GOVERNMENTAL DECISION-MAKERS' VIEWS, PERCEPTIONS, AND CONCERNS REGARDING PRIVACY AND CONFIDENTIALITY ISSUES SURROUNDING PERSONAL INFORMATION, PERSONAL HEALTH INFORMATION, AND ELECTRONIC HEALTH RECORDS IN NEWFOUNDLAND AND LABRADOR

ETIENNE ORR-EWING

Governmental Decision-Makers' Views, Perceptions, and Concerns Regarding Privacy and Confidentiality Issues Surrounding Personal Information, Personal Health Information, and Electronic Health Records in Newfoundland and Labrador

by

Etienne Orr-Ewing

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Abstract

Objective To gain a better understanding of governmental decision-maker's views, perceptions and concerns regarding privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records.

Methods This project employed qualitative research methods. Nine interviews were conducted with public officials of the Government of Newfoundland and Labrador in the Department of Health and Community Services and the Department of Justice. The sample was recruited after consultation with privacy experts in the province and NLCHI.

Results The governmental decision-makers' had a thorough understanding of the terms and concepts involved with personal information, personal health information, and electronic health records. There was agreement that electronic health records can be and are safe. As well, the protection of personal health information should not impact health care or health research.

The participants said they used mainly internal documents for their information on privacy. They also performed extensive searches through other jurisdictions and review similar legislation in other province and countries. Also, they stated that a strong partnership exists with NLCHI.

Most participants believed that privacy is not a big issue in Newfoundland and Labrador. They stated that this is a relatively more trusting culture and that there has been a lack of resources allocated for this area. All agreed that the main reason for the delay in the implementation of the Access To Information and Protection of Privacy Act (ATIPP) and the privacy provisions was due to a lack of government readiness. All

agreed that the privacy provisions would come into force because government now considers this legislation to be a priority.

Participants stated that personal health information was not specifically addressed in ATIPP because it was previously recognized that it was different than personal information, and personal health information legislation is currently being developed.

Conclusion Privacy has not been a major issue in this province for several years. These governmental decision-makers have a comprehensive understanding of both the issues involved with personal health information and the objectives which should be taken into consideration when instituting personal health information legislation. It is imperative that these issues and objectives be addressed during the creation of such an act. In addition, government should make consultation with health researchers a priority when it moves forward with health privacy legislation.

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In addition, it should be noted that the researcher was the only person who was involved in the analysis of the data. The conclusions drawn are my interpretation of the information which was conveyed by respondents during the interviews.

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Governmental Decision-Makers' Views, Perceptions, and Concerns Regarding Privacy and Confidentiality Issues Surrounding Personal Information, Personal Health Information, and Electronic Health Records in Newfoundland and Labrador

Introduction

1.1 Problem

Developments in information technology and advances in medical science have made it possible to create and link health information databases in ways not previously possible. In addition, the legislative environment across Canada surrounding privacy and confidentiality issues governing personal information and personal health information has been transforming rapidly. The capability to access and link diverse data sets provides major research opportunities, will allow the streamlining of various aspects of clinical practice, and also promises to improve health outcomes (CIHI, 2003). Health research, particularly in the areas of health services and policy, population and public health, critically depends on the availability of existing personal data (CIHR, 2002). As an example, in the area of health research, the secondary use of data contributes greatly to the present level of understanding of the causes, patterns of expression and natural history of diseases (CIHR, 2002).

Even with all of these potential benefits, problems do exist. Firstly, the perceived potential for violations of individual privacy rights with regard to personal health information has increased (Callan & Gillespie, 2003). These perceptions exist both within the federal government and with the Auditor General, who over the years has

issued several strongly worded warnings about the wide range of risks inherent in health information technology in government (Atherley, 2005). These concerns must be addressed if governments are to meet their mandate to protect the public and to allow health care providers to provide the best care, even as researchers provide new information.

Newfoundland and Labrador went from being a pioneer in privacy legislation to one of the last provinces to update their public sector privacy statute. There is a need to find out why this was the case as the information would be very relevant to several stakeholder groups as well as government itself. Also, it is important to know if governmental decision-makers feel that Newfoundland and Labrador's new privacy legislation is able to adequately protect privacy with the new ways of conducting health research and handling of personal health information. Furthermore, when dealing with highly private and confidential personal health information and electronic health records, it is important that government officials receive and use relevant and up-to-date information on these current issues. These issues would include, for example, having a provincial electronic health record, linking and sharing health information databases for research purposes, or informed consent for sharing information for research. In addition, it is important for future interactions and relationships that these governmental decision-makers as well as the stakeholder groups involved (health researchers, data stewards, health care providers, etc.) to understand how and why certain privacy and confidentiality related pieces of legislation governing personal information, personal health information and electronic health records are supported by government while other such legislation is not.

1.2 Purpose and Objectives

Presently, there is little research information available on what governmental decision-maker's views are regarding privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records in Newfoundland and Labrador. The purpose of this study is to offer observations and gain a better understanding of their views, perceptions and concerns and how these might affect the manner in which privacy and confidentiality legislation is made within this province. These issues are pertinent to this province but the results from this study could potentially have relevance beyond Newfoundland and Labrador. There are five main objectives of this research project:

1. To gain a better understanding of governmental decision-makers' views, perceptions, and concerns regarding privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records.
2. To gain insight into what information governmental decision-makers are aware of and how they use it in regard to privacy and confidentiality surrounding personal information, personal health information, and privacy legislation (ATIPP).
3. To better understand the factors facing governmental-decision makers' that might influence the development and enactment of certain types of legislation, specifically the *Access To Information and Protection of Privacy Act* (ATIPP), and to gain perspective on reasons why Newfoundland and Labrador was one of the last provinces to enact this type of public sector legislation.

4. To gain insight into the legislative process in Newfoundland and Labrador in regards to how ATIPP was created.
5. To learn about what practices are being used to increase the exchange of information on privacy and personal health information issues between relevant stakeholder groups and the government of Newfoundland and Labrador.

1.3 Rationale

Privacy studies conducted in other jurisdictions have focused primarily on public awareness, understanding, and concerns (Schirdewahn, 2002), or upon stakeholder groups that will be affected by the emerging privacy regimes at both the national and provincial levels (Willison et al, 2003; Berger, 2002). Government is a major decision-maker on issues involving privacy and health information, and in Newfoundland and Labrador there have not been any previous studies specifically addressing the perspectives of government officials and decision-makers on these issues. This project aims to assess this particular group; governmental-decision makers.

This study is an extension of a larger privacy project being conducted throughout Newfoundland and Labrador by researchers based primarily in Memorial University's Faculty of Medicine as well as other university and community based researchers. This study titled: 'Sorry, You Can't Have That Information: Stakeholder Awareness, Perceptions and Concerns Regarding the Disclosure and Use of Personal Health Information', has surveyed numerous stakeholder groups (physicians, pharmacists, social workers, nurses, health researchers, data guardians, and the general public) and also held focus group sessions. That project is in its analysis stage and is hoped to be completed by August 2006. Governmental decision-makers were a group that was not addressed in the

study but were identified as a group whose views would be very important in this privacy context.

There are many stakeholder groups involved in the process of establishing statutes, however, it is government that sets the agenda and content of legislation by which the province and public must abide. This study is important because the information gained could help all groups involved in the privacy and confidentiality realm (government, public, etc.) gain insight and a better understanding of how and why legislative decisions- especially regarding the creation of ATIPP and the possibility of a health information act- are made, what kinds of information such decisions are based upon, and in which ways stakeholders input was taken into consideration. Another major aspect of this study is to identify potential knowledge gaps and the practices used in government with regard to exchange of information between stakeholder groups in the area of privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records. The findings of this study may be useful in designing strategies to close any knowledge gaps and to increase the exchange of information and knowledge between stakeholder groups.

Background and Literature Review

2.1 Definitions

When discussing privacy, privacy legislation, personal information, and personal health legislation, it is necessary to define terms as several of these terms have held different definitions in various domains (CIHR, 2000). As well, in this study, participants were asked to define several of the following terms in order to determine the definitions from a government perspective and to analyze the similarities, differences, and level of expertise. A central component of this study revolves around health research and health information in the context of the health care system. Therefore, several of the following definitions are taken from the Tri-Council Policy Statement (TCPS) which deals with issues of confidentiality and the protection of privacy in research involving human subjects in Canada. Although the TCPS is a policy document and does not have the force of law, over time and continued usage it is believed that it will establish the standard of care against which courts will measure the conduct of health researchers (TCPS, 2003).

Privacy is defined in the TCPS "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" (TCPS, 2003, 3.1). *Confidentiality* is defined as the expectation that information communicated in the context of a special relationship will be held in confidence or kept secret (TCPS, 2003). *Secondary use of data* is when data may have been collected originally for either a non-research purpose (i.e. for health care administrative purposes), or a different research purpose (i.e. for a study on a different but related issue) (CIHR, 2005). *Data linkage* is the linkage of information about

individuals in one database with information about some or all of those individuals in another database (Department of Justice Canada, 2005).

A report released by the Canadian Institutes of Health Research (CIHR) in 2000 called 'A Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research' contains many specific definitions pertaining to legislation. One category of statutes is concerned with the protection of personal information in general. This *personal information* includes basic health information such as, a person's fingerprints, blood type or inheritable characteristics, medical history or health and health care history (CIHR, 2000).

A second category of legislation deals more specifically with the protection of personal health information. These statutes define 'personal health information' in great detail. These definitions include the individual's physical or mental health, any health services provided to the individual, any donation by the individual of a body part or bodily substance and any information derived from an examination of that body part or bodily substance, any sale or dispensing of a drug, device or equipment pursuant to a prescription, as well as any other information that is collected in the course of providing health services to the individual or incidentally to the provision of such services (CIHR, 2000). Current legislation specific to Newfoundland and Labrador defines only personal information and not personal health information (CIHR, 2005).

