

Is There a Privacy Interest in Anonymized Personal Health Information?

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[F]irst and foremost we must distinguish between the different moral reasons that may justify data-protection regimes for health data...I think that some of the hard privacy problems could indeed be resolved if this issue of the practical meaning of privacy would be addressed head-on...¹

One cannot open a newspaper, walk into a bank, or access a reputable interactive website without encountering an item on privacy of information. Ten years ago, Canadians (unlike our neighbours to the South) approached privacy issues in nonchalant fashion...after all, there was nothing to hide. And few were concerned about privacy protections for our health information, because physicians are the most trustworthy of individuals. Besides, who would want to know?

The world can change with the nod of a hat. Privacy, or the lack thereof, has become a matter of immediate and pressing concern for Canadians. Legislative initiatives proceed apace. The common law, while slower to rise to the task, is gradually embracing the need for protection of privacy. Former Federal Privacy Commissioner George Radwanski has referred to privacy as "...the defining issue of this new decade."²

A major reason for this rapid shift is the electronicization of information. The advent of computers has led to a cornucopia of resources, referred to by Dale Gibson as the "personal information industry."³ Mass amounts of data are compiled and are capable of being merged with other databases instantaneously. Most of us remain unaware of the volume and scope of personal information accumulated about ourselves until a scandal erupts. Such was the result of the revelation by then Privacy Commissioner, Bruce Phillips, that Human Resources Development Canada had compiled a database containing information on 33.7 million Canadians,

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¹Jeroen van den Hoven, "Privacy and health information: the need for a fine-grained account" (2000) 12 *International J. Quality in Health Care* 5.

²George Radwanski, Privacy Commissioner of Canada (April 2001), cited in Kevin Whitaker *et al.*, eds., *Labour Arbitration Yearbook 2001-2002*, vol. 2 (Toronto: Lancaster House, 2002) at 1.

³Dale Gibson, "Regulating the Personal Information Industry" in Dale Gibson, ed., *Aspects of Privacy Law: Essays in Honour of John M. Sharp* (Toronto: Butterworths, 1980).

with up to 2,000 items of information per person.⁴ Human Resources Development Canada, already under fire for mismanagement of funds, backed off quickly and announced that it would destroy the database. But so long as the separate databases exist, they are still capable of rapid merger.⁵

Health information is viewed as the most private of information due to its intimately personal nature. LaForest J. on behalf of the Supreme Court of Canada referred to it as "...information that is highly private and personal to the individual. It is information that goes to the personal integrity and autonomy of the patient."⁶ Beyond dispute it is worthy of the highest degree of protection.

The electronic era has had a formidable impact on health information. Electronic databases have been accumulating for many years, primarily for medicare insurance billing purposes. Recent phenomena include a major momentum toward evidence-based decision making in health care, most recently championed in the Romanow⁷ and Kirby⁸ reports. Also, as greater and greater numbers of health care providers may be involved in providing services to a patient, the system has espoused the concept of "seamless care". This in turn requires access by many individuals to personal health information, facilitated by the utilization of electronic health records in various settings in Canada. All of these records are now seen as valuable sources of information for multiple uses, including research, audit and quality control.

It is possible, in a number of contexts, for information to be stripped of personal identifiers prior to its utilization. Electronicization has facilitated our ability to do so, whilst retaining the ability to re-link data where necessary for verification of results. The argument is often made that once information has been anonymized such that individuals cannot be identified, the information may be utilized for various purposes without concern. In this paper, I examine the vexing question faced by governments, the courts, the Canadian research community, and other interest groups as to whether or not there remains a privacy interest in law on behalf of the individual who was the source of the personal information.

⁴Shawn McCarthy "Big Brother files raise privacy fear" *The Globe and Mail* (17 May 2000) A1. The information was compiled from income-tax returns, child-tax benefit statements, immigration and welfare files, social insurance master file, National Training program, Canadian Job Strategy, employment services, employment insurance, and job records.

⁵B.J. Cowan "Feds won't throw Big Brother data away, suggests former CSIS analyst" *The Edmonton Sun* (30 May 2000).

⁶*McInerney v. MacDonald* (1992), 93 D.L.R. (4th) 415 at 422 (S.C.C.) [*McInerney*].

⁷Canada, Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada*, (Ottawa: Commission on the Future of Health Care in Canada, 2002) (Commissioner: Roy J. Romanow, Q.C.) [Romanow Report].

⁸Canada, Standing Senate Committee on Social Affairs, Science and Technology, *The Health of Canadians – The Federal Role*, vols. 1-6, (Ottawa: Government of Canada, 2001-2002) (Chair: The Honourable Michael J.L. Kirby) [Kirby Report].

