DOES THE LAW CREATE BOUNDARIES LIMITING GENEALOGICAL EXPLORATION THROUGH DNA IN CANADA?

MARGARET ANN WILKINSON

Margaret Ann Wilkinson is Professor Emerita in the Faculty of Law, Western University, currently continuing as Adjunct Full Professor.

Where we come from has long been a human preoccupation and, in the twentieth century, contributed to the popularization of the social sciences in history.[1] Now, at the dawn of the twenty-first century, it is new science, rather than social science, that is allowing individuals to respond to their curiosity about their pasts with a heretofore unprecedented level of specificity: the science of DNA. Whereas other scientific discoveries have fuelled progress in many disciplines through many different types of discoveries and methodologies, a key output of research into human DNA has been the discovery of unique and immutable individual-level data. The uses to which this individual-level data can be put are wide-ranging and many – and herein lie the challenges.

If we suppose that limits should be placed upon the use of an individual's DNA information, how would we expect those limits to be created? Typically, one of the sources of control in society is the law. But the effect of laws is limited to the jurisdictions which create them, and one of the problems we are experiencing in the "information age" is that information exchange is very difficult to keep within the bounds of legal borders.

Assuming for a moment that our laws can be effective in regulating the use of DNA information within the boundaries of the jurisdictions that create those laws, on what principles would we wish to have DNA information use limited?

Decades before DNA became the widespread tool it is now, quite a few nations began to worry about whether individuals were legally protected from having data about them shared. Canada was one of those nations. Over the past quarter-century, the

1 Cochran, Thomas C., "The Social Sciences and the Problem of Historical Synthesis," The Social Sciences in Historical Study, Social Science Research Council, New York 1954, pp 154-171.

"quilt" of statutes shown in the table below has been created by Canada's governments in order to protect the privacy of individuals in Canada.

The way these laws work is that the responsibility for adhering to them falls to organizations in Canada. Thus if an individual in Canada is doing genealogy as a hobby – and, in the pursuit of that hobby, collects information about other individuals, that genealogist is not limited in their use of that information in any way. But if an individual in Canada, even that same individual mentioned in the previous sentence, does genealogy in connection with a business, or for another organization (whether an organization in the private sector or the public sector), then, in such as context, there will be limitations put upon that genealogist's ability (a) to collect information about a living individual (or, in many cases, about those who have recently died[2]), or, if the information is collected, (b) to use or (c) disseminate the information or (d) dispose of the information.[3] In the same way, if the hobby genealogist comes upon information that is personally identifiable to another individual (for instance, DNA information for a relative of the genealogist), and tries to provide that information to a public or private sector organization in Canada (for instance, a healthcare organization), it is extremely unlikely, under Canadian law, that that organization would accept that information unless the individual who is most closely connected with it gives their consent.[4] The key principle in these laws is that the individual who is identified in the information held by organizations governed by these laws is the individual whose wishes regarding the treatment of the information bind the treatment of the information by any organization accepting it, holding it, seeking to transfer it, or seeking to dispose of it.

These concepts underlying personal data protection legislation create at least two problems in terms of DNA information: First, to which individual does the

2 Organizations are required to protect personally identifiable information for varying lengths of time in Canada. In most cases, the legislation requires that organizations protect information about individuals for their lifetimes and then for a period of years after their deaths. The number of years after death that information must be protected varies by jurisdiction and by type of personal data protection legislation. The shortest period protected after death is the ten years of protection provided by Manitoba in its *Freedom of Information and Protection of Privacy Act*. The longest period of protection after death is fifty years, in the health sector statutes of Newfoundland and Labrador, Nova Scotia, New Brunswick, Ontario and the Yukon. In Newfoundland and Labrador, Nova Scotia and New Brunswick (but not the Yukon) even if the individual has not been dead for fifty years, if more than 120 years have elapsed since the creation of the record, the individual's information can be released. Indeed, in a number of jurisdictions, in at least one of their enactments, it is provided that personal data can be released by an organization governed under the legislation either a period of years after the death of the individual or, if earlier, a number of years after the record was created. PIPEDA, for example, provides protection for an individual's information held by affected organizations for either 20 years after the individual's death or until the record in question has existed for more than 100 years. Newfoundland's *Access to Information and Protection of Privacy Act*, on the other hand, also provides for 20 years after death but opts, in the alternative, for just 50 years protection after a record was created. In general, jurisdictions have tended to protect individuals' information in health contexts longer than individuals' information in other contexts.

3 Because the activities of that genealogist, acting as part of that organization, will fall under the jurisdiction of one or more of the statutes listed in the table.

4 In *Re Halton Healthcare Services* (8 January 2016) Ontario Information & Privacy Complaint HA14-90, a brother had sought disclosure from a hospital of his deceased sister's health information to himself, his mother and a sister, citing PHIPA (ss. 38(4)(c) "spouse, partner, sibling or child… if the recipients of the information reasonably require the information to make decisions about their own health care or their children's health care," and the hospital had refused to disclose. While the Assistant Commissioner directed the hospital to further consider its refusal to disclose, the Assistant Commissioner did emphasize that "It goes without saying that… the [hospital] turn its mind to the request for disclosure, and whether the person seeking the information meets the conditions permitting disclosure."[para 21].

information "belong"? Secondly, Canada's laws only reach organizations and businesses that are in Canada; if information is sent outside Canada by individuals in Canada, then none of these laws are relevant.

In a recent article, Smart *et al.*[5] connect the uses of DNA information for genealogy with uses related to health and consider how healthcare practitioners should approach possible uses for information gathered originally through genealogical research. Indeed, one of their five recommendations is that:

> Policy-makers and government agencies may wish to reconsider current oversight regimes for direct-to-consumer genetic testing in light of the increasingly porous boundaries between tests for health and ancestry[6].

