea.com/en/	Ancestry/ Genealogy	Saliva	
*Impact Genetics	Canada	http://www.impactgenetics.com/	Health	Saliva and other discrete samples	
*Infinite-Health	Canada	http://www.infinite-health.com/dna/index.html	Relationship, Other	Saliva and other discrete	A Canadian collection site

				samples	for Identigene
Interior Workplace Compliance Testing	Canada	http://www.iwct-testing.com/	Relationship	Saliva	
Inter-national Biosciences	UK	http://www.ibdna.com/regions/CA/EN/	Relationship, Other	Saliva	
Life Genetics	Slovenia	http://lifegenetics.net/	Health	Saliva	
Life Labs	Canada	http://www.lifelabs.com/	Health, Relationship	Saliva, blood	
Map My Genome	India	http://www.mapmygenome.in/	Health, Traits/talent	Saliva	
Market America/Gene SNP	USA	http://yourgenesnp.marketamerica.com/	Health	Saliva	
Maxxam Analytics	Canada	http://www.thednalab.com/	Relationship, Other	Saliva	
Medcan Clinic	Canada	http://www.medcan.com/services/genetics/	Health	Saliva	
MyHeritage	USA	http://www.myheritage.com/	Ancestry/ Genealogy	Saliva	Affiliated with Family Tree DNA (http://www.familytreedna.com/)
Nimble Diagnostics	USA	http://www.nimblediagnostics.com/	Relationship, Ancestry/ Genealogy, Fetal sex/ Prenatal, Other	Saliva or other discrete samples	
Orchid PRO-DNA	Canada	http://www.orchidprodna.ca/	Relationship, Other	Saliva	Canadian Division of Orchid Pro DNA: http://www.pr

					o-adn.com/
Oxford Ancestors	UK	http://www.oxfordancestors.com/	Ancestry/ Genealogy	Saliva	
Paleo-DNA	Canada	http://www.ancientdna.com/	Relationship, Ancestry/ Genealogy, Other	Saliva	
Paternity Testing Centres of Canada	Canada	http://www.paternitydnatesting.ca/	Relationship, Other	Saliva	
Prenatal Genetics Center	Canada	http://www.prenatalgeneticscenter.com/services/	Relationship, Fetal Sex/ Prenatal	Saliva, Blood	
Roots for Real	England	http://www.rootsforreal.com/	Ancestry/ Genealogy	Saliva or other discrete samples	
RPC Genetics	Canada	http://www.rpcgenetics.com/welcome	Relationship, Other	Saliva	
Serotech Laboratories LTD	Canada	http://serotech.com/	Relationship, Other	Saliva	
Spectra Cell Laboratories	USA	http://www.spectracell.com/	Health	Blood	
Swab Test	USA	http://www.swabtest.com/	Relationship, Ancestry/Genealogy	Saliva	
Terraternal	USA	http://www.terraternal.com/Products/ProductDetails/cx/Basic-Telomere-Length-Test/428/102.aspx	Health	Blood	
Test Country	USA	http://www.testcountry.com/	Health, Relationship	Saliva	
The Genetic	USA	http://www.gtldna.com/	Relationship,	Saliva,	

Testing Laboratories			Ancestry/ Genealogy	blood	
TNB Laboratories	Canada	http://www.mun.ca/seabright/tnb/paternity.html	Relationship	Blood	Paternity tests are offered to consumers; other genetic tests offered to clinicians
True Health Labs	USA	http://www.truehealthlabs.com/telomere-testing/	Health	Saliva, Blood	
Universal Genetics	USA	http://www.dnatestingforpaternity.com/index.html	Relationship, Other	Saliva	
Vitamin Mineral Testing	USA	http://www.vitaminmineraltest.com/telomere-testing/	Health, Ancestry/Genealogy	Blood	
Who'z the Daddy?	UK	http://www.whozthedaddy.com/regions/CA/EN/	Health, Relationship, Ancestry/Genealogy, Fetal sex/Prenatal, Other	Saliva, Blood	
*YSEQ	Germany	http://www.yseq.net/	Relationship	Saliva	

* Indicates new additions to the table

Appendix C. List of DTCGT Sites No Longer Available (2015)