2.2 Current Legislation

Health care is treated as a public good in Canada, and as such further discussion in the public forum is needed as to the standards of protection required for health information used in health research (Lachman, 2003; Doll & Peto, 2001). Data

protection legislation has rapidly emerged across the country with different requirements at the provincial, territorial and/or federal levels for access to personal information or personal health information. However, health services and population health research frequently cross provincial and even national borders and at times do require access to both general personal information and personal health information that may be from either public or private sources (CIHR, 2002).

At the present time, Canada has two federal privacy legislations; the Privacy Act and the Personal Information Protection and Electronic Document Act (PIPEDA). The Privacy Act (1983) imposes obligations on 150 federal government departments and agencies to respect privacy rights by limiting the collection, use and disclosure of personal information (Privacy Commissioner, 2005). The PIPEDA sets rules for how private sector organizations may collect, use or disclose personal information in the course of commercial activities (Privacy Commissioner, 2005). However, PIPEDA does not cover provincial or territorial governments and their agents (Privacy Commissioner, 2005).

The PIPEDA came into effect in stages between January 2001 and January 2004, in the face of numerous objections and concerns. In Newfoundland and Labrador, for example, the chair of the province's medical association policy committee, Dr. Gerard Farrell, stated that many doctors wanted to be exempted from PIPEDA as they believed this legislation would force hospital workers to ask too many privacy questions which would be both cumbersome and time-consuming, thus slowing down treatment (CBC, 2003). The association wrote to the Federal Industry minister asking for an exemption and also called for separate legislation designed to deal with the health sector (CBC,

2003). Moreover, the Canadian Medical Association Journal (CMAJ) in a 2003 editorial piece titled 'Paying the PIPEDA' wondered if it was necessary "to need a hippopotamus to remind them to discuss cases somewhere more private than elevators and hallways, to hang charts where visitors cannot read them, and to ensure that private disclosures are not overheard by the stranger waiting in the next cubicle" (CMAJ, 2003, p.5).

Every province and territory does have privacy legislation that governs the collection, use and disclosure of personal information held by government agencies (Department of Justice, 2005); Newfoundland and Labrador has passed such legislation, however, all of the provisions are not yet in force. In Newfoundland and Labrador the act is called the *Access to Information and Protection of Privacy Act* (ATIPP). Some questions that arise are: 1) why was Newfoundland and Labrador the last province to have this type of privacy legislation put into place, and 2) why has it taken so long for these provisions to be put into force?

It should be noted that in 1981, Newfoundland and Labrador enacted the Freedom of Information Act which was initially considered a pioneering piece of legislation. At the time it provided greater rights to citizens of Newfoundland and Labrador than were enjoyed by most other Canadians (Freedom of Information Review Committee, 2001). This Freedom of Information Act remained virtually unchanged for twenty years. During that time, technology and society underwent major changes which were not addressed in that legislation (Freedom of Information Review Committee, 2001). In 2000, the Government of Newfoundland and Labrador established a Freedom of Information Review Committee, which was mandated to review and make recommendations on all aspects of the Freedom of Information Act. The Committee recommended that a new

privacy act should be put into place and that the government enact separate health information legislation to apply to both public and private health organizations. Until such time an act was proclaimed, personal health information in the public sector would be subject to the jurisdiction of the proposed Freedom of Information and Protection of Privacy Act (Freedom of Information Review Committee, 2001).

Several provinces including Alberta, Saskatchewan, Manitoba and Ontario have passed legislation that deals specifically with the collection, use and disclosure of personal health information by health care providers and other health care organizations (Privacy Commissioner, 2005; CIHR, 2005). Newfoundland and Labrador does not have such legislation and the yet-to-be enacted privacy provisions of the Access to Information and Protection Privacy Act do not explicitly address personal health information. This brings about another question: Does Newfoundland and Labrador need a statute that speaks specifically to the collection, use and disclosure of personal health information? If so, why has it not yet been created?

Before Saskatchewan brought in its own personal health information act in 1999, the government conducted a consultation with the public. It revealed that 71.4% of those responding indicated a preference for new legislation aimed specifically at protecting health information (Saskatchewan Government, 1997). Unfortunately there has been no similar consultation or study here in Newfoundland and Labrador to gauge the public's opinion on this topic. Before ATIPP, the collection, use and disclosure of health information was governed by a mixture of separate pieces of legislation: the previously mentioned Freedom of Information Act, the Hospitals Act and other legislation such as the Child, Youth and Family Services Act and the Adoption Act, as well as the health

professions acts (NLHBA, 2001). The Hospitals Act regulates the access, use and disclosure of hospital records held by hospitals in the province; access to this personal information held by the health boards is regulated by ATIPP. The Newfoundland and Labrador Health Boards Association suggested in a 2001 report to the Newfoundland government that they undertake lengthy public consultations with the health community in order to develop a clear definition of health information, and then develop a separate piece of legislation that deals specifically with health information (NLHBA, 2001).

2.3 Health Research and Privacy

The tension between an individual's right to privacy and the broader public good accomplished through health research admits no easy solutions (Jepson & Robertson, 2003). For example, regulators and research ethics boards (REB's) in the United Kingdom have been criticized for giving undue weight to the privacy of the individual (Kent, 2003). While many struggle to interpret how privacy guidelines may affect the work of REB's and researchers (CIHR, 2001), some suggest that public health is threatened by incomplete data more than individual privacy is threatened by disease registries (Branswell, 2004) and the possible accompanying dangers such as inappropriate data-linking and un-secure computer databases. Others have questioned whether individual informed consent is even necessary for participation in health services research (Cassell & Young, 2002). Research conducted by Tu et al. (Tu, J. et al. 2004) suggests that there is a need for legislation on privacy to permit waivers of informed consent for minimal risk observational research. This study revealed that obtaining written informed consent for participation in a stroke registry led to major selection biases such that the registry patients were not representative of the typical patient (Tu, J.

et al. 2004). Additionally, a study in Virginia found that older patients and those in poorer health were more likely to grant consent (Woolf et al. 2000). The concern here is that health research restricted to only those patients that give consent may misrepresent outcomes and results for the general population.

To further the debate, Nick Black, Professor of Health Services Research at the London School of Hygiene and Tropical Medicine (2003), argues that identifiable data is crucial in research as it allows linkage within and between databases, ensures comparisons are meaningful, ensures completeness of recruitment, and permits the researcher to assess the applicability of the findings. He also states that this data helps to understand the natural history of disease, to identify the causes of disease and to assess the effectiveness and equity of health care (Black, 2003). It should be noted that some record linkages can be done without identifiable data as long as there is a common identifier. Health journalist Andre Picard summarizes the tensions nicely: "while striving to respect the rights of the patient, we must ensure that, as a society, we do not inadvertently undermine research that could improve patient care and save lives ...and that legislators, health administrators and research ethics boards have to be careful to not be swayed by a small group of privacy zealots" (Picard, 2005).

Gaining prior consent for a particular kind of study has been thought to lead to potential biased results. An example of this is a study that involved patients assessing their own quality of life (Boter et al. 2003). In this study, the researchers developed a modified consent procedure for a trial on the effectiveness of an outreach nursing care program for patients who returned home after being admitted for a stroke. Because many stroke patients experience reductions in quality of life or are dissatisfied with the care

received after discharge from hospital, the researchers intended using self reported quality of life and satisfaction with care as primary outcomes. However, they were concerned that un-blinded patients could lead to biased results (Boter et al. 2003). Firstly, patients in the control group might be dissatisfied because they knew that other patients were receiving outreach care. Secondly, patients who received outreach care might make a more favorable assessment out of loyalty to the program's staff. Would this study be considered unethical because informed consent was not acquired in advance? Some argue that no ethical principle should be absolute in this way (Dawson, 2004). Despite rigorous efforts by CIHR and the international health research community to address possible problems for health researchers in light of stricter privacy legislation, some uncertainty still exists regarding the perspectives and concerns of various stakeholder groups (CIHR, 2001). Governmental decision-makers play a significant role in finding a balance in regards to these issues and it is hoped that this research project will help address these concerns.

CIHR has taken significant steps over the past several years to work with various stakeholder groups and the provinces towards the establishment of a more harmonized, comprehensive legal framework governing the protection of personal information in the health sector and in health research (McDonald, 2006). The previous Privacy Commissioner of Canada, George Radwanski, stated in a speech to Parliament that he was 'confident that the PIPED Act is entirely compatible with the successful carrying out of health research' (Government of Canada, 2002). Focusing on governmental decision-makers' views and concerns regarding the use of personal health information for the

purpose of health research could provide insight into expectations for health research under ATIPP and/or health information legislation.

In Canada, studies have shown that patients are willing to allow personal information to be used for research purposes; they do, however, want to be actively consulted first (Willison et al.2003). These results were reinforced by another study in which it appeared that many patients want to have some influence in the use of their personal health information (Keshavjee et al., 2001). This concept is endorsed by Willison (2003) who states that 'in all uses of personal information- both data and biological samples- individuals need to be respected as participants with an interest in the use of their information'.

2.4 Electronic Health Records

The creation and linking of electronic health records (EHR) involves many stakeholders such as, but not limited to, patients, physicians, health researchers, pharmacists, and other health care providers, as well as the custodians of information databases and data stewards (Booth, 2003). Many believe that EHR's will have huge implications for how health care in Canada is managed and delivered. Proponents of EHR's contend that it would provide each individual in Canada with a lifetime record of his or her key health history and care within the health care system with many potential benefits in regards to the management and delivery of health care (Canada Health Infoway, 2006). These benefits include: immediate and universal access to a patient's record, easier and quicker navigation through patient's records, elimination of lost charts, clinical data that is formatted to be easy to read and analyze, coding efficiency and

efficacy, alerts for medication errors, a reduction in paperwork, documentation errors and filing activities, and the ability to transmit information electronically to other providers.

