

First Nations Privacy and Modern Health Care Delivery

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This paper discusses First Nations conceptions of privacy, in the context of Canada's electronic health records initiatives. The use of information technology in health care has been cited as a key mechanism by which care providers can improve the quality of care, while simultaneously aiding the long-term sustainability of universal health care systems. Research has shown that many inefficiencies and quality concerns stem from a lack of access to relevant information. As a result, Canada is investing heavily in electronic health records. While attention has been paid to the privacy and security issues of these systems, the unique privacy concerns of Canada's First Nations people have not been addressed to the same extent. The claims of First Nations people to sovereignty and self-determination are expressed in the domain of information technology through the OCAP principles. If these principles cannot be accommodated within the scope of Canada's eHealth initiatives, First Nations communities may face reduced access to health care. This paper serves as an introduction to First Nations privacy in the context of health care. It reviews current initiatives, and outlines the major challenges that have to be overcome if concerns expressed by First Nations people are to be addressed. We hope that this work will bring this understudied issue to the attention of the broader legal community.

I Introduction

Faced with rising service costs and an aging population, the federal and provincial governments in Canada are searching for ways to improve the efficiency of medical care delivery. While there are many opportunities for improvement, a significant number of inefficiencies and quality problems arise from a lack of access to information. Commonly encountered examples include unnecessary duplication of laboratory work and prescription of unnecessary (or even harmful) drugs.

As a result of these concerns, the Canadian government is investing in the development and acquisition of information and communications technology (ICT), with the intent to replace traditional paper-based patient records. While not as pervasive as in Europe, electronic medical record systems are being used in Canada with increasing frequency. Indeed, the Canadian government has funded a federal agency to foster the development of a pan-Canadian electronic health record (EHR) system.¹

Although these initiatives promise benefits for health care delivery, the use of ICT in the health care domain raises new concerns about privacy and security. While numerous commentators and policy makers have examined these privacy risks from the perspective of mainstream privacy law, less attention has been paid to privacy impacts of health care ICT on First Nations people.² The unique nature of First Nations claims to sovereignty and self-determination makes this a glaring omission, as a failure to accommodate the viewpoints of First Nations people risks perpetuating a historical relationship of paternalism and distrust. The end result could be further marginalization of First Nations communities, through exclusion from new methods of care delivery that support holistic models of health.

Thankfully, many First Nations people have expressed their claims to sovereignty and self-determination in the information domain through the principles of Ownership, Control, Access and Possession, or the OCAP prin-

1 See the Canada Health Infoway website at <http://www.infoway-inforoute.ca>.

2 The scope of this paper is limited to First Nations people who are affiliated with a community represented by a Band Council or another governing structure. The authors recognize that many of the concerns that have been raised with regards to the impacts of health care technology and privacy are shared by Aboriginal people throughout Canada: that is, people of First Nations, Inuit and Métis background who self-identify as Aboriginal. As a result, when discussing the concerns that have been expressed, the authors identify such concerns as shared by Aboriginal people. However, when discussing how concerns can be addressed, the discussion is limited in scope to First Nations people. The further limitation to First Nations people affiliated with a community represented by a Band Council or another governing structure arises in large part from the restrictions Canadian courts have placed on collective Aboriginal rights—namely, that such rights belong to the community and can only be asserted by the community.

principles.³ The OCAP principles (described in more detail later in this work) provide a framework for First Nations people to exercise ownership, control, access and possession over their own health information and the manner in which health information is collected, analyzed and disseminated. Several practical initiatives have sought to deploy the OCAP principles in the context of the health care system, including the nascent Tripartite Agreement in British Columbia.⁴ However, there is a gap in the legal literature concerning the difficulties involved in reconciling the OCAP principles with modern data protection regimes, including health information statutes. In an attempt to outline this gap, our paper provides an overview of privacy norms as expressed by many First Nations people in the context of modern health care delivery, as well as suggestions for future research. In our view, reconciling OCAP and Canadian privacy law requires a multi-disciplinary effort by the research community, government, and First Nations communities.

The first section of the paper contains a brief overview of the health care system in Canada, including the division of powers, and the rationale for the development of electronic health records systems. The second section recounts the unique situation of Aboriginal people in Canada,⁵ including the basic arrangements by which health care services are delivered on reserves and other remote communities. We briefly mention the holistic approaches to health care espoused by Aboriginal people, noting that new technologies can provide a means of achieving some of the goals of community-based care. The third section discusses the OCAP principles, and the challenges that arise in reconciling OCAP with modern data protection law. The fourth section describes several current initiatives that seek to implement OCAP, while the fifth section discusses key issues and future work.

Since most of the previous works on First Nations people and informational privacy have dealt solely with the case of data for use in research, our focus on health care information systems provides an expanded perspective on the issue. We believe that privacy concerns as expressed by First Nations people should be high on the priority list of policy makers, if they are to fulfill the federal government's obligation to make health care accessible to all Canadians.

3 See, for example, First Nations Centre, *OCAP: Ownership, Control, Access and Possession*, First Nations Information Governance Committee, Assembly of First Nations (Ottawa: National Aboriginal Health Organization, 2007), at 12 [First Nations Centre].

4 For more information on the Tripartite Agreement, see the First Nations Health Council website at <<http://www.fnhc.ca>>.

5 This aspect of the discussion will deal with Aboriginal people more generally.

II Modern Health Care in Canada: Jurisdiction and Responsibility

The provision of health care in Canada is a joint responsibility between the federal and provincial governments, as it is not an enumerated category within the division of powers listed in Sections 91 and 92 of the *Constitution Act, 1867*.⁶ As a result, both levels of government may pass legislation concerning health.⁷ The provincial governments generally have authority over the administration of health care organizations, including hospitals and laboratories; they also regulate health professionals through the creation of self-regulating bodies, such as the College of Physicians and Surgeons.⁸

A portion of the federal government's responsibilities are outlined in a set of federal statutes that relate to public health concerns, including the *Quarantine Act*, the *Hazardous Products Act* and the *Food and Drugs Act*.⁹ The federal government also has authority over First Nations groups, under subsection 91(24) of the *Constitution Act, 1867*.¹⁰ While Health Canada provides primary health care to hundreds of First Nations communities, the federal government also provides transfer payments as a means of fulfilling its responsibilities.¹¹

In addition, the federal government provides health care funding to the provinces, according to the conditions laid out in the *Canada Health Act*.¹² This statute, which outlines the requirements for publicly funded health care insurance programs, states that the primary objective of Canadian health care policy is to “*protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers*”.¹³ The statute further mandates that provinces and territories fulfill a set of conditions (including universality and accessibility) in order to receive a financial contribution from the federal government.

6 *Constitution Act, 1867* (U.K.), 30 & 31 Vict. c. 3, reprinted in R.S.C. 1985, App. II, No.5 [*Constitution Act*].

7 For a discussion, see M. Jackman, “Constitutional Jurisdiction over Health in Canada” (2000) 8 Health L.J. 96.

8 The shared jurisdiction over health services in Canada includes shared authority over medical record maintenance and storage. Privacy legislation applicable to record maintenance depends on whether a record is held by a provincially or federally regulated body. For example, medical records held by a federally regulated government body would be governed by federal privacy legislation.

9 *Quarantine Act*, R.S.C. 1985, c. Q.1. *Food and Drugs Act*, R.S.C. 1985, c. F-27. *Hazardous Products Act*, R.S.C. 1985, c. H-3.

10 *Constitution Act*, *supra* note 6.

11 Under the Canada Health Transfer program, the federal government provides financial support to provincial and territorial governments to assist them in providing health care services to all citizens within the boundaries of the province or territory, including Aboriginal people.

12 *Canada Health Act*, R.S. 1985, c. C-6 [*Canada Health Act*].

13 *Ibid.*, s.3.

E-Health Initiatives and Collaborative Care Delivery

Unfortunately, both levels of government are being challenged by rising health care costs due to increasingly expensive services and an aging population. In order to meet the obligations outlined in the *Canada Health Act*, governments are attempting to improve the efficacy and quality of health care delivery. The growing complexity of modern health care delivery is partially due to the fact that patients are typically treated by multiple professionals at multiple locations, as opposed to the single physician / single facility model that prevailed in the past. Collaborative care requires health information to be accessible to a variety of professionals in a variety of settings, placing increasing demands on the health system's communications infrastructure.¹⁴

In order to support collaborative care and foster efficiency, governments are investing in information and communications technology (ICT). As we noted above, the accessibility of information is of vital importance. Research shows that many quality problems arise from a lack of access to relevant information. Although the deployment of ICT in the health care space is a challenging endeavour,¹⁵ future health care delivery methods will depend on a robust technological infrastructure.