Name	Country	Link	Tests Available	Sample	Notes
Cygene Direct	USA	http://cygene.infinityarts.com/	Health, Trait/talent	Saliva	Ordering section of site is offline
DNA Dimensions	USA	http://www.detroitdna.com/	Health, Relationship, Other, Ancestry/ Genealogy	Saliva	Testing offered only through appointment/ walk-in
DNA ID Check	USA	http://www.dnaidcheck.com/	Health, Relationship, Fetal Sex/Prenatal	Saliva	Webmaster not available; Website not maintained
Health Check U.S.A.	USA	http://www.healthcheckusa.com/	Health	Blood	Not offering genetic testing to Canadian residents
Home DNA Test Ghana	Ghana	http://www.homednatestghana.com/	Relationship, Other	Saliva	Website is offline
Indigenous DNA	Canada	http://www.indigenousdna.org/	Ancestry/ Genealogy	Saliva	Website is offline; routes to affiliated company Genetrack Biolabs (http://www.genetrackcanada.com/)
Inherent Health	USA	http://www.inherenthealth.com/home.aspx	Health	Saliva	Currently offers genetic testing to US residents only
Matrix	USA	http://www.matrixgenom	Health	Saliva	Website is

Genomics		ics.com/			offline
Natural Care Solution	USA	http://www.naturalcaresolution.com/Telomere-Length-Testing.html	Health	Blood	Ordering section of site is offline; Affiliated with Spectra-Cell (http://www.spectracell.com/)
TeloMe	USA	http://www.telome.com	Health	Saliva	Currently not offering any genetic tests to consumers
Unikey Health Systems	USA	http://www.unikeyhealth.com/product/Telomere_Test/Parasite_Testing	Health	Blood	Currently not offering any genetic tests to consumers
VuGene	USA	http://www.mygenesdirect.com/	Health	Saliva	Website is offline due to extended maintenance
Warrior Roots	USA	http://www.warriorroots.com/	Ancestry/ Genealogy, Trait/talent	Saliva	Website is offline
Youology	Canada/ USA	http://www.youology.com/	Health	Saliva	Website is offline

Appendix D. DTCGT Privacy Survey

What country do you live in?

○ Canada (1) *Note: Only Canadian participants were included*
○ USA (2)
○ Other (3) ____________________

Answer If *Canada* Is Selected

What province or territory do you live in?

○ Alberta (1)
○ British Columbia (2)
○ Manitoba (3)
○ New Brunswick (4)
○ Newfoundland & Labrador (5)
○ Nova Scotia (6)
○ Ontario (7)
○ Prince Edward Island (8)
○ Quebec (9)
○ Saskatchewan (10)
○ Northwest Territories (11)
○ Nunavut (12)
○ Yukon (13)

What is your age (in years)?

What is your gender?

○ Male (1)
○ Female (2)
○ Self identify (3) ____________________

What is your current relationship status?

○ Not dating anyone (1)
○ Casually dating one or more partners (2)
○ In an open relationship (3)
○ Seriously dating one person (4)
○ Living with a partner but not married (5)
○ Engaged (6)
○ Married (7)
○ Other (8)

Do you have any children?

○ Yes (1)
○ No (2)

Answer If Do you have any children? Yes Is Selected
How many children do you have?

How do you describe yourself? Check all that apply:

☐ Black/African Canadian/African American (1)
☐ Middle Eastern/Arabic (2)
☐ South Asian (i.e. Indian, Pakistani) (3)
☐ East Asian (i.e. China, Japan) (4)
☐ Southeast Asian (i.e. Thailand, Philippines, Malaysia) (5)
☐ Hispanic (6)
☐ White/Caucasian (7)
☐ Aboriginal/Native/Indigenous (8)
☐ Other (please describe): (9) ____________________

We are interested in learning about your experiences with direct-to-consumer genetic tests (e.g. paternity tests, finding out your chances of getting cancer, researching your ancestry). These are tests of a genetic sample that you buy directly from a company (for example, through their website, by mail or phone), rather than ordering them through your doctor. Have you ever purchased or considered purchasing a direct-to-consumer genetic test?

○ Yes, I purchased a direct-to-consumer genetic test (1)
○ Yes, I considered it but decided not to buy it (2)
○ No, I have never considered it (3)

Branch 1: *Yes, I* ***considered*** *it but decided not to buy it*

What were your reasons for choosing not to use an online genetic testing company?

Did you have any health concerns that contributed to your decision to consider online genetic testing?

○ Yes (1)
○ No (2)

What were your reasons for considering online genetic testing?

Do you feel that there are any risks to using online genetic testing?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected
What risks do you think might be associated with using these services?

Do you feel that you have better control over your privacy by using an online genetic testing company or through your doctor?

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)
Better privacy online:Better privacy through my doctor (1)	○	○	○	○	○	○	○

To what extent was privacy a motivating factor in considering an online genetic testing company?

Have you ever had a genetic test through your doctor?