There is already evidence of basic application of some of these advantages. In the London Health Sciences Centre in Ontario, X-ray results previously took 4 hours to process. With new film-less technology, patients are now leaving that hospital with their results within 45 minutes (Sibley, 2005). Other signs of support for these possible benefits are recent studies completed in Canada which show that for every 1000 laboratory and radiology tests performed, up to 150 are unnecessary and for every 1000 patient visits with a specialist, those specialists received no patient information for 680 of those visits (Government of Alberta, 2006).

In 2004 a major health information technology and information management project was completed in the Fraser Health authority region of British Columbia. At that time it was the largest project of its kind in Canada, and it was closely followed by the rest of the country due to its possibly major implications and impact. The Fraser Health's PACS (Picture Archiving and Communication System) links all 12 Fraser Health hospitals electronically, allowing them to share patient X-rays and MRI scans across a sizeable geographical area (Canada Health Infoway, 2004). By eliminating searches for X-ray films and duplication of procedures, the system enables radiologists to be more productive. In turn, immediate retrieval of imaging results leads to improved quality of patient care. Four hospitals in the Fraser North area are at least 98% film-less and another four sites in Fraser East are now live on the digital imaging network PACS; four more hospitals will be connected this year. This is an interesting project in that it links an entire health region electronically through a diagnostic imaging network which is

predicted to save the health care system millions of dollars (Canada Health Infoway, 2004). This approach also helps address the challenge of providing technological access to smaller hospitals and clinics which comprise 80% of Canadian facilities (Health Canada, 2006).

However there are critics of this type of online record system. Some allege that these systems provide information that could be used to further privatize health care and that certain governments (i.e. Alberta) will eventually use the record of health system use in the database to bill people on a per-use basis (Mackay, 2004). Critics also cite concerns that doctors can opt out of participating in the system but individual patients cannot (Mackay, 2004). Alberta is the only province that allows physicians to do this; however, their government is currently changing this policy (McDonald, 2006).

During the 1990's there was much public outcry for upgrading of primary care. There had been significant cutbacks in federal funds to the provinces' health sector and many jurisdictions had started to look at what could be done in the area of information management. Experts in the health field had known for some time that the chief way to accomplish this was through the creation of elaborate information systems (O'Reilly, 2005). In Newfoundland and Labrador, a Healthy System Information Task Force was established in 1993 and the vision that was produced focused on a 'Person-Centred' health information system. The Newfoundland and Labrador Centre for Health Information (NLCHI) was formed in 1996 to assume the mandate of realizing this vision (NLCHI, 2004). Several provinces, most notably Alberta, British Columbia, Saskatchewan, Manitoba, and Newfoundland and Labrador began their own electronic health record initiatives. Now all provinces and territories have their own EHR initiative.

Alberta, for example, moved along rapidly with its program- now called Alberta Netcare- to place confidential patient information online for use by health care professionals. The Alberta Netcare (previously called the Alberta Electronic Health Record) contains important information such as prescription history, allergies, and laboratory test results. Patient information is protected by the highest online security standards in the world (Alberta Netcare, 2006). Health care providers using the system must undergo a rigorous security clearance and information is accessed on a need-to-know basis only. For example, a pharmacist would have access only to pharmaceutical information; all other information is blocked. Begun in 1997, this project received overwhelming support from physicians in Alberta, and the database now contains information for 3 million patients (Mackay, 2004). The Government of Alberta has publicly stated that they consider themselves a national leader in EHR development and the Canadian Medical Association's chief technology officer Bill Pascal agrees (CMAJ, 2006). He stated that "Alberta has the best program I've seen and I've looked into the United States as well" (CMAJ, 2006, p. 1396). Alberta is also looking to add text reports of diagnostic imaging results; they have added that by 2007, diagnostic images would be accessible as well (Government of Alberta, 2006).

Newfoundland and Labrador has also taken significant steps in its Electronic Health Record initiative. In 2000, Newfoundland implemented the first province-wide information system that linked all regional health information systems into the initial phases of the provincial EHR (Neville et al., 2004). A partnership was then formed between Canada Health Infoway and the Newfoundland and Labrador Centre for Health Information (NLCHI) to further develop this system into a model that could be adopted

by other regional and provincial jurisdictions (Neville et al., 2005). This Unique Person Identifier/Client Registry System (UPI/Client Registry) connects the registration systems of the Regional Health Authorities into a common master client index. The client registry is considered a basic building block for the development of all EHR's allowing for the identification of specific patient records in feeder and legacy systems (Neville et. al, 2004). The Client Registry is currently live and in production in Newfoundland and Labrador (NLCHI, 2006). The provincial Diagnostic Imaging/Picture Archiving and Communication System (DI/PACS) will be live by the end of 2006. This will be one of the first provincial DI/PACS in Canada (NLCHI, 2006).

NLCHI has also gone on to complete a detailed project scope for the creation of a province-wide comprehensive pharmacy network; this system is the third phase of the provincial EHR. The Newfoundland and Labrador Pharmacy Network is designed to offer on-line, comprehensive, active medication profiles, along with drug information and drug interaction databases (Neville et al., 2005). This increased access to appropriate medication information is intended to enhance the quality of care, facilitate accountability, and promote cost effective usage of medications (Neville et al., 2005). The detailed planning phase for the NL Pharmacy Network has been completed and the implementation phase is due to start in springtime 2006 (NLCHI, 2006).

In addition, a laboratory information system is being planned by NLCHI. This initiative will allow the seamless flow of laboratory information between the regional laboratory information systems and the province's two main reference laboratories (Neville et al., 2005). Furthermore, by creating a real-time electronic exchange of laboratory orders and results between sites, this system will help eliminate duplicate data

entry and will not depend on courier or postal service for results delivery (Neville et al., 2005).

Of course Canada is not the only country in the process of instituting EHR's. For example, the National Health Service (NHS) in the United Kingdom has also been attempting to modernize its health care system by introducing a new electronic system to monitor the quality, effectiveness, and equity of health interventions. In 2003 the UK eagerly invested $3.75 billion U.S. on an integrated care record service (Booth, 2003). As well, in the United States President Bush announced a ten-year goal ensuring that most Americans would by then have an electronic health record and some experts in the U.S. believe that some of its functions could save the health care system at least $29 billion a year (Tanne, 2004).

In Geneva, Switzerland, a community health care information network for all 450,000 of its citizens connecting public and private health care professionals has been created and instituted; it's being currently studied for its usefulness and effectiveness. The government has called this an 'e-toile' (star) project that has three major requirements: a) the medical information is kept at the source of its production; b) on the basis of the simultaneous presence of the patient's and the professional's access card establishing a therapeutic relationship, the information is put onto a virtual patient record which exists only for the duration of the consultation; c) the patient keeps control of which information can and cannot be accessed by the various stakeholders involved in his/her care (Geissbuhler et al., 2004). Experts have agreed that this design of a patient-centered, multi-institutional health care information network has been effective so far and the public has also been pleased with its performance (Geissbuhler et al., 2004).

2.5 Privacy and Security Concerns

The value Canadians place on the privacy and confidentiality of their personal health information is exceeded only by their concern for the privacy of their credit card, bank card or PIN numbers (CMA, 1999). A 2000 study in Alberta showed that 78% of Albertans expressed strong agreement with the importance of protecting individual privacy in the province (Province of Alberta Privacy Commissioner, 2000). When discussing personal health information and privacy and security concerns, a Pan-Canadian Health Information study showed that 25% of respondents had moderate trust in their government health departments and 51% had a great deal of trust (Pan-Canadian Health Information Privacy and Confidentiality Framework, 2004). Locally, a 1995 study found that older people in the province of Newfoundland and Labrador were more willing than younger people to share their personal health information (Segovia, 1995). However, a more recent study indicated that older people were more concerned than younger people about sharing personal health information (NLCHI, 2001). This could be attributed to several possible factors, including the rapid advances made in information technology with which older generations may not be as comfortable as younger people and thus making them less willing to share their health information in this format.

There are certainly many privacy and security issues involved when dealing with personal information and specifically personal health information. In a book titled *For the Record: Protecting Electronic Health Information*, the Governing Board of the National Research Council in the United States identified five major threats. The first threat is an 'insider' who makes mistakes and causes accidental disclosures. He might be the source of overheard conversations between care providers in the hallway or elevator

or he might leave information on a computer screen in a nursing station which onlookers could see. A second threat is the 'insider' who abuses his record access privileges. This individual has authorized access to health data and he violates the trust associated with that access. An example of this would be a health care worker who simply out of curiosity accesses information he has neither the need nor right to know. The third threat is an 'insider' who knowingly accesses information for spite or for profit. This occurs when someone has authorization to some part of the system but not the data he wants. Through technical or other ways, he gains unauthorized access to that data. A fourth threat embodies the unauthorized physical intruder. In this situation, the intruder has physical entry to points of data access but has no authorization for system use or the data he is looking for. In this example, an individual might put on a lab coat and a fake ID badge, walk into a facility and use a workstation or ask other employees for health information. The fifth categorized threat is the vengeful employee or outsider, possibly a vindictive patient who attempts to damage systems and/or disrupt operations. This would be a technical threat, as the intruder has no authorization and no physical access. An example of this might be someone who breaks into a system from an external network and extracts patient records.

As the foregoing has demonstrated, there are many privacy and security concerns at various levels within the information collection, storage and utilization domain. At times these issues arise at the national level. In Iceland, for example, arrangements were made with a private company engaged in genetic research to sell medical information (FIPR, 2003). In the United States, many medical record systems were organized for the benefit of insurers and information was made widely available to employers and

commercial researchers (FIPR, 2003). These two instances bring up serious issues surrounding privacy, confidentiality, and security of personal health information as well as informed consent to share personal information.

