

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

**(Preliminary Report)**

**Review of the literature, DTCGT company websites, and consumer survey**

**September, 2013**

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## **Introduction**

The purpose of this study is to explore the way in which Direct-to-Consumer Genetic Testing (DTCGT) companies communicate privacy risk information to customers and what customers understand of their risks. This document is a preliminary report of the first steps in this process, namely consulting the academic literature and reviewing the way in which DTCGT companies communicate with consumers regarding the use of their private information. These first steps have informed the creation of a survey (also included) that will be used to better understand customers' experiences and understanding of the privacy implications of using the services of private companies to test their genetic material.

## **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, though there is little federal oversight of the practice (Hudson et al., 2007). 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., Cambon-Thomsen, Rial-Sebbag, &

Knoppers, 2007; Heeney, 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 genetic samples with associated 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 some forms of insurance (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. 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. It is for these reasons that we believe that more research is needed regarding the extent to and way in which this model is used by DTCGT. In this first phase of the project, we explore these issues by reviewing the privacy information provided on the websites of DTCGT companies. In the following phase (Fall 2014) we will survey customers to learn more about how they understand the privacy information they are provided.

### **Review of DTCGT Company Websites**

This first stage of the project examines 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 have 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, Erby, Foisie, & Kaphingst, 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 directed 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 provide a genetic sample 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 one of 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 analyzed including their country of origin, their URL, types of tests offered, and sample type required, please see Appendix A.

### *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*

<b>Name</b>	<b>Health Test Type</b>	<b>Overall Rating</b>	<b>Notes</b>
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

<b>Name</b>	<b>(2a) Privacy of Website</b>	<b>(2b) How will information be used</b>	<b>(2c) Definition of Personal Information</b>	<b>(2d) Sample handling</b>	<b>(2e) Confidentiality is discussed</b>
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 information they collect	No	Yes
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*

<b>Name</b>	<b>(3a) Access to information</b>	<b>(3b) Access to sample</b>	<b>(3c) Access to test results</b>	<b>(3d) Protection of PI</b>
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 family involved in medical care	Encryption
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*

<b>Name</b>	<b>(4a) Data Retention</b>	<b>(4b) Sample Retention</b>
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

<b>Name</b>	<b>(5a) Consequences (employment / insurance)</b>	<b>(5b) Consequences (family member)</b>	<b>(5c) Consequences (specific legislation)</b>
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*

<b>Name</b>	<b>(6a) Secondary Use</b>	<b>(6b) If company closes</b>	<b>(6c) Consent - different options?</b>
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	No	No	No

Centre			
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	Yes

		be transferred as a business asset	
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	No contact listed in privacy section	

Solution		
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's 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*

<b>Name</b>	<b>Privacy Policy</b>	<b>Notes</b>
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*

<b>Name</b>	<b>Privacy Policy</b>	<b>Notes</b>
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*

<b>Name</b>	<b>Privacy Policy</b>	<b>Notes</b>
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*

<b>Name</b>	<b>Privacy Policy</b>	<b>Notes</b>
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 genetic samples 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*

<b>Name</b>	<b>"Other" Test Types</b>	<b>Privacy Policy</b>	<b>Notes</b>
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 a review of websites offering DTCGT to Canadians, we have designed a survey to examine what customers understand about the way DTCGT companies use their genetic material. Through the survey, we aim to learn about the following issues relating individuals' use of DTCGT services:

- Their reasons for pursuing this type of testing
- Their experience with the tests and how they use the results
- The way they interpret the privacy-related information provided by the companies
- Whether they have any privacy concerns about providing their genetic material for testing
- Their beliefs about what might happen to their DNA after the DTCGT company has provided them with their test results
- Their understanding of their genetic risks based on their results
- The extent to which they share that information with others (physicians, family, etc)
- Whether they have had any negative experiences as a result of their use of DTCGT
- Their feelings about the types of negative consequences that could occur as a result of the genetic testing
- An assessment of how they believe the potential risks differ when having testing done through a private company (vs. health care system)

Please consult Appendix B for the survey questions.