Following an overview of the legal landscape relevant to personal health information in Canada, I provide a brief examination of the theoretical foundations of the privacy interest in law. My aim in this portion is to grapple with why the privacy interest is seen as worthy of protection. I then apply the various theoretical approaches to the issues surrounding legitimate uses of de-identified personal health information. For our purposes this should be taken to mean person-level health information that has been stripped of identifiers by which an individual may reasonably be identified. There are at present multiple uses made of such information without our knowledge or consent. Governments, researchers and funding agencies alike are striving to delineate the circumstances under which access should be provided to personal health information absent the consent of the individual. The answer surely depends on our view of why health information should be protected.

While no Canadian court has ruled directly on this issue, the English Court of Appeal in *In Re Informatics Ltd.*⁹ has determined that a privacy interest does not subsist in anonymized health information. The Court's analysis was that if there is not a risk of embarrassment to the individual due to disclosure of his/her identity, no privacy interest remains. The Court interpreted the concept of "privacy" in narrow fashion to reach this result.

I compare the approach taken by the English Court of Appeal to that of the Supreme Court of Canada in a number of cases analysing the privacy interest in law, primarily but not exclusively in the context of the *Canadian Charter of Rights and Freedoms*.¹⁰ My preliminary conclusion is that there appears, according to Canadian jurisprudence, to remain a privacy interest that should be taken into account in decisions as to legitimate uses of de-identified personal health information. This does not necessarily imply that consent of the individual must be obtained for use of such information, but rather, that the individual privacy interest must be factored into the analysis and balanced against other interests at stake. I view this paper as an initial step in the analysis of the privacy¹¹ interest in de-identified personal health information.

⁹ [1999] E.W.J. No. 6880 (C.A.)(QL).

¹⁰ Part 1 of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11. [*Charter*].

¹¹ Note that privacy is viewed as the right of the individual to control personal information, and confidentiality as the duty owed by the holder of another's information to safeguard its privacy: Canada's Health Informatics Association, *Security and Privacy Guidelines* (Edmonton: Healthcare Computing & Communications Canada, 1995) at 88-90.

Overview of the Landscape

The Supreme Court of Canada as far back as 1928 identified personal health information as being confidential to the physician-patient relationship,¹² and the Hippocratic Oath¹³ and Codes of Ethics for the various health professions establish the right to confidentiality.¹⁴ However, the common law in Canada has been reticent to establish a right to privacy protection more generally. At present, a handful of trial level decisions in Ontario have found the existence of a common law tort of invasion of privacy.¹⁵ Thus far, these cases have primarily concerned invasions that may be described as forms of harassment as opposed to violations of the protection of information. A number of provinces have enacted privacy acts that establish a statutory tort of invasion of privacy, allowing individuals to sue in limited circumstances for violations of their privacy.¹⁶ The number of suits launched under these statutes thus far has been low, due in part to restrictions within the wording¹⁷ and in part to a lack of awareness by the public.

Governments have identified a responsibility to protect information held by them; thus there are federal and provincial/territorial statutes whose purpose is to safeguard and to specify terms of access to such information.¹⁸

A major legislative initiative occurred recently with the enactment of the federal *Personal Information Protection and Electronic Documents Act*, (*PIPEDA*),¹⁹ which sets limits on the collection, use, and disclosure of information for commercial purposes (whether electronic or otherwise) in the private sector.

¹² *Halls v. Mitchell*, [1928] S.C.R. 124.

¹³ W. Henry Jones, *Hippocrates*, (Cambridge: Harvard University Press, 1923) [translated by author], cited in M. Marshall & Barbara von Tigerstrom, "Health Information" in J. Downie, T.A. Caulfield & C. Flood, eds., *Canadian Health Law and Policy*, 2d ed. (Toronto: Butterworths, 2002) 157 at 190.

¹⁴ "Model Standards of Practice for Canadian Pharmacists", online: National Association of Pharmacy Regulatory Authorities <<http://www.napra.org/practice/standards.html>>; Canadian Medical Association, "Code of Ethics", online: Canadian Medical Association <http://www.cma.ca/menu/displayMenu.do?tab=422&skin=432&pMenuId=1&pSubMenuId=1&pageId=staticContent/HTML/N0/12/where_we_stand/code.htm>; Canadian Nurses Association "Code of Ethics for Registered Nurses", online: Canadian Nurses Association <<http://www.cna-nurses.ca/pages/ethics/ethicsframe.htm>>.

¹⁵ *MacKay v. Buelow*, [1995] O.J. No. 867 (Gen. Div.) (QL); *Palad v. Pantaleon*, [1989] O.J. No. 985 (Dist. Ct.) (QL); *Roth v. Roth* (1991), 4 O.R. (3d) 740 (Gen. Div.).

¹⁶ Arts. 35-40 C.C.Q.; Bill 23, *Privacy Act*, 3d Sess., 54th Leg., New Brunswick, 2000 (order for second reading discharged and subject referred to the Standing Committee on Law Amendments); *Privacy Act*, R.S.B.C. 1996, c. 373; *Privacy Act*, R.S.M. 1987, c. P125; *Privacy Act*, R.S.S. 1978, c. P-24; *Privacy Act*, R.S.N. 1990, c. P-22.