In particular, the Canadian government is focusing much of its energy on the development of electronic health record (EHR) systems. An EHR is a patient record that is digitized and maintained in a computer-based infrastructure. The major benefit of an EHR over the traditional paper-based health records is that the EHR can be shared more easily among health service providers. It also provides a rich repository of information for computer-supported public health surveillance and evidence-based medical research. There are significant financial benefits to an ICT-enabled health care system, including the elimination of unnecessary tests, expensive storage media, improved process efficiency, and better evidence on the efficacy of treatments. In 2002, the Commission on the Future of Health Care stated that “[e]lectronic health records are one of the keys to modernizing Canada’s health system and improving access and outcomes for Canadians”.¹⁶

The ongoing development of the Canadian EHR infrastructure has been assigned to Canada Health Infoway (Infoway), a not-for-profit organization created by the first ministers in 2001.¹⁷ Infoway’s original objective consisted

14 See, for example, Institute of Medicine, *Crossing the Quality Chasm: a New Health System for the Twenty-First Century* (Washington: National Academies Press, 2001).

15 See D. Avison & T. Young, “Time to rethink health care and ICT?” (2007) 50:6 *Communications of the ACM* 69.

16 Canada, Commission on the Future of Health Care in Canada (Romanow Commission), *Building on Values: The Future of Health Care in Canada—Final Report* (2002) (Commissioner: Roy J. Romanow).

17 Canada Health Infoway, *supra* note 1.

of providing EHR access to 50% of Canadian health care providers by 2010, with elements of the EHR solution infrastructure in place across all jurisdictions.¹⁸ While this objective has not been met, an increasing number of electronic information systems are coming online. Infoway's current corporate business plan (2010-2011) reports that 22% of Canadian providers now have access to the EHR and estimates that the 50% target will be reached in 2011.¹⁹

Despite this forecast, some jurisdictions clearly evidence a lack of progress with respect to EHR infrastructure—in particular the Northwest Territories and the Yukon. Strategic efforts to reach the 50% target focus on densely populated urban areas, since they are easier to service than remote rural areas. In a longer-term vision document extending to 2015, Infoway states that “[i]ncreasing the coverage to 100 per cent by completing work in the remaining jurisdictions and extending the mandate to include Aboriginal populations and federally managed healthcare recipients makes sense”.²⁰

Privacy Issues in E-health

While health care information technology initiatives promise benefits for health care delivery, the use of software systems in the health care domain raises new concerns about safety, effectiveness, privacy, and security.²¹ Personal health information (PHI) is among the most sensitive types of personal information; the unauthorized disclosure of an individual's PHI can have significant ramifications including embarrassment, ridicule and discrimination by employers or insurance agencies.

In addition to general concerns about the risk of security breaches, EHR systems raise the issue of *secondary use* of health information. On an abstract level, a given use is secondary if it involves purposes other than the provision of health care. Common examples of secondary uses include medical research, public health surveillance, targeted marketing and accreditation reviews.²² Many organizations have an interest in health information, including governments, pharmaceutical companies, universities and insurance agencies.

Not all secondary uses of EHR data are seen as constituting a risk to personal privacy. In 2007, the Canadian government contracted EKOS Research Associates to conduct a survey on their acceptance of EHRs and privacy-

18 Canada Health Infoway, 2003/04 Business Plan, online: <<https://www.infoway-inforoute.ca/annual-reports-and-business-plans>>.

19 Canada Health Infoway, 2010/11 Business Plan, online: <<https://www.infoway-inforoute.ca/annual-reports-and-business-plans>>.

20 Canada Health Infoway. EHR 2015—Advancing Canada's next Generation of Health Care, (2010) [Infoway].

21 See S. Hoffman & A. Podgurski, “Finding a Cure: The Case for Regulation and Oversight of Electronic Health Record Systems” (2008) 22 *Harv. J.L. & Tech.* 103.

22 For more information on the uses of health information, see L.E. Rozovsky, N.J. Inions, *Canadian Health Information*, 3rd ed. (Toronto: Butterworths, 2002) [Rozovsky].

related questions. A random sample of 2,469 Canadians participated. The poll indicated strong support for secondary use of health information for research, assuming that the health records are de-identified.²³ In contrast, surveys in the United States show that a large percentage of the public has concerns about the privacy and security of EHRs.²⁴

Thankfully, Canada possesses an extensive data protection regime based on international norms of fair information practice. While general purpose statutes exist to regulate the collection, use, disclosure and limitation of personal information by the private and public sectors, some provinces have passed legislation specific to health information.²⁵ Individuals in these provinces enjoy various legal rights with respect to health information, including rights of consent management that afford a degree of a control over who can access their health information, and for what purposes.²⁶

Surprisingly, Canada's privacy regime actually poses difficulties for First Nations communities seeking to take advantage of health care information and communications technologies. The next section discusses the holistic approach to health care favoured by many First Nations people, as well as the unique nature of their claims to sovereignty and self-determination. In the realm of information management, First Nations aspirations to self-government have been articulated in a set of core principles that differ drastically from the norms that form the basis of modern privacy regimes. The resulting tension creates difficulties for First Nations communities seeking to avail themselves of modern health care delivery methods.

III First Nations and Health Care: An Overview of Canada's First Nations

In 2006, the number of people in Canada who identified themselves as Aboriginal²⁷ surpassed the one-million mark, reaching 1,172,790. Since 1996, the Aboriginal population has increased nearly six times faster than the non-

23 EKOS Research Associates, "Electronic Health Information and Privacy Survey: What Canadians Think—2007", online: Canada Health Infoway <https://www2.infoway-inforoute.ca/Documents/EKOS_Final%20report_Executive%20Summary_EN.pdf>.

While the survey asked participants to identify whether they were Aboriginal, the published result did not identify an Aboriginal perspective.

24 Survey conducted by the Health Privacy Project. "Survey Shows Americans are Deeply Concerned about Health Privacy." Nov. 9, 2005. Online: <<http://www.healthprivacy.org>>

25 For example, the *Personal Health Information Protection Act*, S.O. 2004, c.3 [PHIPA].

26 As an example, PHIPA (*supra* note 25) contains consent management provisions that allow patients to restrict access to their personal health information.

27 This section of the paper deals with Aboriginal people more generally as available statistics relevant to health parameters are gathered and organized on the basis of self-identification as Aboriginal. In addition, concerns raised with health care delivery have often been generally expressed in the sources cited as shared by Aboriginal people and not limited to First Nations people.

Aboriginal population, growing by 45% between 1996 and 2006.²⁸ According to Census Canada, Aboriginal Identity means belonging to at least one of the groups of Aboriginal peoples defined by the *Constitution Act, 1982*,²⁹ which includes North American Indians, Inuit and Métis.³⁰ Approximately 83% of the Aboriginal population lives in Ontario, Manitoba, Saskatchewan, Alberta and B.C.³¹

In terms of geography, Canada's Aboriginal population is increasingly located in urban areas. Despite this trend, Canadians of Aboriginal descent are still less likely to live in urban centres than non-Aboriginals. As of 2006, 54% of the Aboriginal population lived in urban areas, including both large cities and smaller urban areas. This represents an increase in the Aboriginal urban population (up from 50% in 1996), but it is still significantly less than the non-Aboriginal population, of which 81% lived in urban centres in 2006. The difference in the distribution of Aboriginal and non-Aboriginal Canadians is largely attributed to the significant number of First Nations people who live on reserves.³²

In addition, Aboriginal people who live in urban centres are also less likely than their non-Aboriginal counterparts to live in large urban centres. While 80% of the non-Aboriginal urban population lives in major metropolitan centres, only 59% of the urban Aboriginal population does. The remaining 41% of the urban Aboriginal population lives in small urban centres.³³ Unfortunately, research shows that Aboriginal Canadians rank lower on many health-related metrics, including longevity; in fact, life expectancy for Aboriginal Canadians is six years lower than the Canadian average.³⁴

Although these statistics are revealing, it is important to remember that they are aggregates. The grouping together of Aboriginal peoples collectively on the basis of self-identity can be beneficial for demonstrating the proportion of the overall population that may be classified as Aboriginal. However, it is important to not lose sight of the diversity that exists within the Canadian Aboriginal population. This diversity is reflected internally, for example in differing cultural practices and language groups, and externally, for instance in governing structures that are formally recognized by the Canadian government and in access to federal and provincial resources.