Critics of proposed information strategies suggest that the focus has been on data flowing from clinicians to administrators instead of between clinicians and patients, creating barriers for patients in accessing their personal health information (FIPR, 2003). However, a 2004 pilot study in New Hampshire revealed that an EHR successfully brought together clinical records from different systems to support clinical care, enabled analysis of data from clinical records, and that clinical staff found great value in a EHR (Sanderson et al., 2004). Proponents of these information strategies believe that it may be necessary to sacrifice some small individual privacy risks to receive the benefits of an EHR (Wermet, 1995). They point out that most people experience a routine loss of privacy in many day to day activities such as having their addresses and phone numbers printed in phone books and directories. However, the vast majority of people are content to lose some privacy if they gain some substantial benefit as well (Wermet, 1995). This, it is argued, would be the case with EHR's.

2.6 Access and Protecting Privacy

Since the time of Hippocrates, the need to maintain privacy and confidentiality of personal health information has been recognized (Kurtz, 2003). In the health care setting, a patient can expect that any personal information collected by a health care provider will be used for his or her care and treatment. Consent will be implied for the collection, use and disclosure of the patient's personal information for care and treatment purposes if when patients are apprised of their rights with regard to the disclosure and use

of their personal information; health care workers will nevertheless continue with that care and treatment (Health Canada, 2006). An individual's personal information protection rights include knowing why personal information is collected, how it is used, and to whom it is disclosed (Health Canada, 2006). However, some personal information may be disclosed without the patient's permission (e.g. Ministries of Health) where required or authorized by law (Privacy Commissioner, 2005).

When discussing linking health information systems, this ability to enhance medical care coexists with the possibility of undermining the privacy and security of a patient's most sensitive information (Goldman & Tossell, 2004). It can be summed up in this way: "The most secure medical record system is one that no one can access; the most user-friendly system is one that anyone can access" (Borzo, 1997, p.1). Some experts believe that these systems can be private as well as accessible if they give patients control over who has permission to view their record, and ensure patients have access to their own medical information while protecting their privacy (Mandl, K., Szolovits, P., & Kohane, I., 2001). A patient who is managing investment accounts and purchases online would expect the same level of control to be extended to his online medical portfolios (Mandl et al., 2001).

Methods

3.1 Sample and Recruitment

This project employed qualitative research methods. Specifically, it was comprised of semi-structured, key informant interviews to gain a better understanding of governmental decision-makers' views, perceptions and concerns regarding privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records and how or if these views might affect how privacy and confidentiality legislation is enacted or impeded within this province.

The study recruited high-level public officials (governmental decision-makers) of the Government of Newfoundland and Labrador in the Department of Health and Community Services and Department of Justice. The sample was recruited after consultation with various experts involved in privacy work in Newfoundland, members of the larger privacy study, and individuals from NLCHI. These people played an important role in assisting with identifying high-level public officials who work within the privacy sector and are involved in the creation of privacy legislation in the Department of Health and Community Services and the Department of Justice. Nine interviews were completed while two interviews were cancelled due to scheduling conflicts on the part of one interviewee, and the unavailability of the other. The saturation approach was taken to sampling. Sampling was continued until the point of data saturation (i.e. no new ideas emerged).

3.2 Instrument

The instrument (interview guide) was developed by building on several of the questions from the larger Privacy project, and was also consulted on extensively with

several privacy experts in Newfoundland and Labrador. Lucy McDonald, the Director of Privacy and Communications at the Newfoundland and Labrador Centre for Health Information (NLCHI) was highly involved in refining the instrument to ensure its face and content validity. In total, there were twenty-four questions. The individuals identified were first contacted by e-mail and then contacted by phone and given information about the study. For those who agreed to be participants, I explained the content of the consent form.

Informants were asked to respond verbally to questions about: 1) their views, perceptions and concerns regarding privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records, and 2) how privacy and confidentiality legislation governing electronic health records is made within this province.

It was agreed that an informant interview, rather than a focus group, was the most appropriate method to collect information from governmental decision-makers about their views due to the sensitive nature of the topic and governmental structure. Informant interviews are more likely to make the respondents more comfortable and they provide a higher degree of anonymity and confidentiality than focus groups.

3.3 Data Collection

Almost all participants were located in Newfoundland and Labrador Government buildings in St. John's, and appointments to interview the participants were made at a time and location that was convenient for each participant. Before the interview, the participant was given a project information sheet, a review of the project by the investigator and a 'Consent to Take Part in Health Research' form from the Faculty of

Medicine, Memorial University. Each document was reviewed by the participant who was then asked if there were any questions regarding the project. After all questions were answered and the consent forms were signed by the participant and the investigator, the taped interview began. Each informant interviews took between 40-70 minutes. Interviews were tape-recorded and transcribed verbatim.

3.4 Data Preparation and Analysis

For anonymity purposes, the name used on each transcript was 'participant'. For this study an ethnography approach was used. I attempted to study the meanings, patterns, and experiences of this defined group of individuals- governmental decision-makers (Polit & Beck, 2004). The aim of ethnography is to learn from members of a defined group, and to understand their view as they perceive it (Polit & Beck, 2004).

A coding template was developed for the transcripts. The template identifies categories based on the concepts and clusters of concepts found in the interviews (Polit & Beck, 2004). It was then used to code the transcripts.

Ethical Consideration

3.5.1 Ethics Approval

The Human Investigations Committee (HIC) application was reviewed by the Co-Chairs of the HIC and full ethics approval was granted from Memorial University's HIC on February 8th, 2006 (Reference #06.45), using the general, non-clinical trial HIC application.

3.5.2 During Data Collection

During the informant interview stage of this study, participant confidentiality was ensured in two ways. The interviews were conducted in a private area, either in the informant's office or in a reserved conference room. Each participant was identified only as 'participant' and given a number on the interview tapes and transcripts. Furthermore, all participants were given a consent form to sign containing information on the purpose of the study, the requirements of participation, the length of the interview, its risks and benefits, and a statement of confidentiality. Participants were also offered the results of the study when finished and would have the opportunity to contact the researcher if they had any questions.

All transcripts and tapes were stored in a secure location at all points during and after the study. Access to data has been restricted to the principal investigator and the supervisor, Dr. Daryl Pullman.

There were relatively few potential risks for participants; the one identified was the loss of time due to taking part in the interview. The information sheet explained to the participants that they were free to not answer any questions and to stop the interview at any point they wished.

3.5.3 During Data Analysis

All transcripts and tapes were stored in a locked room within a locked filing cabinet in the Division of Community Health, Faculty of Medicine at Memorial University of Newfoundland. Data was linked only to the study code to protect participant anonymity and confidentiality. Computer files for all components of the study were saved on a shared network that was password protected. Only the principle investigator and Dr. Daryl Pullman had access to the filing cabinet as well as the password protected computer files.

3.5.4 During Dissemination

All publications and reports will present the study results in aggregate to further prevent responses being linked to individual participants. Participants were informed that their responses will be reported in such a manner as to protect their identity. No names or identifying information will be published or released. Thus, the participant's anonymity will be protected.

Results

A total of nine (N=9) public officials (governmental decision-makers) from the Government of Newfoundland and Labrador's Department of Health and Community Services and Department of Justice were interviewed for this study. All participants had been identified as being highly involved in the privacy and or health information realm and many of them had been involved with ATIPP at some level since or before its inception. Since privacy legislation, specifically ATIPP, covers a wide area, the individuals were selected from many different levels of government. It was intended that this study would elicit their diverse experiences and views to help better understand governmental decision-maker's perceptions on personal information such as personal health information, and to thus clarify the decision-making process involved in the establishment of privacy legislation. Although the interview guide was standardized, some participants had more to share on certain issues than others.

Five major topics were identified from the information gathered in the interviews, and many themes emerged in the discussion of these topics. These topics were as follows: 1) Privacy and confidentiality issues surrounding personal health information and electronic health records, 2) The legislative process and the creation of ATIPP, 3) Information and resources used for issues regarding privacy, protection of personal information, and ATIPP, 4) Privacy legislation issues in Newfoundland and Labrador surrounding personal information, personal health information, and ATIPP, and 5) Newfoundland and Labrador government practices on the exchange of information with relevant stakeholder groups on privacy and personal health information legislation issues.

The following results section has been categorized under these five topics. The results section contains, at times, extensive and lengthy quotations which are rich in information and provide great insight into these issues. Abbreviated quotations have been avoided as they would lessen both the messages and the impact of what the participants were communicating. As this study is based on acquiring governmental decision-makers' personal perspectives, it is only appropriate to supply many concrete examples of exactly what they had to say on these matters.

4.1 Privacy and Confidentiality Issues surrounding Personal Health Information and Electronic Health Records

4.1.1 Definitions

Several definition questions were initially asked in order to ascertain the wide range of perspectives of individuals from different positions, divisions, and departments. All participants had very well-developed definitions of privacy, confidentiality, and security of personal information. The definitions covered a myriad of issues and showed that these individuals had a thorough understanding of these concepts. In terms of privacy of personal information, it was described in many ways.

Participant: Privacy, I guess, would entail the notion that the information contained in the files belongs to me and that access to that information should be provided only with my consent.

Privacy of personal health information was another aspect that was discussed by many of the participants. Implied consent in regards to personal health information was also mentioned.

Participant: I would define it in terms of... that there will be no access to personal health information unless authorized by the person him or herself in terms of what the information is collected on... on the person it was collected and what I would quote "an authorized holder of that information."

Participant: Well, that it's information that's accessible only to the person who owns it, which is the person themselves, and it's accessible to others only by permission either implied or direct by the person who authorizes its release. And when I say implied... because sometimes, for example, if you... by merit of the fact that you accepted an MCP card, for example, you've implied in that that you know the legislation and you know that information can be released for research purposes, for example - that that's implied consent; but the information is always owned by the person. We are just custodians.

The definition of confidentiality of personal information brought about many interesting issues. These included the idea that confidentiality and privacy are interrelated concepts, that health professionals may themselves not be protected legally to protect confidentiality, and that confidentiality is not absolute but a notion.

Participant: Confidentiality and privacy are sort of interrelated concepts, but I would say that confidentiality protects the relationship between myself and, for example, a physician with whom I share that information, whereas privacy relates to the information itself. So the relationship is a confidential relationship, but the privacy attaches to the information.