○ Yes (1)
○ No (2)
○ I don't know (3)

Did you read the company's privacy policy before considering using the service?

○ Yes (1)
○ No (2)
○ The company didn't have a privacy policy (3)
○ I don't know (4)

Did you feel you got enough information about how the company would treat your information?

○ Yes (1)
○ No (2)
○ Not sure (3)

What did the company say about how they treat your information? Please write down anything you remember:

Which of the following would you give permission for the company to do with your results (i.e. the information from your genetic report)? Check all that apply:

☐ Share the results directly to me (1)
☐ Share them with other users (2)
☐ Use them to improve their services (3)
☐ Use them to do their own research (4)
☐ Share them with other researchers (5)
☐ I don't know (6)
☐ Other (explain): (7) ____________________

What do you think would happen with your genetic sample (i.e. the cheek swab, blood, hair, urine, etc. that you sent to the company) after you got your results? Check all that apply:

☐ They destroy it (1)
☐ They store it in case I need it in the future (2)

☐ They store it for their own use in the future (3)
☐ They use it immediately for their own research but don’t store it (4)
☐ They use it immediately for their own research and store anything that’s left over (5)
☐ They give it to other researchers who are studying the same topic (6)
☐ They give it to other researchers who are studying different topics (7)
☐ I don’t know (8)
☐ Other (please explain): (9) ____________________

Which of the following pieces of information would you have to provide if you signed up for the service?

	I would have to provide...	How important is it for you that the company keeps each of these confidential?				
	Check all that apply: (1)	Not at all Important (1)	Very Unimportant (2)	Neither Important nor Unimportant (3)	Very Important (4)	Extremely Important (5)
Name (1)	☐	○	○	○	○	○
Address (2)	☐	○	○	○	○	○
Credit card number (3)	☐	○	○	○	○	○
Race or ethnic background (4)	☐	○	○	○	○	○
Family health history (e.g. family history of heart disease, cancer, etc.) (5)	☐	○	○	○	○	○

Personal health history (e.g. asthmatic, diabetic, etc.) (6)	☐	○	○	○	○	○
Lifestyle information (e.g. smoking, exercise, eating habits, etc.) (7)	☐	○	○	○	○	○
Reasons for undergoing genetic testing (8)	☐	○	○	○	○	○
Other (please explain): (9)	☐	○	○	○	○	○

Are you concerned about the company passing on your information to other people, organizations, or companies?

○ Yes (1)
○ No (2)

Is there any person, organization, or company you would not want the company to share your information (e.g. name, address, health history, test results) with?

Why would you not want the company to share your information with these people or groups?

Do you have any other comments about your experiences with genetic testing?

Branch 2: *Yes, I* ***purchased*** *a direct-to-consumer genetic test*

What genetic tests have you purchased? Check all categories that apply even if they were part of one test:

☐ Ancestry/Genealogy (e.g. What is my ancestral background?) (1)
☐ Paternity/Relationship (e.g. Who is the father of a child?) (2)
☐ Health-related test (e.g What are my chances of developing diabetes?) (3)
☐ Prenatal genetic testing (e.g How likely is my unborn child to have Cystic Fibrosis?) (4)
☐ Other (please explain): (5) ____________________

Answer If *Health-related test* Is Selected

What type of health-related test did you purchase?

Have you ever ordered a genetic test about someone else (for example, to learn more about your partner's health)?

○ Yes (1)
○ No (2)

What company did you use for your online genetic test? Check all that apply:

☐ 23andme.com (1)
☐ Atlas Sports Genetics (2)
☐ Cygene Direct (3)
☐ DNA Plus (4)
☐ easyDNA (5)
☐ Genelex (6)
☐ Geneplanet (7)
☐ Health Check USA (8)
☐ Home DNA Direct (9)
☐ Inherent Health (10)
☐ Map My Genome (11)
☐ Market America/ Gene SNP (12)
☐ Matrix Genomics (13)
☐ Medcan Clinic (14)
☐ Oxford Ancestors (15)
☐ Prenatal Genetics (16)
☐ Spectra Cell Laboratories (17)
☐ TeloMe (18)
☐ The Genographic Project (19)
☐ True Health Labs (20)
☐ vuGene (21)
☐ Who'z the Daddy? (22)
☐ Other (please specify): (23) ____________________

What type of sample did you provide for the company to perform the test? Check all that apply:

☐ Cheek swab or Saliva (1)
☐ Blood (2)
☐ Hair (3)
☐ Urine (4)
☐ Other (please explain): (5) ____________________

Whose genetic material did you provide? Check all that apply:

☐ My own (1)
☐ My child’s (2)
☐ My partner’s (3)
☐ Past partner’s (4)
☐ Another family member’s (5)
☐ Other (please explain): (6) ____________________

If you provided someone else’s genetic material, did you get their permission?