¹⁷ Colin H.H. McNairn & Alexander K. Scott, *Privacy Law in Canada* (Toronto: Butterworths, 2001) at 73. As of the year of publication, there had been less than 25 cases wherein the courts had had to decide whether a defendant is liable for invasion of privacy under the Privacy Acts.

¹⁸ See e.g. *Privacy Act*, R.S.C. 1985, c. P-21; *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5 [PIPEDA]; *Freedom of Information and Protection of Privacy Act*, S.N.S. 1993, c. 5, as am. by S.N.S. 1999, c. 11 and S.N.S. 2002, c. 5; *Access to Information Act*, S.A. 1999, c H-4.8.

¹⁹ *PIPEDA*, *ibid.*

This statute applied as of January 2002 to health information that crosses inter-provincial borders,²⁰ and will apply intraprovincially as of January 2004 unless a province or territory is deemed to have enacted substantially similar legislation.²¹ Quebec has legislation that it is anticipated will be declared by the federal government to meet the “substantially similar” test,²² and Ontario has twice attempted to enact private sector legislation governing personal health information.²³

The Supreme Court of Canada has dealt with the issue of privacy of information under the *Charter*, primarily concerning the issue of unreasonable search and seizure by agents of the state under s. 8,²⁴ but also to a limited extent under s. 7²⁵ of the *Charter*:

Everyone has the right to life, liberty, and security of the person, and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

Finally, in the context of health information, the decision of the Supreme Court of Canada in *McInerney v. MacDonald* dealt specifically with personal information held by a physician.²⁶ Also, a number of provinces have enacted legislation aimed at the protection of health information.²⁷ These statutes are not without procedural difficulties, as discovered by the government of Saskatchewan. Bill 29, *The Health Information Protection Act*²⁸ was tabled on April 23, 1999, and received Royal Assent on May 6, 1999, but the legislation has not yet been proclaimed due to the complexities of implementation.²⁹

An individual whose privacy of health information has been invaded is faced with a confusing array of legal networks by which a remedy may be sought. The avenues of redress are unclear and, even if available, usually unfruitful.³⁰ An

²⁰ *PIPEDA*, *ibid.*, s. 30 (2.1).

²¹ *PIPEDA*, *ibid.*, ss. 26 (2)(b), 30.

²² Arts. 35-40 C.C.Q.

²³ Bill 159, *Personal Health Information Privacy Act*, 1st Sess., 37th Parl., Ontario, 2000 (order for second reading discharged); *Privacy of Personal Information Act*, Ontario 2002 (bill drafted but not introduced to legislature).

²⁴ See e.g. *R. v. Dyment*, [1988] 2 S.C.R. 417 [*Dyment*]; *R. v. Ladouceur*, [1990] 1 S.C.R. 1257; *R. v. Kokesch*, [1990] 3 S.C.R. 3; *R. v. Duarte*, [1990] 1 S.C.R. 30 [*Duarte*].

²⁵ See e.g. *Dyment*, *ibid.*; *Thomson Newspapers Ltd. v. Canada (Director of Investigation and Research, Restrictive Trade Practices Division)*, [1990] 1 S.C.R. 425; *R. v. O'Connor*, [1995] 4 S.C.R. 411; *R. v. Mills*, [1999] 3 S.C.R. 668 [*Mills*].

²⁶ *McInerney*, *supra* note 6.

²⁷ *Personal Health Information Act*, S.M. 1997, c. P33.5; *Health Information Act*, S.A. 1999, c. H-4.8.

²⁸ S.S. 1999, c. H-0.021 (Assented to 6 May 1999, not yet proclaimed in force).

²⁹ Saskatchewan Department of Health, “Saskatchewan Health Legislation: The Health Information Protection Act (HIPA)”, online: Saskatchewan Health <http://www.health.gov.sk.ca/ph_br_health_leg_hipamain.html>.

³⁰ McNairn & Scott, *supra* note 17 at 73. The defendants have succeeded in seventy five percent of the cases litigated to date under a Privacy Act.

American judge referred to the privacy interest as a "...haystack in a hurricane...",³¹ presumably being bandied about by gale force winds. LaForest J. referred to privacy as a "...broad and somewhat evanescent concept...".³² As provinces and territories other than Quebec ponder the appropriate course of action in response to the federal *PIPEDA*, and the common law gradually encompasses privacy protections, the need for clarity in aims and purposes comes into focus. The next section examines various theoretical constructs for the protection of privacy.