28 Statistics Canada, *Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations, 2006 Census* (Ottawa: Minister responsible for Statistics Canada, 2008) at 6 [Statistics Canada].

29 *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

30 Statistics Canada, *supra* note 28.

31 *Ibid.* at 40.

32 *Ibid.* at 12.

33 Statistics Canada, *supra* note 28 at 13.

34 Health Canada, *Statistical Profile on the Health of First Nations in Canada: Determinants of Health, 1999 to 2003* (Ottawa: Minister of Health, 2009) [Health Canada].

Government Responsibility for First Nations Health Care

Aboriginal people are uniquely positioned with respect to health care delivery. As with all Canadians, they are entitled to universal health care administered through the provincial health care systems. However, health care delivery and administration can vary significantly depending on whether one is First Nations living on or off reserve, and whether one is Inuit or Métis. For example, Registered Indians³⁵ receive health coverage from the federal Government for certain medically necessary services not normally covered by the universal health care system, such as prescription drug coverage and vision care.³⁶ Increasingly, health services are also being provided within Aboriginal communities through Aboriginal-run programs.³⁷ Overall, the responsibility for the delivery of health care to Aboriginal people in Canada has been the subject of considerable debate regarding jurisdictional responsibility. The lack of coordination between federal and, provincial governments, and Aboriginal community agencies has resulted in gaps and inadequacies in health services for Aboriginal people.

The difficulty in trying to identify one branch of the government that is responsible for the provision of health care services to Aboriginal people stems from the division of powers. As we mentioned above, the federal government has regulatory authority over Indians,³⁸ with most of its powers being set out in the *Indian Act*.³⁹ This statute allows the federal government to regulate health services for Indians, but does not require the government to do so.⁴⁰ The *Indian Act* also provides Band Councils with the authority to regulate certain health services on reserves, so long as such regulations are consistent with federal regulations.⁴¹

The federal government has accepted responsibility for ensuring the provision of health care services to Status Indians and Inuit. Health Canada provides primary health care in approximately 200 First Nations communities and home and community care in over 600 communities.⁴² However, the provincial government is directly responsible for providing all aspects of health care to all residents of BC, including Status Indians, non-status Indians liv-

35 Registered Indians are individuals registered with the federal government as Indians, in the context of the *Indian Act*. For more information, see the website of Indian and Northern Affairs Canada online at <<http://www.ainc-inac.gc.ca/br/is/tir-eng.asp>>.

36 For current information on benefits, see the website of Indian and Northern Affairs Canada online at <<http://www.hc-sc.gc.ca/fniiah-spnia/nihb-ssna/benefit-prestation/index-eng.php>>.

37 For some examples of such programs see the website of Association of BC First Nations Treatment Programs online at <<http://www.firstnationstreatment.org/>>.

38 *Constitution Act*, *supra* note 6, ss. 91(24).

39 *Indian Act*, R.S., 1985, c. I-5.

40 *Ibid.*, ss. 73(1)(g).

41 *Ibid.*, ss. 81(1)(a).

42 Health Canada, *supra* note 34 at 29.

ing off-reserve, Inuit and Métis people. Therefore, the federal government's responsibility is fulfilled largely by providing provincial governments with block transfer payments for cost-shareable programs, contracted services and Medical Services Plan premiums for Status Indians. In calculating health care expenditures for Status Indians, costs are estimated on a per capita basis, rather than on the basis of actual utilization of services.⁴³

Despite the fact that the federal and provincial governments have cooperated in the delivery of health care, the health status of all Aboriginal Canadians (including Status Indians and Inuit) has consistently been substandard to that of non-Aboriginal Canadians.⁴⁴ Access to health services is of particular concern to the many Aboriginal people who live in remote communities where primary care is for the most part provided by nurses.⁴⁵

Health Transfer Agreements and Community-Based Health Care

In an attempt to address the health inequalities between Aboriginal and non-Aboriginal peoples, the federal government launched its *Health Transfer Policy* (HTP) in 1989. This program allows federal resources to be transferred to First Nations and Inuit communities located on reserves, in order for those entities to design and manage certain community-based health programs. The health services which can be transferred include environmental health, treatment and prevention programs, nursing, community health representatives, and the appropriate Medical Services Branch facilities.⁴⁶ The level of control that First Nations and Inuit communities can exercise under a *Health Services Transfer Agreement* (HSTA) is largely administrative, and encumbered by restrictions.

Under the HTP, communities must design and deliver programs within rigid parameters that vary depending on the type of agreement.⁴⁷ A *General Agreement* allows for delivery of a limited set of specific programs, usually for a one year term; resource allocation is set out in the contract, and the community has no authority to re-direct funds to reflect changing needs. A *Transfer/Targeted Agreement* allows First Nations and Inuit communities to select (within certain restrictions) multiple programs that operate over a three to five-year term. For certain programs, the transfer of control is mandatory and

43 B.C. Ministry of Health Planning Office of the Provincial Health Officer, Report On the Health of British Columbians Provincial Health Officer's Annual Report 2001: The Health and Well-being of Aboriginal People in British Columbia (Victoria, B.C.: Ministry of Health Planning, October 28, 2002) at 86-7 [B.C. Ministry of Health].

44 See Constance MacIntosh, "Envisioning the Future of Aboriginal Health Under the Health Transfer Process" (2008) 67 Health L.J. at 69 [MacIntosh].

45 Health Canada, *supra* note 34 at 29.

46 B.C. Ministry of Health, *supra* note 43 at 87.

47 T.M. Bailey, T. Caulfield & N.M. Ries, *Public Health Law & Policy in Canada*, (Toronto: LexisNexis, 2005) [Bailey].

funds must be spent in accordance with the contract; in other cases, the community has some discretionary control over allocation of funding. Finally, an *Integrated/Targeted Agreement* allows the community to take responsibility for developing a larger health management structure; however, the community has limited ability to adjust programming and the allocation of resources once the agreement is in place.⁴⁸ Under all three types of transfer agreements, the amount of funding is based on the number of individuals with status who are living on the reserve at the time the agreement is entered into. Funding does not reflect the rates at which services are accessed, nor does it respond to changes in the size of the population.⁴⁹ This leaves the quality of programming highly vulnerable to changes in the costs of delivery of services.

Despite the restrictiveness of HSTAs, many First Nations communities have pursued this option.⁵⁰ One of the reasons for the popularity of HSTAs is that they are much less onerous than treaties; treaties are complex agreements that can take decades to negotiate, while HSTAs can be implemented in just a few years.⁵¹ Although this expediency is attractive to many communities, commentators have noted that HTSAs can potentially worsen existing jurisdictional gaps in health service provision.⁵²

Lastly, efforts at the provincial level are also attempting to close some of the gaps in health service delivery. To take but one example, British Columbia has been moving towards decentralizing authority for the planning and management of health services to regional health authorities. Since 2001, each health authority is required to create an *Aboriginal Health Plan* to identify and address Aboriginal health service priorities for its region. The objective of these plans is to improve access to health services, increase Aboriginal involvement in decision-making and planning, and establish a meaningful working relationship with Aboriginal communities within the service region.⁵³

First Nations Conceptions of Health

Many of Canada's Aboriginal people take a holistic, community-centered approach to health care.⁵⁴ To take a single example, the Assembly of First

48 MacIntosh, *supra* note 44 at 71-2.

49 Bailey, *supra* note 47 at 363.

50 As of March 2008, the number of eligible communities that had signed an HTSA had stood at 46%, while an additional 37% of First Nations communities were involved in the control process through a variation agreement. See *supra*, note 25 at p.73, and Health Canada, First Nations, Inuit and Aboriginal Health, "Transfer Status as of March 2008", online: Health Canada <http://www.hc-sc.gc.ca/finiah-spnia/finance/agree-accord/trans_rpt_stats-eng.php>.