○ Yes (1)
○ No (2)

Did you have any health concerns that contributed to your decision to use online genetic testing?

○ Yes (1)
○ No (2)

What were your reasons for choosing to use an online genetic testing company?

Do you feel that there are any risks to using online genetic testing?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected

What risks do you think might be associated with using these services?

Do you feel that you have better control over your privacy by using an online genetic testing company or through your doctor?

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)
Better privacy online:Better privacy through my doctor (1)	○	○	○	○	○	○	○

To what extent was privacy a motivating factor in considering an online genetic testing company?

Have you ever had a genetic test through your doctor?

○ Yes (1)
○ No (2)
○ I don't know (3)

Answer If *Yes* Is Selected

How was the experience of having a genetic test through your doctor different from ordering it directly from a company?

Did the genetic testing company provide you with any guidance or counseling before you signed up for the service?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected

Please explain what kind of guidance or counseling they provided before testing:

Did the genetic testing company provide you with any guidance or counseling after giving you your results?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected

Please explain what kind of guidance or counseling they provided after testing:

How well did you understand the results that you were given?

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)
I didn't understand them at all:I understood them very well (1)	○	○	○	○	○	○	○

How did you use the results of your genetic test?

Did you contact your doctor or other health care professional after receiving your results (for example, to help you understand the results or to request additional testing)?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected

Please explain what you contacted them about:

Did you discuss the results of your test with anyone?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected

Please explain who you talked to about your test results:

Have you had any negative experiences as a result of this test or the results that you received?

○ Yes (1)
○ No (2)

Answer If *Yes* Is Selected

Please describe your negative experiences:

Did you read the company's privacy policy before signing up for the service?

○ Yes (1)
○ No (2)
○ The company didn't have a privacy policy (3)
○ I don't know (4)

Did you feel you got enough information about how the company treats your information?

○ Yes (1)
○ No (2)
○ Not sure (3)

What did the company say about how they treat your information? Please write down anything you remember:

Which of the following did you give permission for the company to do with your results (i.e. the information from your genetic report)? Check all that apply:

- ☐ Share the results directly to me (1)
- ☐ Share them with other users (2)
- ☐ Use them to improve their services (3)
- ☐ Use them to do their own research (4)
- ☐ Share them with other researchers (5)
- ☐ I don’t know (6)
- ☐ Other (explain): (7) ____________________

What do you think happens with your genetic sample (i.e. the cheek swab, blood, hair, urine, etc. that you sent to the company) after you get your results? Check all that apply:

- ☐ They destroy it (1)
- ☐ They store it in case I need it in the future (2)
- ☐ They store it for their own use in the future (3)
- ☐ They use it immediately for their own research but don’t store it (4)
- ☐ They use it immediately for their own research and store anything that’s left over (5)
- ☐ They give it to other researchers who are studying the same topic (6)
- ☐ They give it to other researchers who are studying different topics (7)
- ☐ I don’t know (8)
- ☐ Other (please explain): (9) ____________________

Which of the following pieces of information did you provide when you signed up for the service?

	I would have to provide...	How important is it for you that the company keeps each of these confidential?				
	Check all that apply: (1)	Not at all Important (1)	Very Unimportant (2)	Neither Important nor Unimportant (3)	Very Important (4)	Extremely Important (5)
Name (1)	☐	○	○	○	○	○
Address (2)	☐	○	○	○	○	○
Credit card number (3)	☐	○	○	○	○	○
Race or ethnic background (4)	☐	○	○	○	○	○
Family health history (e.g. family history of heart disease, cancer, etc.) (5)	☐	○	○	○	○	○

Personal health history (e.g. asthmatic, diabetic, etc.) (6)	☐	○	○	○	○	○
Lifestyle information (e.g. smoking, exercise, eating habits, etc.) (7)	☐	○	○	○	○	○
Reasons for undergoing genetic testing (8)	☐	○	○	○	○	○
Other (please explain): (9)	☐	○	○	○	○	○

Are you concerned about the company passing on your information to other people, organizations, or companies?

○ Yes (1)
○ No (2)

Is there any person, organization, or company you would not want the company to share your information (e.g. name, address, health history, test results) with?

Why would you not want the company to share your information with these people or groups?

Do you have any other comments about your experiences with genetic testing?