Theoretical Foundations

An analysis of the privacy interest at law commences with the work of Warren and Brandeis.³³ In the late 1800s, Mr. Warren was appalled at developments in journalistic scandalmongering, particularly when his daughter's wedding and his wife's house parties became the focus of gossip column attention in the *Saturday Evening Gazette*.³⁴ He and his former Harvard Law School colleague, Mr. Brandeis, authored a seminal article arguing in favour of the establishment of a tort of invasion of privacy. They examined several apparently disparate areas of law, including defamation, intellectual property, implied contract, and property. The context may in part have determined the analysis, in that by focussing on importunate media intrusions, they primarily conceive the privacy interest as the "right to be let alone".³⁵ They also refer to the right of inviolate personality, although supplying little by way of definition.

Some sixty years later, Dean Prosser undertook a review of the case law on privacy that had developed since publication of the Warren/Brandeis article.³⁶ He determined that rather than privacy being one interest, as presaged by Warren and Brandeis, the case law suggested four distinct interests protected (and presumably worthy of protection) in American law.³⁷ First is intrusion upon seclusion, in circumstances in which the individual has a reasonable entitlement to privacy. This intrusion may consist of a physical intrusion, but may also comprise eavesdropping or "peeping tommying". He suggests that Warren and Brandeis simply did not have this type of invasion of privacy in mind. Second is the quintessential Warren/Brandeis formulation, i.e., the public disclosure of embarrassing private facts. Unlike in defamation, the truthfulness of the facts does not serve as a defence. One limiting factor is the requirement that the circumstances of disclosure must be offensive and objectionable to a reasonable person of ordinary sensibility.

³¹ *Ettore v. Philco Television Broadcasting Co.*, 229 F.2d 481 (3d Cir.1956) at 4.

³² *R. v. Wise*, [1992] 1 S.C.R. 527 at para. 67, LaForest J. (in dissent).

³³ Samuel D. Warren & Louis D. Brandeis, "The Right to Privacy" (1890) 4 Harv. L. Rev. 193.

³⁴ A.T. Mason & L.D. Brandeis, "A Free Man's Life" (1946), cited in William L. Prosser, "Privacy" (1960) 48 Cal. L. Rev. 383 at 383.

³⁵ Drawing on the work of *Cooley on Torts*, 2nd ed. at 29, cited in Samuel D. Warren & Louis D. Brandeis, "The Right to Privacy" (1890) 4 Harvard L.R. 193 at 195.

³⁶ *Supra* note 34.

³⁷ *Ibid.* at 389.

The remaining types of interest suggested by Prosser to be protected were not discussed by Warren and Brandeis. One is the portrayal of an individual in a “false light” in the public eye. The interest to be protected is that of reputation. An example given is to falsely attribute an opinion to someone. The portrayal need not be defamatory, but frequently is; therefore this area has significant overlap with the area of defamation. The fourth type of violation of privacy identified by Prosser is the appropriation of one’s name or likeness for commercial advantage. The interest protected is proprietary.

From the unifocal interest described by Warren/Brandeis as fundamentally that of the “inviolate person”, then, with Prosser’s analysis we move to a series of protected interests coming under the rubric of privacy, i.e., respectively, mental health (intrusion upon seclusion), reputation (public disclosure of embarrassing private facts and portrayal in a false light in the public eye), and commercial or proprietary (appropriation of one’s name or likeness).

An innovative approach to the topic of privacy is taken by Israeli scholar Ruth Gavison.³⁸ She discerns in the privacy interest three separate but interrelated elements that may be worthy of protection: those of information or knowledge about an individual, attention paid to an individual, and physical access to an individual. These correlate respectively with the values of secrecy, anonymity, and solitude. They share in common the characteristic of accessibility. In other words, she defines the state of perfect privacy as a state of inaccessibility of the individual to others, including the suppression of information, of attention being paid, and of physical access to the individual.

The final major theoretical approach to the privacy interest to be discussed is that of a proprietary interest in information. Alan Westin has defined privacy as “...the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.”³⁹ Ultimately, he argues in favour of a legal approach that views personal information as property:

First, personal information, thought of as the right of decision over one’s private personality, should be defined as a property right, with all the restraints on interference by public or private authorities and due-process guarantees that our law of property has been so skilful in devising.⁴⁰

³⁸ Ruth Gavison, “Privacy and the Limits of Law,” in E. J. Bloustein, “Privacy as an aspect of human dignity: An answer to Dean Prosser” in Ferdinand David Schoeman, ed., *Philosophical Dimensions of Privacy: An Anthology* (New York: Cambridge University Press, 1984) 346.

³⁹ Alan F. Westin, *Privacy and Freedom* (New York: Atheneum, 1970) at 7.

⁴⁰ *Ibid.* at 324-25.

The analysis of personal health information as property has arisen primarily in the context of genetics,⁴¹ but also has broad implications more generally.