51 Bailey, *supra* note 47 at 362.

52 See for example, MacIntosh, *supra* note 44 at 77-8.

53 B.C. Ministry of Health, *supra* note 43 at 87.

54 In particular, groups allied with the Assembly of First Nations express a holistic approach to health care.

Nations (AFN) recently developed a “First Nations Wholistic Policy and Planning Model”⁵⁵ that emphasizes the importance of community by explicitly positioning the individual (and his or her health) in the context of local social and cultural factors. According to the AFN, “[the claim that] population level factors which determine health and well-being for any collectivity have their origins in upstream historic, cultural, social, economic and political forces... has been articulated for almost a decade”.⁵⁶

Broadly speaking, a holistic approach to health care means that the various determinants of health should be taken into account in all aspects of health care delivery, including planning and resource allocation. Health determinants include the social, economic and ecological environments in which people live. Among the examples cited by the AFN are the impact of diet on health, and the role of external factors in creating psychological stress that causes poor health outcomes.⁵⁷

Furthermore, Aboriginal stakeholders have recognized that many non-Aboriginal health care initiatives are compatible with holistic approaches to health care. To take but one example, the AFN recognizes the utility of (properly managed) longitudinal records and public health surveillance.⁵⁸ First, longitudinal (comprehensive) records are of critical importance, as a holistic view of health care requires information on a variety of factors that affect an individual’s health, including her past health history. Accessing a comprehensive and longitudinal health record allows a health care provider to ensure that an accurate diagnosis and appropriate care plan can be implemented, based on improved access to contextual information that is required for decision-making. In the words of the AFN, given the “*multi-dimensions of health, a silo approach to information management will not create the depth or breadth of information required*”.⁵⁹

Second, public health surveillance—the process of systematically collecting, analyzing and interpreting outcome-specific data—can be particularly beneficial to the planning, implementation and evaluation of public health practices as they relate to particular health concerns affecting Aboriginal communities. This is because surveillance is specifically directed towards understanding, monitoring, and responding to specific health issues within defined populations.⁶⁰ Without relevant information, the ability of communities to plan, implement and evaluated health practices is drastically reduced.

55 J. Reading, A. Kimetic & V. Gideon, *First Nations Wholistic Policy and Planning Model: Discussion Paper for the World Health Organization Commission on Social Determinants of Health*, Assembly of First Nations, (Ottawa: 2007) [Reading].

56 *Ibid.*, at 11.

57 *Ibid.*, at 12.

58 Reading, *supra* note 55.

59 First Nations Centre, *supra* note 3.

60 MacIntosh, *supra* note 44 at 78.

Challenges Posed by Holistic Models

Unfortunately, cultural diversity can pose problems for top-down models of health care provision. At a basic level, the complexity involved in providing culturally sensitive means of care-giving can come into conflict with traditional norms such as efficiency and standardization. As a starting point, an individual's cultural background can be highly influential on their conceptions of both health and health care. Culture may influence the manner in which people: (a) participate in prevention-oriented health programs; (b) access health information; (c) make lifestyle choices; and (d) understand and prioritize health and illness. For example, an individual who views health as the absence of any form of disease will exhibit different attitudes towards influenza vaccinations than an individual who accepts this type of ailment as routine (and even salutary, from an immune system perspective). Similarly, a person with an expansive, systemic view of health may care far more for social determinants of health than a person who has a more narrow view.

Generally speaking, traditional health care systems in Canada were not designed to be responsive to cultural diversity. While there are many factors at work, one of the main reasons systems are non-responsive is the emphasis placed on developing best practices for treatment. Although many academics and practitioners have emphasized the importance of adopting a patient-centered perspective, the quality and efficiency of health care also depend on the standardization of medical practices, terminology and information systems.⁶¹ Diversity of beliefs and practices can pose problems for standardization efforts in at least the first two of these areas, since standardization inevitably involves a decision (often a compromise) between competing alternatives.

The difficulties to health care provision posed by cultural diversity are particularly salient in the context of Canada's Aboriginal people. First, the relatively wide dispersal of Aboriginal people in remote regions and smaller urban centres poses logistical difficulties. Second, the hierarchical nature of many health care programs can leave local communities without control over health care delivery, including priorities and funding. Third, a common critique of existing health services in Canada is that they are not designed and delivered in a fashion that is culturally appropriate for most Aboriginal people.⁶²

The effective provision of health care to Aboriginal people requires solutions to each of these issues. A health care system tailored for the unique needs of Aboriginal communities requires an understanding of cultural values relating to health, as well as respect for claims to autonomy and self-

61 Finding methods to accommodate patient-centered care within a top-down model of health care delivery is an active area of research and development.

62 Bailey, *supra* note 47 at 352.

determination. In general, the more that various governments vest control in local communities, the more the health care system will allow for cultural autonomy and preservation of traditions.

Although a thorough response to these challenges will likely involve many elements, it is clear that some recent trends in health care offer partial responses. The trend towards patient-centered care may provide a means to accommodate cultural differences. In turn, new models of collaborative care could devolve power and decision-making from the provincial and federal levels to local communities. However, both of these broad methodological trends rely intimately on the use of information systems to achieve quality, safety and accessibility. As a result, they are dependent on the use of IT in health care. The use of IT for purposes of First Nations health care is the topic of our next section.

IV First Nations and E-Health

As we have seen, a common approach to health care taken by First Nations people is holistic, putting the community at the centre of care and emphasizing the range of determinants that impact health care. Thankfully, electronic health record (EHR) systems provide several functions that can support holistic health care. First, EHR systems offer a comprehensive and longitudinal view of a patient's health. Second, the information in an EHR system can be used to support public health functions, including population surveillance, infectious disease reporting and research. Third, EHR systems are a key means of supporting collaborative care. Without a means of exchanging information, distributed teams of health professionals will not be able to coordinate to provide care.

Despite these benefits, First Nations people have good cause to be wary of the use of information technology in the health care domain. In addition to issues concerning efficacy, safety, privacy and security,⁶³ the history of interventions by the federal and provincial governments has left First Nations communities with a well-earned and profound distrust of new information management initiatives. In particular, past research initiatives focusing on First Nations communities are often regarded by First Nations communities as detrimental; among other activities, governments have gathered data on First Nations people without their knowledge, consent or participation; many of these data collection activities have occurred in a manner that does not respect individual or community confidentiality. In some countries, data gathering efforts focusing on Aboriginal populations have been used to elicit information

63 For a review of these issues, see J. Williams & J. Weber, "Regulation of Patient Management Software", (2010) 18 Health L. J.

on political dissidents, leading to individual or collective punishment at the hands of the state.⁶⁴

The main issue with respect to health information management of First Nations data concerns the right to control: (a) what data is collected, and (b) who has access to that data. The case of public surveillance is instructive in this regard, as there is often a mismatch between the organization that receives public health surveillance information, and the organization that is responsible for providing health programming and dictating the terms of service provision. As noted by MacIntosh, provincial regulations may require that information regarding the spread of communicable diseases on reserve be reported to the province, while the federal government has responsibility for overseeing programming, and the First Nations community itself may exercise some administrative control over the delivery of services.⁶⁵

One must, however, be careful to maintain a broad perspective when using public health surveillance and issues surrounding research as models for the difficulties posed to First Nations communities and individuals by EHR systems. In general, the privacy and security issues involved in using data for research are less complex than those involved in using data in health care. At a high level: (a) information in an EHR system is used for a wider variety of purposes,⁶⁶ by a wider variety of users; and (b) the data is updated routinely, instead of being an inert historical archive. EHR systems are living repositories of information that are utilised in multi-way transfers between health care providers and patients.

In fact, the AFN points out that little progress has been made to date at accommodating First Nations views of health care within the framework of Infoway's pan-Canadian EHR.⁶⁷ Although many First Nations people are enthusiastic about the benefits of the new technology, insufficient attention to First Nations concerns was a key factor in the poor uptake of the First Nations Health Information System (FNHIS).⁶⁸ While some First Nations communities are still using the FNHIS in a limited capacity, others have moved to purchasing or developing their own health information systems. The key issue in each of these cases is a mismatch between the unique claims to sovereignty and self-determination of First Nations communities, and the approaches to health information management that are found both in the Canadian regulatory system and in practice.