Participant: Well, confidentiality means that you don't disclose anything until you have permission to do so or that you have legislative authority to do so. You always have to fall back on any legislative parameters. If you go... you know, only lawyers really have true legislative right to... for example, to protect information. To give you an example, if I were to... if a lawyer went to court and he was asked about a particular case and whether or not something happened to his client, he can refuse to answer on the ground that he is protecting client privilege. Health people... personnel don't have that level of protection of privileges. So if I were a physician- and I have gone to court as expert witness, for example - and I was asked by the prosecutor as to whether or not... you know, about a certain issue, my response was, well, I'd prefer not to answer that question because it's... it would be violating the trust that my patient placed in me; but if a judge says to me, you know, I order you to release that information, then I have no choice but to release it.

Participant: Confidentiality is a misnomer, I think. People think if they stamp confidentiality on it, you... it's confident - that it's held, you know, between the parties involved. Confidentiality is really about the notion of either expressed or implicit will to hold a communication as in the boundaries of the parties involved. That would be definition of confidentiality. Is it a right or is it paramount over any other aspect of.. related to personal information or health information held by governments - no - not in an absolute sense. There are different privileges that supersede rights like that or processes like that.

Another distinctive point involved the idea of confidentiality not being used in legislative terms. The individual went on to explain how confidentiality can actually be 'more', in a legislative sense, than privacy.

Participant: Well, confidentiality is not really something that we see in legislative terms. You know, everything is... every word, whether you use 'privacy' or 'confidentiality' is only what it is defined to be for that purpose. Confidentiality would be... it's more than privacy in a funny way because privacy, in its legislative context, has certain limitations. Confidentiality often is another layer of protection because of some things provided on a confidential basis. Sometimes then it warrants additional protection, rather than information that is subject only to privacy rules because privacy is what is defined and, usually, it's consistent for the purpose for which it was... for which it's given. So you'll see sometimes in legislative policy something extra attached too, if it was provided on a confidential basis.

4.1.2 Security of Personal Health Information

The question of defining security of personal information introduced a great deal of accompanying information. Participants wanted to discuss physical and electronic storage, and protection.

Participant: Security means, I guess, applying all reasonable attempts to prevent unauthorized access to the information. In a paper copy, I guess it means making sure the charts are in a locked room. In electronic, making sure that you don't access it except with appropriate passwords or protective firewalls necessary to prevent unauthorized access.

Participant: Security can speak to the physical storage of information. It can also speak to the electronic storage of information, and that it is in a safe environment and there is controlled access through various protocols.

The idea of security being much different than privacy was discussed, as were the accompanying budgetary implications. Also, a participant felt that security must ensure that the integrity of information is kept intact.

Participant: Well, security, I think, is much different than privacy. Security is about the whole budget issue, ranging from sort of the IT solution in terms of encryption. You know, it's about that integrity; it's about that maintenance, whether it be electronic or paper form. It's about the human resources that revolve around security issues such as, you know, if you're in a hospital and you have a computer screen lit up and you have

patient files on it, who can see that. What access is there? What is the physical environment? You know, can I have a nursing station and a computer terminal and I see it from the other side of the nursing station? Those are the security issues in terms of affecting a breach in terms of individual privacy. So it's a combination of certainly the physical environment, as well as the technical solutions, whether it be a locked file cabinet in a vault or whatever.

Participant: I guess security relies... it goes a little farther, I guess. It's not only confidentiality, but probably the integrity of the information - so making sure the information is as it was when it... it's kept; nobody has the ability to modify that information. It's kept for the timeline by which it needs to be kept, so the authenticity, integrity and those things remain.

A question which resulted in a great deal of rich information dealt with the safety of personal health information in the form of electronic health records. Participants were asked if they had any concerns with this. A common theme was that they were indeed safe and that government was doing a good job in this regard. Government must, however, be vigilant to use best practice and continue to improve its methods for keeping this private information safe in the light of today's constantly changing technical environment.

Participant: I always have concerns. You know, one of the things that we labour with from the IT side of things ... which is the automated areas that never had information systems - a real double standard - and the standard in the old paper-based world was much, much lower in my view then where the bar is set for the IT side of things. I mean, you've always got to be, you know, constantly vigilant. I mean, you always... it's not... it's not an end state, but it's a journey. I think... like reality is - you're never done; but, by and large, I think we do a good job. Could we do a better job - absolutely; do we need to - sure - because the standards are getting raised and, you know, the environment is changing.

Participant: I think the simple answer is, yes, it is safe. Can it be made safer in terms of protection of personal information. Can we have more comprehensive methodology in terms of how we both get the information in the first instance, but how we obviously store and access it through electronic mean...we've always got to be ever vigilant that we use, you know, the best practices and best electronic and other systems in place to ensure that the collection and... of the information - storage and utilization - always embrace the best practices on all fronts, and that we've got to constantly remain current on that.

Some suggested that electronic records do not pose any more of a risk and actually are safer than paper-based records.

Participant: Electronic charts could be more secure in the sense that you have to have passwords to get access to it and so on. Now, I mean, you can get dishonest people who will try to break into the system - break your password - just as you get dishonest people who will break your window to get into your building and get a paper copy. So I don't think that electronic health records any more of risk for privacy than the paper copies right now. Electronic records is... can be safe, if not safer than the way we do business now, and for years we've done that without ATIPP, without anything else, and things seemed to work.

Other comments involved the conducting of privacy risk assessments, the comparison of electronic health records to information being shared in the banking sector and how government could use those methods.

Participant: Our objective will be to do a reasonable risk assessment at any point in time to make sure we avoid any undue disclosure of personal health information to... of those parties that obviously should not have access to it.

Participant: At the end of the day it comes down to an evaluation and a risk assessment, for the lack of a better word, in terms of are we making sound decisions in collection and use with intention and disclosure - disclosure of personal health information and ineffective balance.

Participant: Using the example of the banking sector, I always say that people would be more willing to give their personal health information to "a stranger" than they will their financial information, and I think the banking sector has certainly captured the essence of privacy and we can emulate some of their practices for sure, probably if there are... I think, when you go to the banking sector as an example, there's still a lot of lessons to be learned there.

One concern involved the possibility of more errors and breaches when records become more electronic.

Participant: I mean, there's... as you get more and more electronic, there's more opportunity for persons that are interested, either directly in terms of a malicious act to obtain access to the... one's personal information or in a... by accident in terms of, you know, like a virus corrupting and sending e-mails and those kinds of things. So, you know, there is a lot more opportunity than the safety of personal information from a security perspective. Likewise, in terms of the old paper records, there was opportunity there too, but it's different. There are dimensions of problems.

Another group of responses centered on the public's confidence in the safety of electronic health records, the provincial government's good history of protecting personal health information, and that changing to electronic health records would not be considered a major leap.

Participant: I think that as information technology... as a discipline develops, the possibilities for sharing information obviously become greater and I think that our... in some ways, I think there's a fear that the ability to protect the information in an electronic environment is not as great as we would like it to be; and I think we have to increase the level of consumer confidence in our ability to protect this information, if we're to get buy-in from the general public.

Participant: We have a long history of collecting health information in this province, and we have very few examples where there have been misuses, mis-access to that information, so... and I think we have a strong history and culture of ensuring maximum protection of the information. So, for us, it's not a big leap of faith to moving to electronic systems, or what have you, to make better... you know, to just be more efficient in how we use that... how we store and use that information on a go-forward basis.

In addition, it was mentioned that privacy and confidentiality issues and sharing of information is more of a concern for government than the individual or patient.

Participant: What I've found is that the issue of privacy and confidentiality from a patient's perspective is often... a bigger concern for those who are drafting the legislation than it is for the patients themselves. Most patients are quite happy to have their information shared, as long as it's in their best interest - as long as there's no malicious abuse of it...in the world of delivered care... care delivery, I think patients are pretty relaxed in allowing that information to be shared around professionals within that circle. That's my experience, and I think we can take this whole issue of privacy and confidentiality to a height that it creates more problems than solutions, really.

One participant gave an example of when the state could use personal information for the greater public good. In general, it was agreed by all that EHR's were the right direction to follow.

Participant: It's also about the public right. The reason we have government is so we can have democracy in terms of balancing the rights of individual privacy versus the

rights of the state to be able to use personal health information for the greater public good. So, for instance, we have a lot of personal health information respecting incidence... case-specific incidence of a type of cancer that affects a particular part of this province, that information is extremely useful to study some of the reasons why that spike occurs and analyzing what kind of measures could be put in place to alleviate that spike in a particular cancer, whether it be genetic, environmental, you know, socio-demographic - whatever the case may be in terms of reasons and rationales for the secondary purpose of research perspective and why that cancer occurs.

Participant: My personal opinion is that it's (EHR's) a very important place for us to go. I think it will make more information available more easily to various participants in health care to better serve us in health care. So for me, personally, I think that's a positive direction.

A follow-up question asked the respondent if they felt that the current legislation and technical environment provided enough protection for personal information and electronic health records. This question produced many different answers and related information. From an information technology perspective, it appeared that there was no absolute protection and that there was a need to enhance current systems.

Participant: You know, you're never... I suppose, you know, I can't really say it's never enough because at some point, you know, you... we can't... there's no absolute way to protect privacy. So, I guess, you know, it's a question of how much do you do and what's appropriate. Do we need to... absolutely, we need to do more. You know, we've got different systems built in different eras that may not have had, you know, the benefit of the same consideration review - you know, formal assessments - so, yeah, I mean... we've... we've... you know, to be honest, yeah, we've got places we probably need to enhance systems, and the related processes.

Some suggested that a separate piece of health information legislation was needed and it was currently being worked on and that Part IV of ATIPP was not sufficient enough for health information.