The Various Theoretical Approaches as Applied to De-identified Health Information

Let us turn, then, to the question of whether there rests a privacy interest in personal health information that has been stripped of identifiers. A multitude of uses exist and/or are being developed for such information, including monitoring health and disease patterns, ensuring that health care practices are based on the best available evidence, checking quality assurance, and providing seamless care services to the patient despite there being numerous successive healthcare providers. Much of the analysis in this area to date has been undertaken by health researchers,⁴² who have, naturally, a major interest in unimpeded access to de-identified personal information. In the Kirby Report, in the context of discussion of a fully integrated pan-Canadian health care delivery and information network, the confidentiality of personal information and the legal and ethical issues in establishing such a network are referenced as “barriers” to implementation:

According to witnesses, the implementation and full deployment of the pan-Canadian Health Infostructure faces three major barriers: the protection of personal information, legal and ethical issues, and the interoperability of the various systems.⁴³

Planned uses other than research, quality control, and evidence based medicine include targeted physician marketing by pharmaceutical companies, genetic mapping, and other for-profit ventures. Many would view certain forms of research as repugnant, such as that carried out by Phillippe Rushton at the University of Western Ontario purporting to find brain size, and hence IQ, differences by race.⁴⁴ In the National Film Board production “Making Perfect Babies”, Connie Panzarino suffers from a rare neurological disorder called Werdnig-Hoffman disease. She poignantly describes her repulsion to having her genetic material analyzed in order

⁴¹ *Moore v. Regents of the University of California*, (1990) 271 Cal. Rep.146 (Cal. S.C.). See also Lori Andrews & Dorothy Nelkin, *Body Bazaar: The Market for Human Tissue in the Biotechnology Age* (New York: Crown Publishers, 2001); E. Richard Gold, *Body Parts: Property Rights and the Ownership of Human Biological Materials* (Washington: Georgetown University Press, 1996).

⁴² See the extensive and skilled analysis undertaken by the Canadian Institutes of Health Research, *A Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research*, Patricia Kosseim, ed., (Ottawa: Public Works and Government Services Canada, 2000); *Personal Information Protection and Electronic Documents Act: Questions and Answers for Health Researchers*, (Ottawa: Public Works and Government Services Canada, 2001); *Secondary Use of Personal Information in Health Research: Case Studies*, (Ottawa: Public Works and Government Services Canada, 2002).

⁴³ Kirby Report, *supra* note 8, vol. 2 at 116.

⁴⁴ Phillippe Rushton, “Race as a Biological Concept” (4 November 1996), online: David Duke Online <<http://www.duke.org/library/inmate/rushtonracebio.html>>.

that "...no-one else can be born like me. I cannot in all conscience contribute to the elimination of people like myself."⁴⁵

Thus it is appropriate to view different uses of information as falling across a spectrum ranging from societally beneficial through benign to detrimental. Our de-identified personal health information may be utilized for any number of purposes on this spectrum. In light of this, let us turn to a number of theoretical approaches to privacy. Assume, for purposes of discussion, that the information has been sufficiently encrypted that there is no risk of linking the information back to the individual.⁴⁶ Does a privacy interest remain?

Warren and Brandeis' definition of privacy as the "right to be let alone"⁴⁷ would appear to preclude de-identified information being considered as falling within the privacy interest. Since the information is not readily linked back to the individual, the individual *de facto* is being "let alone" when such information is utilized. Likewise, when they speak of a right of inviolate personality, a concept not well developed in their argument, one might reason that no aspect of the personality is invaded by use of personal information that has been de-identified. One would therefore surmise that under the Warren/Brandeis analysis, use of de-identified information, regardless of purpose of the use and regardless as to whether consent has been granted, is acceptable.

The four interests identified by Prosser⁴⁸ likewise do not seem to include under the concept of privacy the use of de-identified information. Such use does not appear in any way to 'intrude upon seclusion'. There is no public disclosure of embarrassing private facts, as the individual is not identifiable from the information. Likewise, the individual is not being portrayed in a false light in the public eye, such that his/her reputation may be sullied. Finally, the fourth interest is that one's name or likeness not be appropriated for commercial advantage. One of the potential uses of de-identified information is for sale of information, as IMS Health Canada does with prescription information collected from pharmacies.⁴⁹ Certainly there is commercial advantage, but the identity of the patient has been stripped from the information such that his/her name and likeness are no longer attached to the

⁴⁵National Film Board, *On the Eighth Day: Perfecting Mother Nature – Part II: Making Perfect Babies*, (1995). Information about this film is available online:

<<http://cmm.onf.ca/E/titleinfo/index.epl?id=33152>>.

⁴⁶This is acknowledged as a major and questionable presumption in the context of many of these uses. However, for purposes of this paper, I chose to deal with the question of whether a privacy interest subsists independently of the possibility of identification of the individual.

⁴⁷*Supra* note 33 at 195.

⁴⁸*Supra* note 34 at 389. Note that of these specified interests, Canadian jurisprudence has only squarely acknowledged that of appropriation of one's name or likeness for commercial advantage, see *Krouse v. Chrysler Canada Ltd.* (1973), 40 D.L.R.(3d) 15 (Ont. C.A.). Aspects of intrusion upon seclusion and portrayal in a false light may be protected at common law under the torts of trespass, nuisance and defamation.