64 For more on these issues, see B. Schnarch, "Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research" (2004) 1 *Journal of Aboriginal Health*, at 82 [Schnarch].

65 MacIntosh, *supra* note 44 at 79-80.

66 See Rozovsky, *supra* note 22.

67 First Nations Centre, *supra* note 3 at 15.

68 First Nations Centre at NAGO, First Nations Health Infrastructure Recommendations, Briefing # FNC04-043.

The OCAP Principles

The concerns expressed by many First Nations people with respect to information management have been synthesized into four key principles, namely: ownership, control, access and possession (OCAP). As described by the Assembly of First Nations (AFN), the OCAP principles were first developed at a committee meeting of the First Nations Regional Longitudinal Health Survey (RHS) in an “*attempt to translate the First Nations inherent ways of knowing about information into something that could be easily described and interpreted to the research community*”.⁶⁹ The original focus of the OCAP principles was to provide a framework concerning data ownership, collection, analysis and dissemination for the RHS.⁷⁰ The principles, as they have been defined by the AFN, can be summarized as follows:

1. The **ownership** principle concerns the relationship of a First Nations community to its cultural knowledge and collective information. Certain information is owned collectively, much as an individual owns their personal information.
2. The **control** principle reflects a First Nations community’s aspirations and inherent right to regain control of information. Control extends to all aspects of information management, including policy development, implementation, review processes, and data management.
3. The **access** principle entails a right to have access to information about oneself, and one’s Nation or community. First Nations communities and organizations have the right to access and manage (and make decisions regarding access to) their collective information, no matter where it is stored.
4. The principle of **possession** is a mechanism to assert and protect ownership. Information in the possession of other parties is difficult to control, as a result of conflicting policies and legal instruments.

The OCAP principles are designed to be a high-level framework; each First Nations community may determine how these principles are to be interpreted and enforced at the community or Nation level. In the words of the AFN, it is the community that decides what OCAP means. Some communities may even eschew the term OCAP, defining their own approach to self-governance of information in their own terms. OCAP is therefore but one manifestation of a First Nations community’s claims to self-governance and self-determination in the domain of information.

69 First Nations Centre, *supra* note 3 at 1.

70 The RHS was a data collection initiative. Although the OCAP principles were first developed in the context of a particular research program, the principles can be applied in other settings. As stated in Schnarch, *supra* note 64, OCAP is “*broadly concerned with all aspects of information, including its creation and management*”. This paper represents the first in a series of attempts to apply the OCAP principles to patient management software.

OCAP and Canadian Privacy Law

Privacy law in Canada is composed of a patchwork of statutes, regulations, bylaws, common law decisions, professional codes of conduct and voluntary industry standards. Despite this diversity, however, the protection of personal information in the health care space is largely a product of statutory law. In addition to general purpose privacy statutes, some provinces in Canada have also passed legislation that specifically addresses health information. We briefly recount the fundamentals of both types of statute in the paragraphs below.

Whether general purpose or specific to health information, Canadian privacy legislation is based on a core set of “fair information practices” that are derived from international privacy norms. In response to Canada becoming a signatory to the Organization for Economic Cooperation and Development (OECD) *Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data*,⁷¹ the Canadian Standards Association (CSA) created the *Model Code for the Protection of Personal Information* (Model Code) in 1996.⁷² The Model Code outlines ten key principles of fair information practice:⁷³

1. **Accountability:** An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization’s compliance with the following principles.
2. **Identifying Purposes:** The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.
3. **Consent:** The knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate.
4. **Limiting Collection:** The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.
5. **Limiting Use, Disclosure and Retention:** Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfillment of those purposes.

71 *Guidelines Governing the Protection of Privacy and Transborder Data Flows of Personal Data*, Sept 23, 1980, Organization for Economic Cooperation and Development.

72 Standards Council of Canada, CAN/CSA-Q830-96.

73 See, for instance, the summary available online at: <<http://www.csa.ca/cm/ca/en/privacy-code/publications/view-privacy-code/article/principles-in-summary>>.

6. **Accuracy:** Personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.
7. **Safeguards:** Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.
8. **Openness:** An organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.
9. **Individual Access:** Upon request, an individual shall be informed of the existence, use and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.
10. **Challenging Compliance:** An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

The explication of the privacy principles formulated by the CSA became law when the Model Code was incorporated into the *Personal Information Protection and Electronic Documents Act*⁷⁴ (PIPEDA), a federal statute that applies to organizations that are engaged in commercial activities. While Canada already possessed a privacy statute binding on the federal public sector,⁷⁵ the development of a statute covering the private sector was spurred by a directive of the European Union⁷⁶ that prohibited member states from transferring data to jurisdictions with inadequate privacy protection. Although PIPEDA was originally described as a means to enhance consumer confidence in electronic commerce, final draft contains numerous provisions that regulate the collection, use and disclosure of personal information in a wide variety of additional contexts. To this end, PIPEDA explicitly incorporates the CSA *Model Code* in the form of a schedule, albeit one that is slightly modified by provisions in the statute's main text.⁷⁷

In turn, PIPEDA (and the embedded Model Code) served as an exemplar for the development of subsequent legislation targeting health information. For instance, *Ontario's Personal Health Information Protection Act* (PHIPA) and its accompanying regulations⁷⁸ were drafted out of a concern that the general purpose privacy statutes such as PIPEDA were not suitable for applica-

74 *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c.5.

75 The federal *Privacy Act* came into force on July 1st, 1983.

76 Directive 95/46/EC.

77 For more on this issue see, for example, S. Perrin, *et al.*, *The Personal Information Protection and Electronic Documents Act: An Annotated Guide* (Toronto: Irwin Law Inc. 2001).

78 *Personal Health Information Protection Act*, S.O. 2004, c.3, and its accompanying regulation O. Reg. 329/04.

tion in a health care environment. In particular, health care delivery requires the interchange of information between disparate health care providers, such as physicians, laboratories and mobile occupational/physical therapists.

Although the details of these statutes are beyond the scope of the paper, it is of the utmost importance to note that the Model Code—and hence Canadian statutory privacy law—is based on an *individualistic* notion of privacy. Returning to the ten Model Code principles, it is clear that they are phrased in individualistic terms, with “personal information” serving as the key asset. To take but one example, the Consent principle imposes a prima facie duty on an organization to obtain the knowledge and consent of the individual before collecting, using and disclosing personal information. Community interests are not mentioned explicitly, leading one to infer that a community’s privacy interest is seen under Canadian law as being reducible to the privacy interests of its members.

Although exceptions exist, the individualistic approach to privacy is typical in the literature of the North American and European legal, philosophical and scientific communities. As we shall discuss below, there are deep conceptual difficulties involved in reconciling communal privacy interests (such as those articulated in the OCAP principles) with individualistic conceptions of privacy. In addition, the dearth of discussion in the legal literature suggests that the topic is understudied.

Implementing OCAP

OCAP is about the assertion of self-governance. According to the AFN, if a First Nations community is not given an opportunity to participate in governance over its information, the OCAP principles have not been respected.⁷⁹ In its report, the AFN stated that OCAP is only a barrier to collaboration when there is “*no willingness to respect First Nations rights to self-governance, including over our information*”.⁸⁰

One method of starting to implement OCAP would be to develop the capacity of First Nations communities to fully manage their information from collection and analysis to dissemination. The AFN urged that “*all entities that make use of First Nations data should be making investments into community capacity building for information management*”.⁸¹ As we mentioned above, some First Nations communities are beginning to purchase or build their own health information systems; however, it seems unlikely that every First Nations community will be able to summon up the human and financial resources to make such an investment.

79 First Nations Centre, *supra* note 3.

80 *Ibid.*, at 5.

81 *Ibid.*, at 4.

Even more worrying is the fact that empowering First Nations communities to run their own information systems is not sufficient; we live in a world where individuals (including members of First Nations communities) may receive care in a wide variety of settings. A First Nations person who visits a hospital during a vacation may leave a trail of information in the various paper charts, x-rays and electronic records systems. In this way, information about First Nations communities may appear in legacy systems that are managed by governments and health authorities. Data from these systems can be used for a wide variety of functions, including accreditation, research, teaching and quality control. While some existing systems allow administrators to flag a record as belonging to a person of “aboriginal” descent, whether those flags are used in the bewildering variety of clinical and administrative processes (including reporting and data analysis) is another question.