**Methods**

The survey will be made widely available and advertised in both targeted and general media. First, the researchers have contacts within the biobanking and genetic testing community and may have the opportunity to advertise the study through their publication outlets. For example, Genetic Alliance has indicated their interest in this research and has given preliminary permission to advertise the research through their weekly newsletter. While this is a US-based organization, we will use our relationship with this organization to connect with similar groups in Canada. This method has the advantage of connecting with people who already have an interest in genetic issues, though they might be more informed about these issues than the average DTCGT customer. As a result, we will also advertise the study more broadly across Canada. For example, we may use online advertising, newspapers, or radio advertising. This method is less selective, but has the potential to reach many people and may therefore be more effective.

Confirmed participants will be directed to the online survey. The analysis of the survey data will be primarily descriptive, though we will also look for demographic differences in the use of these services. In addition to this quantitative information, we have numerous open-ended questions that enable participants to describe their experiences and concerns. We will look for themes in terms of the types of concerns that participants have in relation to their privacy and compare their understanding of their privacy rights with the information presented by the DTCGT companies.

**Next Steps**

We are in the process of applying for ethics approval from the University of Guelph Research Ethics Board. We anticipate that we will begin participant recruitment

in the late summer or early fall of 2014. Once data collection is complete, we will analyse the data and write our final report documenting the study design and methods, a description of the participants, the key and detailed findings, and conclusions and implications of this research.

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## Appendices

### Appendix A. Companies Included in Analysis

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

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

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

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

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

Life Genetics	Slovenia	<a href="http://lifegenetics.net/?Gclid=CNnr3MDLmbgCFZE-MgodWDAAQA">http://lifegenetics.net/?Gclid=CNnr3MDLmbgCFZE-MgodWDAAQA</a>	Health	Saliva	
Life Labs	Canada	<a href="http://www.lifelabs.com/Lifelabs_ON/default.asp#">http://www.lifelabs.com/Lifelabs_ON/default.asp#</a>	Relationship	Saliva, blood	
Map My Genome	India	<a href="http://www.mapmygenome.in/">http://www.mapmygenome.in/</a>	Health, Traits/talent	Saliva	
Market America/Gene SNP	USA	<a href="http://yourgenesnp.marketamerica.com/">http://yourgenesnp.marketamerica.com/</a>	Health	Saliva	
Matrix Genomics	USA	<a href="http://www.matrixgenomics.com/testinterpret.php">http://www.matrixgenomics.com/testinterpret.php</a>	Health	Saliva	
Maxxam Analytics	Canada	<a href="http://www.thednalab.com/">http://www.thednalab.com/</a>	Relationship, Other	Saliva	
Medcan Clinic	Canada	<a href="http://www.medcan.com/services/genetics/">http://www.medcan.com/services/genetics/</a>	Health	Saliva	
MyHeritage	USA	<a href="http://www.myheritage.com/">http://www.myheritage.com/</a>	Ancestry/ Genealogy	Saliva	Family Tree DNA
Natural Care Solution	USA	<a href="http://www.naturalcaresolution.com/Telomere-Length-Testing.html">http://www.naturalcaresolution.com/Telomere-Length-Testing.html</a>	Health	Blood	Connected with Spectra-Cell
Nimble Diagnostics	Un-specified	<a href="http://www.nimblediagnostics.com/">http://www.nimblediagnostics.com/</a>	Relationship, Ancestry/ Genealogy, Fetal sex/ Prenatal, Other	Saliva or other discrete samples	
Orchid PRO-DNA	Canada	<a href="http://www.pro-adn.com/en/index.php">http://www.pro-adn.com/en/index.php</a>	Relationship, Other	Saliva	Related to <a href="http://www.orchidcellmark.ca">http://www.orchidcellmark.ca</a>
Oxford Ancestors	UK	<a href="http://www.oxfordancestors.com/content/view/22/40/#collection">http://www.oxfordancestors.com/content/view/22/40/#collection</a>	Ancestry/ Genealogy	Saliva	
Paleo-DNA	Canada	<a href="http://www.ancientdna.com/paternity.html">http://www.ancientdna.com/paternity.html</a>	Relationship, Ancestry/	Saliva	