⁴⁹See Privacy Commissioner of Canada, "PIPED Act Case Summary #14", online: Privacy Commissioner of Canada <http://www.privcom.gc.ca/cf-dc/cf-dc_010921_e.asp>.

information. Therefore none of the interests identified by Prosser would appear to recognize a privacy interest in de-identified information.

The analysis of Ruth Gavison,⁵⁰ the reader will recall, identified the elements of information about, attention paid to, and physical access to an individual. She connected these to the values of secrecy, anonymity and solitude, all of which share the characteristic of accessibility of the individual to others. The analysis of a privacy interest in de-identified information would seem to depend on from whose perspective the analysis of accessibility is framed. In other words, if we view the situation from the perspective of the outsider, looking in on the individual, there is no "individual" to be gazing in on in the case of de-identified information. However, if we view accessibility from the perspective of the individual, the values of secrecy and anonymity are respected but the value of solitude in particular may well not be similarly respected. In other words, the individual may legitimately feel that the use of her/his de-identified information without consent violates her solitude, in making her personal information accessible to the outside world. Therefore one is left uncertain on the analysis of Gavison whether or not a privacy interest flows in de-identified personal information.

Finally, the approach that views information as property of the individual⁵¹ would not logically draw a distinction between identifiable and de-identified information; surely if one has a proprietary entitlement to that information, it is only surrendered voluntarily. This implies that the individual chooses subsequent uses for the information. She may decide to part with it, but revealing such information in a situation of trust, such as in the health care provider/patient relationship, is not a surrender of the information but rather a limited and necessary revelation for a specific purpose. The issue of identifiers is irrelevant to the interest at stake. The individual in whose information property vests is entitled to control its distribution and use regardless as to whether that individual is subject to identification via the information.

It may be concluded that the various major theoretical approaches to privacy that have helped to shape our jurisprudence are divided as to whether or not a privacy interest survives once personal health information has been de-identified. The Warren/Brandeis and Prosser formulations would not suggest a privacy interest. Under the Gavison analysis, the outcome of this issue is uncertain. On the other hand, the Westin proprietary approach would squarely acknowledge such an interest. Let us now turn to Canadian judicial interpretation of the privacy interest in law.

⁵⁰ *Supra* note 38.

⁵¹ *Supra* note 34 at 7.

Canadian *Charter* Jurisprudence

The Supreme Court of Canada has formulated the privacy interest in law primarily in the context of the *Charter*. Specifically, the right to privacy has been identified as fundamental to the analysis of s. 8 of the *Charter*, which grants everyone the right to be secure against unreasonable search or seizure. In interpreting this section, LaForest J. stated:

[S]ociety has come to realize that privacy is at the heart of liberty in a modern state; see Alan F. Westin, *Privacy and Freedom* (1970), pp. 349-50. Grounded in man's physical and moral autonomy, privacy is essential for the well-being of the individual.⁵²

In *Duarte*, the Court took a decidedly informational approach to the subject of privacy in the context of search and seizure when it stated as follows:

If privacy may be defined as the right of the individual to determine for himself when, how, and to what extent he will release personal information about himself, a reasonable expectation of privacy would seem to demand that an individual may proceed on the assumption that the state may only violate this right by recording private communications on a clandestine basis when it has established to the satisfaction of a detached judicial officer that an offence has been or is being committed and that interception of private communications stands to afford evidence of the offence.⁵³

Likewise, in *R. v. Plant*, Sopinka J. for the majority indicated that:

Consideration of such factors as the nature of the information itself, the nature of the relationship between the party releasing the information and the party claiming its confidentiality, the place where the information was obtained, the manner in which it was obtained and the seriousness of the crime being investigated allow for a balancing of the societal interests in protecting individual dignity, integrity and autonomy with effective law enforcement.⁵⁴

In addition to the values of physical and moral autonomy, the Court includes within the concept of privacy the values of dignity and integrity of the individual.

The Court has also discussed the privacy interest in the context of s. 7 of the *Charter*. As identified by Letourneau and Robertson J.J.A. of the Federal Court of Appeal in *Ruby v. Canada (Solicitor General)*:

⁵² *Dyment*, *supra* note 24 at 427-28.

⁵³ *Supra* note 24 at para. 25.

⁵⁴ *R. v. Plant*, [1993] 3 S.C.R. 281 at 293.