As a result, it is clear that respecting the OCAP principles requires more than mere capacity building. Existing health care systems must somehow accommodate First Nations conceptions of self-governance and autonomy with respect to information. Before analyzing some of the key issues that have to be solved in order to fully integrate these conceptions into health care delivery, we briefly review some of the major initiatives that have tried to accommodate the OCAP principles in a health care setting.

V Current Work

Several existing initiatives are attempting to put OCAP into practice, in the domain of health care. We sample these projects in the sub-sections below.

Regional Longitudinal Health Survey

As mentioned above, the RHS project spurred the development of the OCAP principles. Although it involves research (and not full-lifecycle health information management), an understanding of the controls used in the RHS is quite useful as an introduction. As described by Schnarch,⁸² the system designers developed a simple protocol to deal with collective ownership of data. Community level data is not released without the permission of community authorities, while a select steering committee makes decisions about the release of nationally aggregated information. Additional controls include:

1. Releasing data only after there has been adequate time for the First Nations community to disseminate its own interpretation.
2. Releasing data only for specific and agreed upon purposes.
3. Releasing only tabular or statistical data for quantifiable information, not record-level information.

82 Schnarch, *supra* note 64.

4. Reserving a right to veto any publications based on the data.

Without detracting from the merits of the RHS as a tool for research, it is clear from preceding sections that the controls outlined above have limited application in the domain of health information systems. In a health care setting, where First Nations people may receive care at a variety of geographically distributed facilities, the issue of control becomes much more difficult. In addition, once information has left a repository (and has ended up in the custody of a data recipient), it is almost impossible to exercise control over that data.

First Nations Client Registries

In addition to research initiatives, “client registry” programs have significant implications for governance of health information of First Nations people. The purpose of a client registry is to provide a single source of “truth” about the electronic identity of a patient, by matching identifiers and demographic information contained in a variety of health information systems.⁸³ Since individuals may receive care at more than one location, their PHI may be contained in multiple information systems. Identifying a patient’s records across information systems is a difficult, time-consuming and error-prone endeavour. A client registry allows health care providers to uniquely determine the identity of a given patient, through the use of probabilistic matching algorithms that take demographic and care history information into account.⁸⁴

In addition, client registries could help maintain some control over health information. According to Wildman and Barker,⁸⁵ a client registry run by First Nations communities could “[a]void storing personal information in provincial/territorial CRs that could be used to distinguish First Nations individuals from other individuals.” The client registry could contain demographic information that was also contained in hospital and provincial information systems. However, it could also contain information that would not be found in other information systems, such as registration status, clan affiliation, and community affiliation.

Infoway recently funded the Assembly of First Nations (AFN) to initiate the development of a First Nations client registry. One of the objectives of the project involved identifying existing jurisdictional issues around privacy; another objective involved the development of technology that would meet

83 According to Infoway, a client registry is “a component of an electronic health record (EHR) system that supports the centralized storage and retrieval of client (i.e. patient) identification data, and enterprise client identifiers (ECIDs).” Online: <<https://www.infoway-inforoute.ca/working-with-ehr/solution-providers/certification/what-infoway-certifies/client-registry>>.

84 The use of a client registry to link health records from a variety of locations is a critical component of Infoway’s infrastructure. A client registry contains demographic information only, as opposed to information about an individual’s health history.

85 T. Wildman & K. Barker, (proprietary report to Canada Health Infoway).

both the OCAP principles and the Infoway Privacy and Security Architecture. Since OCAP principles were not considered in the design of Infoway's Privacy and Security architecture, it is questionable whether this objective is attainable at all, since privacy safeguards are much less effective when added as an afterthought.⁸⁶ Progress on the First Nations Client Registry project is steady, but deployment is still a year or two away.

Tripartite Agreements

In British Columbia, a working group was created to negotiate a draft data sharing agreement for data pertaining to First Nations people.⁸⁷ Entitled the "Tri-partite Data Quality and Sharing Working Group", membership is drawn from federal, provincial and First Nations governments. The purpose of the agreement is to: (a) improve the quality of data pertaining to First Nations people; (b) facilitate data sharing; and (c) ensure that information on First Nations people in the custody and control of the federal/provincial government is properly used and shared. The OCAP principles have served as a key framework in the drafting process, and the First Nations participants have been working to create rules around the collection, use and disclosure of community information.⁸⁸

Summary of Current Work

The disparate projects that we have summarized above are similar in at least one respect—namely, they are focused on asserting First Nations sovereignty and self-determination in the domain of health information. Our sampling was necessarily incomplete, out of a concern for brevity, and the reader should be aware that there are additional projects underway in Canada.⁸⁹ In general, the academic literature fails to reflect the amount of activity devoted to OCAP in both First Nations communities and the various levels of government.

One of the main issues with existing efforts is the tension between individual and communal rights. Although some First Nations communities have pointed out that Canadian courts are often faced with the task of balancing individual and group rights, it is not clear that the situations are entirely

86 For more on this claim, see the Information and Privacy Commissioner of Ontario's information materials, available at <<http://www.privacybydesign.ca>>.

87 Online: <http://www.fnhc.ca/index.php/initiatives/research_and_data/tripartite_data_sharing_agreement/>.

88 At the time of writing, the draft agreement is under legal review, and therefore unavailable to the research community.

89 For instance, we did not cover the First Nation Administrative Health Database (FNAHD), which contains data from three First Nations communities (Miawpukek First Nation—Conne River, Mushuau Innu First Nation—Natuashish and Sheshatshiu Innu First Nation—Sheshatshiu) in Newfoundland and Labrador.

equivalent, owing to the unique formulation of community privacy contained in the OCAP principles. In the next section, we examine this issue in more detail when we discuss opportunities for future work.

VI Areas for Future Work

To further the discussion on First Nations and modern health care delivery, this section identifies several areas for future work. Our selection is not intended to be exhaustive, as a thorough treatment is beyond the scope of this paper. While we detail practical problems that must be solved, we believe that the legal aspects of the problem are fundamental. Simply put, OCAP cannot be respected without a deeper understanding of the ways in which First Nations conceptions of communal privacy interface with the individualistic conceptions that form the basis for Canadian data protection law. Although a core part of the issue lies in reconciling individual and communal interests—a task not foreign to aboriginal law, as we detail below—there are other components that have not been addressed in either the jurisprudence or the legal literature.

Participation

In our discussion of the OCAP principles, we related a view held by many First Nations communities that respecting the OCAP principles requires more than mere capacity building. Existing health care systems must accommodate First Nations conceptions of self-governance and autonomy with respect to information. In particular, the OCAP Control principle entails that First Nations communities should have input on all aspects of information management, including policy development, implementation, review processes and data management.

This requirement raises a number of concerns. First, given the large number of First Nations communities in any given province, it is difficult to see how First Nations stakeholders could be involved in all aspects of policy development and data management. Current eHealth initiatives in many provinces have been criticized as expensive and ineffective, even without additional stakeholders. The requirement to obtain consensus from each First Nations community in a province could stall entire projects. New models of collaboration that respect both First Nations interests and the practical realities of information systems deployment are required.

Second, the difficulties inherent in obtaining input from First Nations people may have led government agencies to avoid the issue altogether. For instance, Canada Health Infoway has set up a “Standards Collaborative” that draws participation from a large number of constituents.⁹⁰ The Collabora-

90 Infoway Standards Collaborative website, online at <<https://www.infoway-inforoute.ca/lang-en/standards-collaborative>>.

tive has several working groups, including one (Group 8) focusing on privacy and security. Representatives from First Nations communities are noticeably absent from this group, and a search of the forum postings for keywords “aboriginal” or “first nation” has not returned a single entry. While public documents show that Infoway is acutely aware of the issues surrounding control over EHR systems,⁹¹ the lack of First Nations representation is a major outstanding gap.