			Genealogy		
Paternity Test Canada	Canada	<a href="http://www.paternitytestcanada.ca/">http://www.paternitytestcanada.ca/</a>	Relationship	Saliva	<a href="http://www.easyna.ca/paternity-test.html">http://www.easyna.ca/paternity-test.html</a>
Paternity Testing Centres of Canada	Canada	<a href="http://www.paternitytesting.ca/">http://www.paternitytesting.ca/</a>	Relationship, Other	Saliva	
Prenatal Genetics	Canada	<a href="http://www.prenatalgeneticscenter.com/services/">http://www.prenatalgeneticscenter.com/services/</a>	Relationship, Fetal Sex/Prenatal		
Roots for Real	England	<a href="http://www.rootsforreal.com/service_en.php">http://www.rootsforreal.com/service_en.php</a>	Ancestry/Genealogy	Saliva	
RPC Genetics	Canada	<a href="http://www.rpcgenetics.com/welcome">http://www.rpcgenetics.com/welcome</a>	Relationship, Other	Saliva	
Serotech Laboratories LTD	Canada	<a href="http://serotech.com/index.php">http://serotech.com/index.php</a>	Relationship	Saliva	
Spectra Cell Laboratories	USA	<a href="http://www.spectracell.com/clinicians/products/telomere-testing/">http://www.spectracell.com/clinicians/products/telomere-testing/</a>	Health	Unspecified	
Swab Test	USA	<a href="http://www.swabtest.com/">http://www.swabtest.com/</a>	Relationship	Saliva	
TeloMe	USA	<a href="http://www.telome.com">http://www.telome.com</a>	Health	Saliva	
Terraternal	USA	<a href="http://www.terraternal.com/Products/ProductDetails/cx/Basic-Telomere-Length-Test/428/102.aspx">http://www.terraternal.com/Products/ProductDetails/cx/Basic-Telomere-Length-Test/428/102.aspx</a>	Health	Blood	
Test Country	USA	<a href="http://www.testcountry.com/">http://www.testcountry.com/</a>	Relationship, Health	Saliva	
The Genetic Testing Laboratories	USA	<a href="http://www.gtldna.com/">http://www.gtldna.com/</a>	Health, Relationship, Ancestry/Genealogy	Saliva, blood	

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

**Appendix B. DTCGT Privacy Survey**

We are interested in learning more 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 a direct-to-consumer genetic test?

Yes

No [end]

**About You**

What country do you live in?

Canada

USA

Other (please specify):

[If Canada]

What province or territory do you live in?

Alberta

British Columbia

Manitoba

New Brunswick

Newfoundland & Labrador

Nova Scotia

Ontario

Prince Edward Island

Quebec

Saskatchewan

Northwest Territories

Nunavut

Yukon

[If USA]

What state do you live in?

Alabama  
Alaska  
Arizona  
Arkansas  
California  
Colorado  
Connecticut  
Delaware  
Florida  
Georgia  
Hawaii  
Idaho  
Illinois  
Indiana  
Iowa  
Kansas  
Kentucky  
Louisiana  
Maine  
Maryland  
Massachusetts  
Michigan  
Minnesota  
Mississippi  
Missouri  
Montana  
Nebraska  
Nevada  
New Hampshire  
New Jersey  
New Mexico  
New York  
North Carolina  
North Dakota  
Ohio  
Oklahoma  
Oregon  
Pennsylvania  
Rhode Island  
South Carolina  
South Dakota

Tennessee  
Texas  
Utah  
Vermont  
Virginia  
Washington  
West Virginia  
Wisconsin  
Wyoming

What is your age (in years)? [restrict to 3 numbers]

What is your gender?

Male  
Female  
Other or questioning

What is your current relationship status?

Not dating anyone  
Casually dating one or more partners  
In an open relationship  
Seriously dating one person  
Living with a partner but not married  
Engaged  
Married

Do you have any children?