Participant: That's an issue we are... as a department, are trying to grapple with. Obviously, we have the... you know, the federal legislation. We have our own provincial legislation, but we are working on a new piece of legislation that will be focused solely on personal health information in the province, and we think to give greater certainty, if nothing else, to the collection storage and access of information and use for specific

purposes, that we need to beef up our provincial and legislative regime because that's something we're dealing with as we speak.

Participant: I mean, Part IV access to information is a good start; but, personally, is it large enough for health information - probably not - and are we doing things about that- yes. We are deliberating on other mechanisms to deal with some of these features of personal health information because there's such a large body of it and it's so sensitive.

Another stated that legislation will always be playing catch-up to technology.

Participant: There is going to be some new legislation in place, in terms of health information. So I guess at this point in time the legislation itself may... you know, until there's actually new legislation in place, may be a little antiquated, in terms of dealing with some emerging issues or just technology itself. As you know, technology advances quite quick... ...and to get legislation to actually catch up with the new technological advances, will... there's always a bit of catch-up there.

Furthermore, several participants said that although the current technical environment is protected in some respects, security and protection were not really an issue in Newfoundland because of its size and culture.

Participant: The short answer would be - yes, in some ways, and no in others. It's like a moving train. I mean, what we have today may be adequately secure, from a technological perspective, for a whole variety of reasons. Some may be because we have the technology and some may be because we're building good technology, and some may be for the fact that security is not really an issue in Newfoundland as it would in a larger jurisdiction. So it... it... well... well, benchmarking on whether or not people would want maliciously certain information in this jurisdiction may not be an issue. That's not necessarily a good security protocol, but it is a cultural reality.

Others suggested that the federal government had a large role to play in this matter and added that significant implications for research were involved.

Participant: I think the federal government has a big role here too, particularly... this information, you know, is... has huge potential in terms of across borders, across provincial boundaries across national and international boundaries. It has great potential for research, particularly in... for catastrophic diseases like AIDS and so on.

Another added, with an example, that there have been no similar privacy or confidentiality problems surrounding electronic records to date, though it was difficult to gauge because there has yet to be a true EHR.

Participant: Like the protection we have now, for example... we have... MCP, for example, has a database that contains a lot of information on people. That's... you know, we're not... not everyone can get access to that; but if there's research to be done, the minister can release the data as long as it's stripped of identifiable information, and then that can be used for the purpose of the research. That's been used in this province for years and years and years, and I'm not aware that there's ever been an issue of a breach of confidentiality with respect to that. The banks have done this for years, right? I mean, people don't seem to fear the fact that their bank accounts are not safe. There are technical ways for managing this.

Participant: I mean, we got bits and pieces all over the place but could we have a true electronic health record at this point in time; and until you do - until you have, you know, a ship in the water, you don't know whether it's going to balance properly.

Also, there were concerns over how confidentiality translated on the 'ground' (in actual practice), as well as how security is not actually dealt with in legislation as it is assumed.

Participant: There is this understanding within the... - the health community, I'll call it - that these records are "confidential." Okay? But how that actually translates on the ground is very different because it seems like when things are being operationalized - if it's practical to share the information; if it's one less step - then, automatically, information is being shared and there isn't always a consent providing that information to be shared.

Participant: Our legislation doesn't deal with electronic records specifically. It doesn't set up standard codes. So, you know, I look at other pieces of legislation across the country, and most of those type of security issues are not dealt with in the legislation. They are... they are, basically, internal government policy. I don't know that... I've never seen, in any of the legislation, specific rules with regard to safe handling practices. It... all the legislation assumes the best and safe handling practices because, obviously, it requires that the information be protected.

4.1.3 Impact on Patient Care

A topic that resulted in many assorted and at times opposing views was regarding what the participants thought the protection of personal health information would mean for patient care and health research. As the following series of quotations demonstrates with regard to the issue of patient care, one participant felt that it would result in more administration, possibly less effective care, and that information being shared against the patient's wishes should only happen when it is absolutely necessary.

Participant: I suppose it will mean more administration. (chuckles) I don't see a way around that... it may mean less effective care. There's going to be information that really, really, really would be to your benefit if it could be shared, but you may choose and I think you need to have that right with certain information not to have that shared, and in some cases they may impede your care. There's certain principles we must respect and we can only be sharing information which is, I suppose I might say, against the patient's wishes only when that's absolutely necessarily.

On the other hand, another individual believed that it would enhance patient care.

Participant: Hopefully, it will enhance patient care. Sharing of the information will enhance patient care, and be a boon to research in the province.

Still another said that there would be only minor improvement, if any. Another thought it could provide confidence to the general public that their personal health information is being protected.

Participant: For patient care, you know... I suspect, you know, one could argue that there will be... should be a marginal or incremental improvement because the data is being collected for a very specific purpose and can be used for a very specific purpose.

Participant: For patient care, I'm hoping that it will not impinge the ability of providers to be able to share information in the interest of the patients. At the same time, provide reasonable access to... in confidence to the people that their information is not going to be just loosely distributed at random, that it's... it's, you know, that it's on a need-to-know basis concept.

Finally, one said that there was no relationship between the two but it was nevertheless important for having good public policy.

Participant: In terms of patient care, I don't think it really has a relationship in patient care. The quality of...sorry... in the context of a person receiving services. In terms of having good sound, evidence-based, public policy for patient care, a whole lot.

4.1.4 Impact on Health Research

In terms of what protection of personal health information could mean for health research, all agreed that it would have a significant impact, both positive and negative, for various reasons. Some thought it would be good as long as health research was considered from the start but that more consent could lead to less people participating.

Participant: It's got to be built into the whole process – if health research becomes an afterthought, then it's probably not going to be very effective because you're not going to get consent or you're not going to get it properly and so, therefore, you're going to be limited or excluded from using sources of information.
But we'll have to get more consent. So I guess my first take is that would not be good because people are... some percentage of people are going to decline, from what I understand from other jurisdictions.

Others spoke about how it would help study diseases prominent in Newfoundland.

Participant: We have, for example, quite a number of prominent diseases in our population, which we know that if we collect and use information based on a current information can help and research to achieve a daily better outcomes in the short and, ideally... certainly, the short term but, more important, for the longer term and that that's something this would allow... could allow - I shouldn't say 'would' - could allow a better and informed and resourced research community.

Participant: For instance, like we're looking at, you know - again, to get back to the cancer example - if we have an incidence of disease that's totally preventable, and we could stylize... structure our programs based on looking at real, real data from real individuals to, you know, implement programs in the community to prevent or have some early implemented strategy.

Participant: If you... you know, the old saying - if you can't measure it, you can't manage it. So we have to be able to measure it; we have to be able to then study it, and that's important because you can keep on doing the wrong things forever if you don't study it

and you never improve the system and that's, in essence, denying improved care over long term.

One participant spoke about how it would clarify the researcher's role.

Participant: Setting up the rules for health research - you know, giving health researcher clear rules on how they actually go ahead and do that. So it would give you clear guidelines and rules on how you actually do your business and the fact that, you know, once you actually have your report, the fact that you de-identify information - those type of rules as well. You know, just making things clear that, yes, you do need, you know, the information.

Another concluded that it was all about finding the right balance between an individual's privacy and the public good.

Participant: So, I guess, some of this, I guess, boils down to protecting the individual privacy versus the public good, and finding that balance between the two.

4.2 The Legislative Process and the Creation of ATIPP

A key objective of this study is to gain a better understanding from a governmental decision-makers' perspective, of the legislative process in terms of how privacy legislation is created in this province, especially as it applied to ATIPP. Some interview questions involved the actual process of drafting legislation; others dealt with the types of concerns or issues that were raised during this process; still others concerned the amount of stakeholder consultation involved throughout the development of ATIPP.

4.2.1 Process for Creation of ATIPP

For the first part, a general theme emerged from the participant's responses to the effect that the previous privacy legislation was outdated and needed to be changed. Hence ATIPP was developed by the Department of Justice.

Participant: I think it was back around 2000. The Liberal government at the time decided that the Freedom... the old Freedom of Information Act, which was enacted in 1981, was antiquated, and government decided to move forward and to actually change the legislation.

Participant: ATIPPA evolved much the same way. The only difference is that the policy was developed by the Department of Justice, not by the Department of Health and Community Services; and as a result, the Department of Justice consulted with us.

One participant gave an extremely detailed account of how ATIPP was created, providing great insight into all the steps involved in the thorough legislative process.

Participant: Government first commissioned a task force, and that task force studied the inadequacies - this was a committee of the House of Assembly, is my understanding - studied the process and identified the process in applying the old act and recognizing deficiencies... identifying deficiencies in the old Act and ask if they'd make recommendations for new legislation. That committee reported to the House... filed its report. Those recommendations came forward then to government. They were accepted and government, out of those recommendations, would have prepared in the normal course what's called a Cabinet Paper. That Cabinet Paper would've been submitted to the Executive Council, the Lieutenant in Council, the Premier and his Cabinet colleagues and there... it would have, in addition to the report of the committee, would've been supplemented... or augmented by research that was done by a group of people - some of them lawyers in the Department of Justice, which would've involved an across-Canada survey and... in addition to an international survey - typically would involve the Commonwealth and not so much the United States, but sometimes the United States. And out of that research and analysis, there would've been a further analysis of the recommendations that came out of the committee, and this would've been distilled and into the Cabinet Paper that went forward to Cabinet for discussion. When the Cabinet Paper goes up for discussion, it is first vetted by two committees - the Social Policy Committee, which is a committee of ministers and officials which reviews the Act for its effect, and then the Economic Policy Committee, which would review the economic implications of the legislation and its implementation. And if, after economic review, there were Treasury Board implications, Treasury Board would have a crack at the document in vetting the costs associated with that implementation. Out of that review of the Cabinet Paper, those two committee reviews, there would then be a sense... a document would be prepared, providing a sense of the impact on government and its... and government's current readiness or not for such legislation and then of that entire package of information then, through a regional Cabinet Paper and the committees' report, would go to Cabinet then for consideration. As a result of that process, an Order in Council would be prepared, and that Order in Council would provide drafting instructions to legislative council's office, and legislative council then would prepare a draft act based upon the directions provided in the Order in Council.
It's a pretty extensive process.