Section 8 of the *Charter* has been identified as having as its fundamental purpose the protection of individuals from unjustified state intrusions upon their privacy. However, there is an emerging view that an individual's right to privacy is also enshrined in one's liberty interest set out in section 7. This is so because the protection of private life is considered to be at the heart of liberty in a democratic society. Indeed, the Supreme Court's constitutional privacy jurisprudence demonstrates that the Court views privacy as a personal right of the individual based on autonomy, dignity, liberty and security interests.⁵⁵

On appeal, the Supreme Court of Canada declined to address squarely the issue of whether a right to privacy is granted in s. 7 of the *Charter*. Rather, Arbour J. for the full court assumed, without deciding that such a right exists, that the deprivation claimed in this case did not violate the principles of fundamental justice.⁵⁶

It would appear to be well established that privacy is deserving of protection under s. 8 and possibly s. 7 of the *Charter*. However, the content and scope of privacy has not been discussed at length; indeed, it would appear that the privacy analysis is in a primitive phase. We do know that it is to be balanced against other competing interests, including societal needs and the interests of the state in law enforcement, security, and monitoring. This apparently inevitable balancing has found its way into the jurisprudence in part because so much of the analysis has been done under the *Charter*, the framework of which requires such weighing of interests.

In *Mills*, the Supreme Court of Canada discussed privacy concerns as being "...at their strongest where aspects of one's individual identity are at stake..."⁵⁷ One may reasonably infer that other, albeit lesser, concerns are present where one's identity is not implicated.

Charter jurisprudence suggests that the privacy interest in law is grounded in one's dignity, integrity, and autonomy, and may include an interest independent of having one's identity exposed to others. Therefore one may tentatively conclude that a privacy interest exists even if one's personal health information has been de-identified.

⁵⁵ *Ruby v. Canada* (2000), 187 D.L.R. (4th) 675 (F.C.A.) at para. 165.

⁵⁶ *Ruby v. Canada (Solicitor General)*, [2002] S.C.J. No. 73 (QL).

⁵⁷ *Mills*, *supra* note 25 at 722.

Re Source Informatics Ltd.

The English Court of Appeal dealt with the issue of whether or not there subsists a privacy interest in anonymized information in *Re Source Informatics Ltd.*⁵⁸ Source Informatics wanted to collect from pharmacists prescription information that identified physicians' prescribing patterns but did not identify the individual patients receiving the prescriptions. Pharmacists and physicians were to receive a small stipend for their participation in the scheme. Source Informatics would aggregate the information broken down by individual physician and sell it to pharmaceutical companies. The companies would in turn be able to target their marketing strategy to physicians on an individualized basis, with prior knowledge of their prescribing behaviour.

The U.K. government was concerned that the Source Informatics scheme would result in increased prescription drug costs for the National Health Service. They issued a policy statement claiming that in their view, physicians and pharmacists participating in the scheme would be in breach of confidence vis-a-vis their patients, and that anonymization does not obviate the need for consent for use of personal health information. Source Informatics applied for judicial review of the government's policy document. The application was dismissed at trial level, but subsequently granted at the Court of Appeal.

Simon Brown L.J. wrote the judgment for the Court of Appeal. After considering and rejecting an argument that the interest at stake concerns exploitation of the commercial potential of the prescription information, he analysed the interest as follows:

The concern of the law here is to protect the confider's personal privacy. That and that alone is the right at issue in this case. The patient has no proprietary claim to the prescription form or to the information it contains. Of course he can bestow or withhold his custom as he pleases ... But that gives the patient no property in the information and no right to control its use provided only and always that his privacy is not put at risk ... If, as I conclude, his only legitimate interest is in the protection of his privacy and if that is safeguarded, I fail to see how his will could be thought thwarted or his personal integrity undermined.⁵⁹

Not only was the concept of a proprietary interest rejected, but also the idea that the individual should have any control over subsequent uses of her or his information. Finding that adequate protections were in place such that the identity of the patient would be protected and not linked with the information, Simon Brown L.J.

⁵⁸ *Supra* note 9.

⁵⁹ *Ibid.* at para. 35.

ruled that the duty of confidentiality was not breached by Source Informatics' scheme, either by participating physicians or pharmacists.⁶⁰

McInerney v. MacDonald

While no Canadian courts have dealt specifically with the issue of anonymized personal health information, guidance as to a proposed approach to the topic can be found in the Supreme Court of Canada decision of *McInerney*.⁶¹ The case concerned Mrs. MacDonald's right to access the personal health information contained in her medical files, which had been compiled by Dr. McInerney and contained information garnered from previous health care professionals. Counsel for Mrs. MacDonald argued that while the physician owned the physical medical records, the patient held a proprietary entitlement to the information in those records. At trial level, Turnbull J. had found ownership of health information to rest with the patient.⁶² LaForest J. for the Supreme Court of Canada discussed this approach but ultimately found it unnecessary to find a property interest on the part of the patient, preferring instead to rest his decision in equity:

I find it unnecessary to reify the patient's interest in his or her medical records and, in particular, I am not inclined to go so far as to say that a doctor is merely a "custodian" of medical information. The fiduciary duty I have described is sufficient to protect the interest of the patient. The trust-like "beneficial interest" of the patient in the information indicates that, as a general rule, he or she should have a right of access to the information and that the physician should have a corresponding obligation to provide it.⁶³