Yes  
No

[If yes]

How many children do you have? [restrict to 2 numbers]

How do you describe yourself? Check all that apply:

Black/African Canadian/African American  
Middle Eastern/Arabic  
South Asian (i.e. Indian, Pakistani)  
East Asian (i.e. China, Japan)  
Southeast Asian (i.e. Thailand, Philippines, Malaysia)  
Hispanic  
White/Caucasian

Aboriginal/Native/Indigenous  
Other (please describe):

**Details of the 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?)

Paternity/Relationship (e.g. Who is the father of a child?)

Health-related test (e.g. What are my chances of developing diabetes?)

Prenatal genetic testing (e.g. How likely is my unborn child to have Cystic Fibrosis?)

Other

**[Branch based on test type]**

[If Health]

What type of health-related test did you purchase? **[open ended]**

[If other]

Please explain what type of genetic test you purchased: **[open ended]**

**[For each test]**

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

23andme.com

Atlas Sports Genetics

Cygene Direct

DNA Plus

easyDNA

Genelex

Geneplanet

Health Check USA

Home DNA Direct

Inherent Health

- Map My Genome
- Market America/ Gene SNP
- Matrix Genomics
- Medcan Clinic
- Oxford Ancestors
- Prenatal Genetics
- Spectra Cell Laboratories
- TeloMe
- The Genographic Project
- True Health Labs
- vuGene
- Who'z the Daddy?
- Other (please specify):

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

- Cheek swab or Saliva
- Blood
- Hair
- Urine
- Other (please explain):

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

- My own
- My child's
- My partner's
- Past partner's
- Another family member's
- Other (please explain):

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

Yes

No

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

Yes

No

### **Using the Service**

What were your reasons for choosing to use an online genetic testing company? [open ended]

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

Yes

No

[If yes]

What risks do you think might be associated with using these services? [open ended]

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

Better privacy online... Better privacy through my doctor

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

Not a motivating factor.... Strong motivating factor

Have you ever had a genetic test through your doctor?

Yes

No

[If yes]

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

### **Using the Results**

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

I didn't understand them at all... I understood them very well

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

Yes

No

[If yes]

Please explain what kind of guidance or counseling they provided before testing: [open ended]

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

Yes

No

[If yes]

Please explain what kind of guidance or counseling they provided after testing: [open ended]

How did you use the results of your genetic test? [open ended]

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

No

[If yes]

Please explain what you contacted them about: [open ended]

Did you discuss the results of your test with anyone?

Yes

No

[If yes]

Please explain who you talked to about your test results: [open ended]

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

Yes

No

[If yes]

Please describe your negative experiences: [open ended]

### **Privacy and Genetic Testing**

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

Yes

No

The company didn't have a privacy policy

I don't know

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

Yes

No

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

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

Only share the results directly to me

Share them with other users

Use them to improve their services

Use them to do their own research

Share them with other researchers

I don't know

Other (explain):

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

They store it in case I need it in the future

They store it for their own use in the future

They use it immediately for their own research but don't store it

They use it immediately for their own research and store anything that's left over

They give it to other researchers who are studying the same topic

They give it to other researchers who are studying different topics

I don't know

Other (please explain):

Which of the following pieces of information did you provide when you signed up for the service? Check all that apply

Name

Address

Credit card number

Race or ethnic background

Family health history (e.g. family history of heart disease, cancer, etc.)

Personal health history (e.g. asthmatic, diabetic, etc)

Lifestyle information (e.g. smoking, exercise, eating habits, etc.)

Reasons for undergoing genetic testing

Other (please explain):

How important is it for the company to keep each of these confidential?

Not at all important... Very important

Name

Address

Credit card number

Family health history (e.g. family history of heart disease, cancer, etc.)

Personal health history (e.g. asthmatic, diabetic, etc.)

Lifestyle information (e.g. smoking, exercise, eating habits, etc.)

Reasons for undergoing genetic testing

Other (please explain):

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

Yes

No

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? [open ended]

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

Do you have any other comments about your experiences with genetic testing? [open ended]