4.2.2 Concerns Identified During the Formation of ATIPP

The participants were asked if any concerns were raised regarding patient care or health research during the formation of ATIPP. All agreed that questions were raised surrounding both patient care and health research. One participant voiced concerns about ATIPP and patient care, and described how the previous privacy legislation had worked well in certain cases for health research.

Participant: We were concerned that we couldn't share information within the health circles; and, you know, if you refer a patient to a specialist, for example, well, we were concerned that ATIPP would prevent us from being able to do that, because... you know, because of the commercialization of it - that that was again considered to be very confidential. You had to get a patient's consent and all kinds of matters that would create such barriers that access to care would be compromised; but, you know, different interpretations on that have suggested that that can be the relaxed.

Participant: It did, but, again, researchers - again, another component of that - and we were reasonably happy the way our legislation was worded with respect to MCP. You could, you know, use that as a template.

In addition, there were comments about how government knew it was a sensitive issue due to previous experiences.

Participant: Yes... there would be a great deal of sensitivity to the issue of health research - one of them - because government has been down this road before with the Advanced Health Care Directive Legislation, which had a significant impact on the research community. Any legislation which involves sort of privacy of information and consents, you know, government has a... government would have familiarity with that side, and we would've consulted with the Department of Health.

Another mentioned that presentations had been made to MUN after the fact but that there were provisions in the current privacy legislation for research which brought about some discussion.

Participant: I know after the fact, you know, we did some presentations to MUN and let them know about this legislation and the fact that it was going to be proclaimed, and there was some concern and some questions about research, for sure. Now the Act does

contain the ability for someone to actually... you know, to conduct research. There are a couple of provisions there under the privacy provisions, which allow for disclosure of personal information for research purposes.

One participant stated that it was always known that health care was a different entity.

Participant: There was always an acknowledgement that personal health information was a separate... and that that was something would be addressed separately apart... outside of ATIPP. I think in the review committee consultations, they had representations - but I know it was not within our mandate to deal with separate legislation for personal health care. You know, our mandate at that time was, basically, related to the Terms of Reference of the Freedom of Information Review Committee.

One important consideration was if and how stakeholder groups to be affected by ATIPP were consulted or involved in its creation. All participants recalled that open forums were held all across the province and that stakeholder groups were approached, generating talk of separate legislation dealing specifically with personal health information.

Participant: There was a public consultation process, which was given high visibility and was widely open and they encouraged... the stakeholders and interest groups and what have you were invited to participate and present on the issue, and which then led to a report which was submitted to government, which in turn was the basis of moving forward with the legislation at that time.
I know in terms of the public hearings and the consultations around access to information that led up to the drafting of legislation, that was a particular issue in the public domain at that time. There were some recommendations made by some parties - that fact: there needs to be separate legislation for personal health information, and whether or not... I can't speak whether the government of the day recognized that principle.

In addition, one participant said that that was already decided during the ATIPP process.

Participant: Well, we would've been... we would have... there was a separate Health Information Act piece. That piece is exempted out of the initial legislation. We will have separate legislation dealing with the health information piece here in Newfoundland, and that was the strategy that was decided upon during the ATIPP process.

One individual suggested that it is a normal procedure to automatically consult stakeholder groups before considering any legislation which impacts health care workers.

Participant: Yes... any legislation that impacts any health care worker... before any legislation is done, automatically there's consultation with external groups. Now you may not always agree with their feedback, but you'll at least consult with them, and so you want... you know, I mean, you don't want to be blindsided with something that you're not aware of because you didn't talk to people. So that's a normal process we go through.

4.3 Information and Resources Used for Issues Regarding Privacy, Protection of Personal Information, and ATIPP

One aim of this study is to offer some insight into what information governmental decision-makers are given and use about privacy and confidentiality surrounding the protection of personal information, personal health information, and privacy legislation (ATIPP).

4.3.1 Protection of Personal Information and Personal Health Information

Regarding the protection of personal information and health information, almost all participants responded that they receive a great deal of their information from internal documents, senior officials, cabinet reports etc.

Participant: Well, most of my information I'm getting is largely through briefings by senior officials here in the department, who in turn would either be doing the... you know, reading the reports involved in any of the federal/provincial committees or the interdepartmental committees in government. Anything else that I've come across has been in the form of either internal documentation reports, cabinet papers, as well as some of the federal/provincial reports.

Additionally, many are given advice on these issues from their legal department. They also examine government publications from other jurisdictions, and many engage in inter-department consultations across Canada. Others stated that they keep themselves up-to-date through continuing legal education, by following of recent court case

decision's which may have implications for them and by working with the Newfoundland and Labrador Centre for Health Information (NLCHI). All agreed that there was a tremendous amount of resources available on these topics.

Participant: Committees, seminars, articles. We have continuing legal education programs that deal with some aspects of health information. We do... of course, there is a... there is a... this is a developing area of health law.
Law reports, textbooks - you know, public education committees, public legal education committees - various sources.
So we in government receive this information from many, many sources; and, of course, in the Department of Justice, we receive circulars from all the major law firms, which have their own research groups.

Participant: We also monitor web stuff. I monitor periodically what's happening in access, as well as privacy, in terms of web for the departments of health, as well as judgments that are made through the courts - McKinley, as an example, which is a legal web service, as well as through the various information and privacy legislation across the country. And we link with Justice, and they keep us abreast about their connections in terms of access and privacy. I correspond verbally and otherwise with the Centre for Health Information and their privacy shops. So there are all kinds of things that's important for this particular area. You know, it's sort of a never-ending process you develop in terms of access and privacy.

One participant, however, stated that from an information technology perspective, government departments always seemed to be on different pages.

Participant: It was a provincial system, so it was supporting six organizations, which were largely in the same ballpark but not on the same, identical page all the time.
It was challenging, but it would be good in the sense that you would have to try to sort of identify that least common denominator or the greatest common denominator is probably the better way to put it, and make sure that, you know, the application will meet everybody's needs.

4.3.2 Information Accessed During Creation of ATIPP

During the creation of ATIPP, participants said that there was a review of similar legislation from across Canada and other areas of the world, in order to define best practices in this area and to find where legislation stands on key points. They agreed that this was a common approach to issues of this nature.

Participant: Well, our information on ATIPP would've come from the review of similar legislation from across the country and around the world. So there are now any number of texts that deal with access to information issues.

Participant: Most often with the federal government and the territories, we will have numerous discussions around future policy directions. Usually, we will commission work that provinces... all jurisdictions will share. There will be an attempt to define best practices, to find where the literature is and where the law is on these key points, and this crosses all of that. There is a framework in... a federal/provincial framework in place around personal health information, one which we have - at the department level for sure - have adopted because we've been participants in its drafting. And that would be a common approach to issues of this nature.

Some participants felt that they were given more information than they could handle, and that this was a sign of it being a thorough process.

Participant: In my capacity now, I was given a whole realm of stuff. I was given, you know, the federal legislation and given all the feedback from other jurisdictions. You know, the draft... the draft of eventual legislation - the whole thing - more than I had time to read, to be quite frank.
So it's pretty thoroughly worked on.

4.3.3 Information Accessed Since Inception of ATIPP

Since ATIPP has been in force, participants felt that ATIPP coordinators have played a large role in collecting relevant information and informing departments. One participant was pleased that privacy considerations are now being built into governmental projects from the beginning.

Participant: The department has an ATIPP coordinator who would... you know, held information sessions and because, you know, I was on the IT side of things, there was a little bit more follow-up with us because we had, I guess, help... help the department be prepared to respond. So I got information that way. I guess it's become more and more a norm that privacy considerations being built into projects.

Also, the legal divisions collaborate with other provinces and jurisdictions to discuss privacy issues and share information.

Participant: In my working with ATIPP, there is a vast amount of information out there in terms of both privacy and access. All other jurisdictions in Canada have access and privacy statutes and, you know, from a legal perspective, there's a big body of jurisprudence and maybe out of information and privacy commissioners' offices. There's, you know... , it's amazing how much... how much information is out there and, as well, you know, once again, you actually have colleagues in other jurisdictions which you actually go ahead... and you can actually, you know, have a little working group and chat with those people as well.

4.4 Privacy Legislation Issues in Newfoundland and Labrador

During the interviews there was much discussion about why Newfoundland and Labrador was the only province that did not have legislation in force to protect the privacy of personal information in the public sector.

4.4.1 Newfoundland and Labrador and Privacy Legislation

Several themes emerged including that it was not considered a priority by the government of the day and also that Newfoundland and Labrador was a more trusting culture than other provinces.

Participant: Mainly because it wasn't viewed as a significant public issue in the broadest... in a broader sense - or in the broader community, probably better stated.

Participant: Not the issue of the day, many more issues to deal with, small jurisdiction, not the same sense of problems that would occur in larger jurisdictions - any number of those kinds of reasons.

Participant: I suppose it's being a more trusting lot here than other places. You know, we tend to sue less. We tend to help our neighbour more.

As well, participants stated that Newfoundland and Labrador lacked the resources to undertake this task for a number of reasons, one of which involved the Federal government pushing ahead with PIPEDA and expecting provinces to follow suit. At the time, Newfoundland and Labrador was in disagreement with the Federal Government over resources which never materialized to effect these changes.

Participant: We're here in this information age when information is being created faster than we can keep up with it; and in Newfoundland, I think, especially, where there are less resources to go around, it takes longer to implement change and to start making the organizational shifts that you have to make to accommodate this information, and it's just moving faster and faster and faster all the time.