But first, before considering this recommendation in Canada, it must be established, under Canadian law, whether it would be appropriate for healthcare professionals (or anyone) to use information about living (or recently deceased) relatives, gathered through DNA testing, without the relatives' express permission.

In light of the definitions of "personal information" in these laws,[7] DNA from any individual does not belong to a relative (even if the DNA results of one individual were connected closely to those of another) and the medical practitioner would only be able to consider the DNA information of their patient (unless there was an independent consent provided from the other person). Another problem with DNA information gathered through genealogical research is that there is no one, under Canada's laws, who can give consent to allow the gathering of personal information about individuals who are deceased but whose data is still protected by the relevant personal data protection statute: a deceased person's personal representatives (such as an executor) does not have this power.

So, indeed, in answer to our initial question, the law in Canada *does* create boundaries limiting genealogical exploration through DNA. However, *a further question* remains for Canadian lawmakers and those in Canada who value their privacy: does the law in Canada apply to the DNA-related activities of Canadian genealogists? Here the problem is that the major genealogy databases are not subject to Canadian laws: AncestryDNA, FamilyTreeDNA and 23andME are all based in the United States and use labs located there. Not only are the activities of these companies not protected under Canadian law but, as Patrick Cain said some years ago: "Whatever the privacy policies of any given company may say, you have no way of knowing whether they are being adhered to or what may happen to your sample as companies are bought and sold in the future."[8]

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5 Andrew Smart, Deborah Bolnick & Richard Tutton, "Health and genetic ancestry testing: time to bridge the gap" (2017) 10:3 BMC Med Genomics.

6 Ibid, p 8.

7 See, for example, PIPEDA, s 2(1) where personal information is defined as "information about an identifiable individual."

8 Patrick Cain,"Privacy risks lurk in DNA tests, experts warn," *Global News* (15 August 2016), www.globalnews.ca/news/2879276/privacy-risks-lurk-in-dna-tests-experts-warn.

TABLE 1. PERSONAL DATA PROTECTION STATUTES IN CANADA

PROVINCE OR TERRITORY	GOVERNING PRIVATE SECTOR ORGANIZATIONS	GOVERNING PUBLIC SECTOR ORGANIZATIONS	GOVERNING HEALTH INFORMATION IN BOTH PUBLIC & PRIVATE SECTORS
In Federally Regulated Institutions	*Personal Information Protection and Electronics Documents Act*[9] [PIPEDA]	*Privacy Act*[10]	PIPEDA
Newfoundland and Labrador	PIPEDA	*Access to Information and Protection of Privacy Act*[11]	*Personal Health Information Act*[12]
Nova Scotia	PIPEDA	*Access to Information and Protection of Privacy Act*[13]	*Personal Health Information Act*[14]
Prince Edward Island	PIPEDA	*Access to Information and Protection of Privacy Act*[15]	PIPEDA and *Health Information Act*[16]
New Brunswick	PIPEDA	*Access to Information and Protection of Privacy Act*[17]	*Personal Health Information Privacy and Access Act*[18]
Quebec	An *Act Respecting the Protection of Personal Information in the Private Sector*[19]	*Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information*[20]	PIPEDA and An *Act to amend the Act respecting health services and social services*[21] and *Health Insurance Act*[22] and *Act respecting* the Régie de l'assurance maladie du Québec[23]
Ontario	PIPEDA	*Freedom of Information and Protection of Privacy Act*[24]	*Personal Health Information Protection Act*[25]
Manitoba	PIPEDA	*Freedom of Information and Protection of Privacy Act*[26]	PIPEDA and Personal Health Information Act[27]
Saskatchewan	PIPEDA	*The Local Authority Freedom of Information and Protection of Privacy Act*[28]	PIPEDA and *Health Information Protection Act*[29]

9 RSC 2000, C 5.
10 RSC 1985, c P-21.
11 SNL 2015, c A-1.2.
12 SN 2008, c P-7.01.
13 RSNS 1993, c 5.
14 SNS 2010, c 41.
15 RSPEI F-15.01.
16 SPEI 2014, c 31.
17 SNB 2009, c R-10.6.
18 SNB 2009, c P-7.05.
19 CQLR, c P-39.1.
20 CQLR, c A-2.1.
21 CQLR, c S-4.2.
22 CQLR, c A-29.
23 CQLR c R-5.
24 RSO 1990, c F-31.
25 SO 2004, c 3.
26 CCSM 1997, c F175.
27 CCSM c P33.5.

Alberta	*Personal Information Protection Act*[30]	*Access to Information and Protection of Privacy Act*[31]	PIPEDA and Health Information Protection Act[32]
British Columbia	*Personal Information Protection Act*[33]	*Access to Information and Protection of Privacy Act*[34]	PIPEDA
Nunavut	PIPEDA	*Access to Information and Protection of Privacy Act35*	PIPEDA
Northwest Territories	PIPEDA	*Access to Information and Protection of Privacy Act*[36]	PIPEDA and *Health Information Act*[37]
Yukon	PIPEDA	*Access to Information and Protection of Privacy Act*[38]	PIPEDA and *Health Information Privacy and Management Act*[39]

28 RSS 1990-91, c L-27.

29 SS 1999, c H-0.021.

30 SA 2003, c P-6.5.

31 SA 2003, c P-6.5.

32 RSA 2000, c H-5.

33 SBC 2003, c 63.

34 RSBC 1996, c 165.

35 SNWT 1994, c 20 (currently being used by Nunavut; see www.gov.nu.ca/eia/access-information-and-protection-privacy-atipp-act).

36 SNWT 1994, c 20.

37 SNWT 2014, c 2.

38 SY 2018, c 9.

39 SY 2016, c 16.