While explicitly *not* finding a property interest on the part of the patient to the information contained within his/her records, other parts of the judgment imply that such an interest exists. For instance, LaForest J. refers to his previous judgment in *Dyment*⁶⁴ as follows: "...I noted that such information *remains in a fundamental sense one's own*, for the individual to communicate or retain as he or she sees fit." He also states: "...information about oneself revealed to a doctor acting in a

⁶⁰ Several groups were granted intervenor status before the Court of Appeal: *Source Informatics Ltd. v. Department of Health*, [1999] E.W.J. No. 4841 (C.A.)(QL). They argued that the trial level finding that confidentiality was breached by the Source Informatics scheme would cause dire problems in a number of areas in which de-identified health information was routinely utilized. These areas include medical research, marketing, fulfilment of regulatory duties, collection of government statistics, adverse event monitoring, product withdrawals, and stock taking. The Court of Appeal found that these uses were generally justified as being in the public interest, and went further in finding that in addition, identifiable data must be utilized for some of these purposes in order to audit the accuracy of research and management findings. The Court found these uses of identifiable information to constitute acceptable limitations on the duty of confidentiality.

⁶¹ *Supra* note 6.

⁶² *Ibid.* at 418.

⁶³ *Ibid.* at 425.

⁶⁴ *Supra* note 24.

professional capacity *remains, in a fundamental sense, one's own*”, and finally, “[n]ot only is the information *in some fundamental sense that of the patient*; the doctor has primary access to it. In comparison, the records are unavailable to the patient.”⁶⁵

With respect, the above analysis, reverberating throughout the judgment, could well be accepted by the reader as implying a proprietary interest in the information. It would appear that LaForest J. was seeking to avoid this style of analysis in order to leave scope for the physician, and subsequently the court, to find in a given circumstance that disclosure would reasonably be foreseen to cause harm to the patient, and therefore to deny access. Therefore he grounded his analysis in equity, the fiduciary duty of a physician to hold such information in trust, which provides greater scope for flexibility on a case-by-case basis.⁶⁶

However, the law of trusts has as its core the holding of property by one individual or institution for the benefit of another. Is not an equitable analysis in essence a property interest, such property being held in trust by the fiduciary on behalf of and in the interest of the other party to the relationship?⁶⁷ This is of significance in the context of de-identified information, in that the proprietary interest in one's information continues to flow and is not surrendered by placing it in trust in the hands of another.

Of further note, Dr. McInerney had in the first instance provided Mrs. MacDonald with copies of medical records and reports that she had prepared herself. At issue in this case was whether or not she was also obliged to provide copies of records and reports prepared by physicians that had examined or treated Mrs. MacDonald prior to her becoming a patient of Dr. McInerney. LaForest J. therefore went on to state: “The patient's interest being in the information, it follows that *the interest continues* when that information is conveyed to another doctor who then becomes subject to the duty to afford the patient access to that information.”⁶⁸

This finding has important implications for the question of whether a privacy interest subsists in de-identified information. If the person's interest in the information flows with the information itself, one may conclude that the privacy interest runs with the de-identified information and includes subsequent uses.

Conclusion

Ultimately, the analysis of LaForest J. in *McInerney* may set the most appropriate balance. That is, to view one's health information as confidential because I *own* it may be too extreme. There are problematic aspects of a property

⁶⁵ *Supra* note 6 at 422, 424, 427 respectively (emphasis added).

⁶⁶ *Ibid.* at 427.

⁶⁷ Donovan W.M. Waters, *Law of Trusts in Canada* (Toronto: Carswell, 1974) at 5.

⁶⁸ *Supra* note 6 at 425 [emphasis added].

analysis in the health context. But to view information as being placed in the hands of health care providers *in trust*, for my benefit and my benefit alone, may offer the best solution. This concept has some support in recent privacy legislation, which refers to information holders as “custodians”⁶⁹ or “trustees”⁷⁰ of the information. The law of equity respects autonomy and provides flexibility for legal developments. Its beauty lies in placing the interests of the individual whose health information is under scrutiny as the primary focus of law.

To find that there subsists a privacy interest in de-identified health information does not imply that research and other legitimate uses of such information must grind to a halt; nor does it necessarily lead to the conclusion that individual patient consent is required for each subsequent use of personal health information. It does, however, signify that at a minimum there must be a balancing of interests in determining whether subsequent uses may proceed without individual consent. Therefore the social value of the proposed use will be relevant, and at a minimum, the privacy interest will need to be weighed against other competing interests in determining whether de-identified personal health information should be utilized in the absence of patient consent.

⁶⁹ *Health Information Act*, *supra* note 26; *Personal Health Information Act*, *supra* note 26.

⁷⁰ *The Health Information Protection Act*, *supra* note 27.