OCAP and the EHR Blueprint

In addition, the specific needs and aspirations of First Nations communities have received insufficient consideration in the design of Infoway’s reference EHR architecture, as released in 2005 and 2006. This situation has created technical barriers for First Nations communities to participate in and benefit from the EHR. To take but one example, the current EHR design does not provide participating health care providers with a means of properly identifying records belonging to individuals of Aboriginal ancestry. Such functionality is a prerequisite necessary for enacting specific policies on the control and distribution of health information belonging to First Nations people. CHI has recently included plans on “*extending the systems to cover Aboriginal Canadians*” as a next step in a vision document describing further development of the EHR up to the year 2015.⁹² However, few details are known on how to implement this objective.

In response to concerns about privacy, Infoway has developed a *consent management framework*⁹³ jointly with select health care jurisdictions. From a privacy perspective, a patient’s consent directives are themselves considered part of this patient’s health record. Different provincial privacy legislations define different forms of consent for PHI, including (1) *express consent*, in which patients (or their representatives) perform an action to authorize the collection, use or disclosure of their PHI; (2) *implied consent*, in which consent can be reasonably inferred from an action or inaction taken by a patient (e.g., a patient presenting herself to a caregiver); and (3) *deemed consent*, in which it does not matter whether a patient has actually consented. Jurisdictions operating under an express or implied consent model allow patients to withdraw their consent at any time.

91 See Chapter 10 of Infoway’s “Privacy and Security Project—an Overview”, which states that “the success of the interoperable EHR depends in part on governance issues being adequately addressed”.

92 Canada Health Infoway, “EHR 2015: Advancing Canada’s Next Generation of Health Care” (2008).

93 Canada Health Infoway, “Consent Directives Management Services Guidelines” (2007).

Despite this flexibility, a withdrawal will normally not have a retroactive effect on the information already collected, used or disclosed.⁹⁴ Ontario's *Personal Health Information Protection Act*, section 19(1), for example, provides that a withdrawal of express or implied consent "shall not have retroactive effect". Moreover, data collection may even continue after consent has been revoked, since some provincial privacy laws allow (or require) providers to override consent revocations. Infoway's requirements specification on the EHR consent directives management system (CDMS) architecture specifically states that "*it should be recognized that the [...] CDMS has no ability to control the subsequent use of PHI once access has been allowed*".⁹⁵

First Nations communities are acutely aware of the shortcomings of the current EHR architecture. In their recent report on OCAP and data management, the AFN stated that the challenges facing Infoway in developing a pan-Canadian EHR model can serve as a precedent for OCAP-compliant systems.⁹⁶ Infoway is faced with developing a network that respects the needs of each jurisdiction, while communicating information between jurisdictions in a way that respects privacy. In fact, the AFN provided a model for the development of information systems that respect OCAP, consisting of interchange of information (through secure channels, using standardized protocols) between systems that contain data pertaining to First Nations communities and individuals. Unfortunately, this model is completely inadequate. As stated by the AFN itself, once information leaves the custody of First Nations communities, enforcing restrictions on the use and disclosure of that information is very difficult.⁹⁷ The AFN model addresses interoperability at the data level alone.

A robust approach to allowing interoperability while maintaining control necessitates the use of more than just data interoperability mechanisms. At the time of writing, work is underway on new models for privacy preservation in distributed EHR architectures. More research in this direction is required, if the pan-Canadian electronic health infrastructure is to be OCAP compliant.

Privacy

There are at least two major issues with respect to Canadian privacy law and the OCAP principles—namely, gaps in Canada's regulatory framework, and difficulties in reconciling communal privacy interests with modern data protection regimes. We consider each issue in turn.

94 Canada Health Infoway. *EHR Privacy and Security Requirements, Reviewed with Jurisdictions and Providers*, V. 1.1, Revised, 2005, at 26.

95 Canada Health Infoway. *Consent Directive Management Services (CDMS) Requirements Framework*. V 1.1., August 6, 2007 [Canada Health Infoway CDMS].

96 *Supra* note 3 at 15.

97 Canada Health Infoway CDMS, *supra* note 95.

Gaps in Privacy Law

Although Canada's privacy regime is constituted from a wide variety of sources, there are significant gaps when one considers the privacy protections available to individuals living on reserves. In the words of the National Aboriginal Health Organization (NAHO), there is "*no law in place that protects personal health information in First Nations communities, outside of federal, and some provincial activity*".⁹⁸ While a detailed analysis of the regulatory protections offered to individuals living on reserves is beyond the scope of this paper, it is clear that many of the protections offered to Canadians living off reserves do not apply.⁹⁹

In order to address this gap, the National Aboriginal Health Organization (NAHO) has urged OCAP be "*brought to life by community codes or laws*".¹⁰⁰ As part of its toolkit, it published a sample Model Code for the protection of personal information on reserves. Created by former British Columbia privacy commissioner David Flaherty, this document was based on the ten principles of the CSA Model Code; the NAHO intended local communities to modify it to suit their individual needs.

While the adoption of community codes or laws is a positive step, from the NAHO's perspective, using the fair information principles as an exemplar carries a risk of incommensurability. Simply put, these principles are highly individualistic in nature, whereas the conception of privacy often expressed by First Nations groups is a communal one (as evidenced, for example, in the OCAP formulation). In the next section, we argue that these different notions of privacy are quite difficult to reconcile.

Reconciling Communal and Individualistic Conceptions of Privacy

The difficulties involved in reconciling individualistic and communal conceptions of privacy prompted the AFN to state that Canada's privacy laws form the "*biggest barriers to First Nations attempting to assert control over their information*".¹⁰¹ This is by no means unique to Canada, as data protection law in North American and European countries is typically formulated in terms of individuals and their rights or interests.¹⁰² It is no surprise that the AFN em-

98 See First Nations Centre, Privacy Toolkit, (Ottawa: National Aboriginal Health Organization), online: <http://www.naho.ca/firstnations/english/documents/toolkits/FNC_PrivacyToolkit.pdf> [First Nations Centre, Privacy Toolkit].

99 For instance, PIPEDA will generally not apply to aboriginal health care organizations operating on reserves, since such organizations will likely not meet the criteria set out in sub-section 4(1).

100 First Nations Centre, Privacy Toolkit, *supra* note 98 at 6.

101 First Nations Centre, *supra* note 3 at 9.

102 Although beyond the scope of this paper, individualistic formulations of privacy are also common in the jurisprudence and research literature. For a rare exception, see Westin, who defined (informational) privacy as "*the claim of individuals, groups or institutions to determine for*

phasized the importance of reconciliation, stating that “*aligning OCAP with privacy legislation and providing resources to First Nations to enact their own privacy legislation would assist in enabling First Nations to take control over their own information...*”¹⁰³

The difficulties in reconciling individualistic and communal conceptions of privacy are understudied in the research literature, perhaps on account of the fact that communal conceptions of privacy have not been accepted by many privacy scholars.¹⁰⁴ For our purposes, it is sufficient to mention but one issue—namely, the difficulties that emerge when an individual’s interests are placed (by some set of circumstances) in opposition to those of her community. As stated in numerous documents (including publications by the AFN and NAHO), one of the main interests in First Nations communities concerns the well-being of their populations. Some commentators have suggested that this emphasis on communities is similar to select areas of Canadian law and policy, particular public health. If this analogy is apt, the presence of hard cases in public health law that pit individual rights against the well-being of populations is evidence for the existence of similar difficulties in the case of communal privacy.

It seems intuitive, therefore, that conflicts could arise between an individual’s privacy interests, and the privacy interests of her community. Although it is beyond the scope of this paper to investigate circumstances that could arise, possible scenarios could include genetic information, or the sale of health information for profit. In the first case, an individual could sell their genetic information for research purposes, even though their community wishes to keep genetic information on its members unavailable for research. In the second case, an individual may wish to prohibit disclosure of their personal information to marketing agencies, while community leaders are relying on the sale of bulk data to provide revenues for selected programs.

Although somewhat trite, these examples are not outside the realm of possibility. They raise the issue of commensurability between OCAP and legal regimes based on the fair information principles. Although it is common to characterize courts as engaging in “balancing acts” between competing rights, most cases up for adjudication take place within a settled legal jurisdiction. The unique claim of First Nations people to sovereignty and self-determination adds an additional layer of complexity, since one the issue of which system of privacy protection should have precedence is up for debate.

themselves when, how, and to what extent information about them is communicated to others”.
A. Westin, *Privacy and Freedom* (New York: Atheneum, 1967).

103 First Nations Centre, *supra* note 3 at 17.

104 For a rare paper discussing rights to cultural privacy, see Chandran Kukathas, “Cultural Privacy” (2008) 91:1 *The Monist* 68.

Some jurisprudence exists on the tension between individual and community interests of members of First Nations bands. An example of the difficulty of reconciling individual versus communal rights in the context of tort law has been provided by *Thomas v. Norris*.¹⁰⁵ In that case, the BC Supreme Court considered whether spirit dancing is a protected aboriginal right (under ss. 35 and 52 of the *Constitution Act, 1982*) that rendered inoperative the plaintiff's claims of assault, battery and false imprisonment. The plaintiff, a member of the Lyackson Indian Band, was abducted from his home and placed in a longhouse, where he was forcibly confined for several days, before finally escaping with an ulcer, dehydration and multiple bruises.

One of the defenses offered by the defendants was a constitutional defense that they had the legal right to initiate the plaintiff into the Coast Salish Big House Tradition, by means of the spirit dance. In performing the dance, the defendants claimed, they were not bound by the common law. Instead, the plaintiff's civil rights were subordinated (with the help of ss.35(1) of the *Constitution Act, 1982*) to the collective right of the "aboriginal nation to which he belonged".¹⁰⁶

Although the Court eventually declined to consider spirit dancing an aboriginal right "recognized or protected under law",¹⁰⁷ it nevertheless addressed the defendants' argument that the plaintiff's civil rights were subordinated to the collective right of his nation. As paraphrased by the Court, the argument for the defence went as follows:

*The onus is on the plaintiff to show a valid objective to be served by infringing the aboriginal right. The only possible valid objective is to protect one member of a group of people whose rights are constitutionally projected. There is little valid objective to be served by applying the common law of torts to the defendants in the exercise of their aboriginal rights. The rights of the individual must be subject to the collective rights of the nation to which he belongs. To hold otherwise, the constitutional protection of the defendants' aboriginal rights under s. 35 are a hollow protection.*¹⁰⁸

The Court made it clear that this line of reasoning was unpersuasive in the circumstances, finding that even if spirit dancing was an aboriginal right, "those aspects of it which were contrary to English common law, such as the use of force, assault, battery and wrongful imprisonment, did not survive the coming into force of that law".¹⁰⁹ The Court further opined on the relation between aboriginal rights and common law rights, stating that "[t]he assumed aboriginal right, which I perceive to be more a freedom than a right, is not absolute and the

105 *Thomas v. Norris* (1992), CanLii 354 (BCSC), 2 C.N.L.R. 139 [*Thomas v. Norris*].

106 *Ibid.*, at 29.

107 *Ibid.*, at 40.

108 *Ibid.*, at 47.

109 *Ibid.*, at 47.

Supreme Court of Canada reaffirmed this in Sparrow. Like most freedoms or rights it is, and must be, limited by laws, both civil and criminal, which protect those who may be injured by the exercise of that practise”.¹¹⁰

It is worth noting that the decision in *Thomas v. Norris* predates the Supreme Court of Canada’s decision in *Delgamuukw v. B.C.*¹¹¹ In *Delgamuukw*, the Supreme Court of Canada clarified Canadian law regarding Aboriginal and treaty rights and held that in cases involving Aboriginal and treaty rights, courts may need to give greater consideration to oral histories than written evidence. If *Thomas v. Norris* had been decided in accordance with the analysis espoused in *Delgamuukw* it is likely that the court’s reasoning would have differed, but just as likely that the court would have come to the same conclusion in the end. Following *Delgamuukw*, the decision in *Thomas v. Norris* has continued to be relied on for the proposition that an Aboriginal right does not include civil immunity for coercion, force, assault or other unlawful tortious conduct.¹¹² Canadian courts have yet to contend with a situation where an asserted communal right does not cause harm.

Given the enhanced recognition of Aboriginal rights within Canadian law as it has developed since *Thomas v. Norris*, the greatest barrier to an assertion of communal privacy is not likely to be encountered under the doctrine of Aboriginal rights, but rather under the doctrine of standing. While the court in *Delgamuukw* recognized that Aboriginal and treaty rights are exercised by individuals, as collective rights they are not possessed by individuals. The reasoning in *Delgamuukw* with regards to communal rights has created a significant barrier in regards to the ability of individual members of a First Nations community to assert Aboriginal rights. The general approach of Canadian courts to Aboriginal rights has been that individual members of a First Nations community cannot claim an Aboriginal right. If the right exists, it belongs to the Band and can only be asserted by a representative of the Band who is recognized, under Canadian law, as the lawful representative of the community.¹¹³

The law on standing as it applies to Aboriginal rights currently prevents an individual from advancing a claim of a rights violation when the asserted right is rooted in his or her status as a member of a First Nations community. Similarly, a group of individuals would be unable to advance such a claim if

110 *Ibid.*, at 48.

111 *Delgamuukw v. B.C.*, [1997] 3 S.C.R. 1010 [*Delgamuukw*].

112 See *Moulton Contracting Ltd. v. Her Majesty the Queen in Right of the Province of British Columbia*, 2010 BCSC 506. At the time of the writing of this paper, the decision of the BC Supreme Court in *Moulton* is under appeal.

113 See for example *Cameron v. Albrich*, 2011 BCSC 549; *Moulton Contracting Ltd. v. Her Majesty the Queen in Right of the Province of British Columbia*, 2010 BCSC 506; *Te Kiapilanoq v. British Columbia*, 2008 BCSC 54; and *Canadian National Railway Co. v. Brant* (2009), 96 O.R. (3d) 734 (Ont. S.C.J.).

they are not recognized as the lawful representatives of the community under Canadian law. Members of a First Nations community must rely on their elected council to assert a communal right on behalf of the community.

If, however, a communal right to privacy is asserted on behalf of a community by the Band council, it is likely the right will gain significant recognition under the doctrine of Aboriginal rights. Given the current approach to Aboriginal rights, the weight given to oral evidence and the fiduciary relationship that is said to exist between First Nations people and the Crown, significant weight ought to be given to the communal interests of First Nations people in the realm of health care and privacy.

One thing that can be said with certainty is that the relationship between communal and private rights is complex, involving interlocking systems of norms. One of the challenges facing stakeholders dealing with this issue involves finding ways of analyzing tensions (and of providing mechanisms for resolving them) that do not assume the primacy of one system over another. Respecting First Nations self-determination and sovereignty would be best served by finding solutions that do not assume the priority of one system over another. The question of whether this can be done in the context of health information privacy is our focal point for future work in this area.

VII Conclusions

This paper has served as an introduction to the issue of First Nations privacy in the context of modern health care delivery. In particular, we have examined the most common formulation of privacy interests expressed by First Nations stakeholders (the OCAP principles) in light of electronic health information systems. A common approach to health care taken by First Nations communities is one that is based on a holistic model of health and which emphasizes the importance of community. Since electronic health records systems provide comprehensive views of patient information, support for public health functions, and mechanisms to enable collaborative care, they provide incremental improvements towards a fully holistic health system. Barriers to adopting these technologies will further disenfranchise First Nations communities, to the detriment of their members.

While several noteworthy initiatives are examining the integration of OCAP into electronic health records architectures, there is quite a bit of work left to do in both the practical and academic domains. In terms of practical barriers, ensuring First Nations groups are represented in key industry working groups and committees is vital for respecting the OCAP Control principle. In addition, First Nations concerns should be incorporated into future versions of the Infoway architecture, since Infoway is the guiding agency for the development of provincial and territorial EHR systems. Lastly, technical

work is underway on new models for privacy preservation in distributed EHR architectures that enable the realization of the OCAP principles.

The most critical task, however, involves examining the interface between communal and individualistic conceptions of privacy. While it is tempting to assume that tensions between individual and communal rights may be settled by a balancing process akin to what common law courts engage in, more work is needed to validate this claim. In addition, First Nations' claims to sovereignty and self-determination add an extra layer of complexity on top of what is already an intricate issue. As in other areas of Canadian law relating to Aboriginal rights, finding a solution that does not merely assume the primacy of one system is going to be a difficult problem. We hope that this introductory paper spurs discussion among a variety of stakeholders, including First Nations, government, and the research and legal communities.