Participant: The federal government then, being driven basically by the European Union and commitments that had been made to the European Union, to move forward with PIPEDA, there was a serious constitutional debate between the provinces and the federal government as who had authority to legislate in this area. The matter was referred to the Uniform Law Conference of Canada. The Uniform Law Conference of Canada prepared draft legislation for implementation by the various provinces around this issue, and the federal government sort of pushed its way ahead and enacted PIPEDA, notwithstanding the constitutional issue because information within the province is within the legislative purview under the Constitution Act - 1867 - of the province and not the federal government. PIPEDA legislated in... or purported to legislate in this area as well and our fight, basically, with the federal government was around resources and money. You guys are going to do it; now you pay to put in place an adequate regime. The federal government never came to the table with the money to put in place adequate resources necessary to legislate in this area.

Participants also mentioned that although Newfoundland and Labrador still does not have such legislation enacted it would be incorrect to characterize them as the only or last province without such a statute, and that this province was at one point a leader in this field of legislation; despite the fact that they did fall behind, other provinces were still not that far ahead.

Participant: I think it's incorrect to characterize the province as the only province in Canada not to have... or the only province in Canada that... not to be sort of labouring in this field, as it were. We were the first province in Canada to have freedom of information legislation at all. We were, in the 1980's, leaders in the field. Admittedly, as time went by, we fell behind.

Participant: Well, we still don't.
Privacy, in terms of legislative initiative across the country, was moving very fast and, while Newfoundland might have... technically have been the last to put some on their books, I'm... you know, some of the other provinces were not that much probably ahead. New Brunswick had just brought in... just brought in privacy legislation. Prince Edward Island had brought it in but it had not been proclaimed. We might technically have been

the last, but this was an issue that was being addressed by a lot of the smaller provinces. I don't think we were particularly behind at that time.

4.4.2 Reasons Why Privacy Provisions Have Not Been Enacted

Another important topic described in great detail involved why the privacy provisions of ATIPP had yet to come into force and whether the participants were confident that these provisions would eventually be put into place. A major theme which all respondents stated was that bureaucratic and operational readiness was a significant factor. Because this enormous process would affect so many municipalities that used various methods for maintaining privacy and confidentiality, government wanted all stakeholders to be ready for implementation.

Participant: It's all question of readiness and preparation. So it's... you know, there are issues around ensuring that all the stakeholders in the process are ready for implementation. Remember, our ATIPP legislation applies to almost 500 municipalities in the province. So you have town councils with one and half clerks and a part time clerk or... with filing systems sophisticated as a shoe box with notes in it to... up to a very sophisticated electronic records in a big city like St. John's. So our concern was to make sure that there was stakeholder readiness for implementation of the Act.

Participant: Readiness of the bureaucracy to respond and that has taken some time and it's still ongoing, as I understand it, which obviously has caused this to be delayed longer than, I guess, was intended; but I know the Department of Justice is dealing with that as we speak, and we... you know, it's caused some delay in us moving forward on some of our... our objectives around personal health information.

Participant: Operational readiness. It's the implications of it all; and there again, you know, it speaks to the whole resource issue, you know. This is not a rich, rich province; and with what little there have... there are, you're in constant competition for the little resources there are, and the resources don't seem to grow. And so if you want... you know, in this office, yes, we push because we want Part IV to be proclaimed and so on and so forth; but in the meantime, we can't do that without certain resources, and we don't want to just proclaim and have institutions and public bodies unable to respond. And when we talk about responding, we talk about having people in place who can handle the volume of requests. We're talking about training for those people. We're talking about ongoing training. We're talking about training materials. We're talking about production of a manual. We're talking about all the pieces that come into play around privacy too, and we mentioned privacy impact assessments but, I mean, there are

a number of ways in which we collect private information in government, and it's not even clear to the people we're collecting it from what we're doing with that information.

A lack of training and resources was mentioned, in that government could not just simply enact a piece of legislation without having everyone ready for it. As well, one participant explained that even though ATIPP was a high priority piece of legislation, it still had to compete with other priority legislation.

Participant: Resources are always an issue. What else - training. Once again, this will be new to the Government of Newfoundland and Labrador. Before you actually proclaim any piece of legislation such as this, which actually... it's quite... it's an excellent piece of legislation, but it's also... you know, will change the... well, can't say change the rules, but will actually set the rules on how you collect, use and disclose personal information. You need to make sure that everyone is, you know, up to speed, I guess, with respect to this so that, you know, you can't just can't proclaim and people not be ready for it.

Etienne: So you talked about operational readiness, little resources - so you're saying then ATIPP is not... is it not considered a high priority by government.

Participant: Yes, it is.
Etienne: Okay.

Participant: But so is other legislation.
Etienne: Sure.

Participant: So even when you have priority, you're still competing with other things that are high priority, right?

Another participant stated that government wanted to make sure that the system was responsive to ATIPP before bringing in the privacy provisions.

Participant: The major thrust, I should say, not more important of ATIPPA, ... making sure that the system is responsive to ATIPPA before you bring the much more complicated aspects of privacy because access is... you know, when you've done it for awhile and you've seen it and you've developed philosophy and a culture about this transparency, access is not technically complicated.

There was also talk of a lack of planning by the government in certain areas.

Participant: So, for example, the ATIPP coordinator position in the Department of Justice - it was un-staffed for one year. Brand new piece of legislation, okay - nobody in that position coordinating or doing anything for one year. Void. Meanwhile, the Office of the Information and Privacy Commissioner is fully staffed. So you have somebody doing all these reviews, but nobody to coordinate the work for the coordinators; and we (government) don't want to be in that position again where we're proclaiming legislation and then somehow there's this void in terms of the operational readiness. We don't want to do that. So it's holding things up because we're insisting, no, we have to do step one, step two, step three, step four because when we deliver the service we want to deliver it well.

4.4.3 Proclamation of Privacy Provisions

As talk moved toward how confident the participants were of these privacy provisions being enacted, all strongly believed that this would happen. The consensus was that there is a desire on the part of both government and the public to see this part of the legislation proclaimed; the government was even on record for these provisions to come into force by 2007.

Participant: It's the building sort of the bureaucracy in getting the bureaucracy - in terms of government - to engulf, as it were, to deal with these provisions, and that's taken the... it's delayed this. I don't think it's anything more than that. It's not a matter of principle or different policy directions.

Participant: Oh yes, very much so. There's a real... it's not even the political will that I'm talking about. There's a real desire on the part of government and on the part of the public to see this legislation proclaimed, and the questions are constant: When is it going to happen and how. And so since I've been in the position, we've been moving... I mean, that has been the big thrust of what we've been doing here is moving this massive machinery; and it's massive in Newfoundland and Labrador because we're talking about over 460 public bodies that all need to be, you know, trained and ready.

Participant: Absolutely. And they're... they are... the premier is on record as indicating that the privacy provisions will come into force 2007. That's government's current plan. That's not a secret. Government is making efforts to move towards that date.

One respondent said that the 'system' had committed to it and that there was a precedent in the province for legislation to be proclaimed this way. The participant admitted, however, that the process was not ideal.

Participant: Oh yeah, absolutely.
Well, I'm confident it'll come into play because government has committed to it, and the system is committed to it. I'm also confident because this is not unusual. The Child Youth Family Services Act was proclaimed about two years before Part VIII of the management of records was proclaimed. So, I mean, it's not an ideal process. So there's a precedent in the past that shows this kind of staging and implementation.

4.4.4 Amendments for ATIPP

When asked whether ATIPP needed any amendments, all acknowledged that legislation should constantly be reviewed and updated as it is an ever-changing environment. Government should go ahead and apply it first, see how it works, and then make changes later if necessary. One participant stated that ATIPP contained a provision for review five years after proclamation.

Participant: I think all legislative policy should... you know, needs to be reviewed and updated all the time. This is a moving area. Every time another jurisdiction has a court interpretation or has privacy commissioners work on areas, it's always moving. I think the most important thing is to get legislation in place - see how it works, apply it - and then if it needs amendment, then that's just an evolving legislative process. I mean, if you do a piece of legislation and you look at it three years later... in three years, you know, the ground can shift beneath your feet.

Participant: So the thing about it is, you know, probably, you know, a more pragmatic approach is to actually go ahead and start working with it; and then if you find that there are glitches or there are things which were, you know... which just aren't working, then at that point in time, you know, contemplate changes, because actually this Act actually has provisions in it for review five years... five years after proclamation to have a review done then. So I think that would be a good opportunity to do some... do some housekeeping type of work, I guess - look at provisions that are working; look at ones which are not - both for access and privacy.

Another believed that the legislation was properly designed for its intended purpose and on par in relation to legislation in other provinces and jurisdictions. There

could, however, be more work done regarding sector-specific personal health information.

Participant: I mean, I think what it was designed for and what it's intended to do in terms of personal information, I think it's appropriate. I think it comparable, reflective, relates very well to other jurisdictions and legislations mantra. So, to that extent, no. Do I think there are other things that we could do in the statutory, legal or policy framework regarding sector specific personal health information - absolutely. So those are two very different questions.

4.4.5 ATIPP and Personal Health Information

A subject that yielded a great deal of rich information involved why personal health information was not specifically addressed in ATIPP. Participants were also asked if they thought that Newfoundland and Labrador needed a statute that explicitly dealt with personal health information, as is the case in Alberta, Saskatchewan, Manitoba, Ontario and others. Responses were varied. Some said that it was recognized by committees from the beginning (Striking the Balance in 2001) that personal health information was different and should be handled separately and that a separate personal health information act was on its way.

Participant: It's reflective of our committee. What they said - this is the direct quote from this document: "The issues surrounding personal health information are often unique and may give rise to conflicting perspectives." And their recommendation in their report is that "government enact separate health information legislation to apply all health organizations."

Participant: I think it was because it was recognized that - number one, personal health information is slightly different and it's different to manage. It's held only in certain places. Only certain people who get access to it. It's not the same as, you know, an employee record, which tends to be the same everywhere, right, and which you find in most public bodies. Health information has certain kinds of people and collects certain kinds of information, and it's also subject to a different kind of interpretation. So there needs to be a separate piece of legislation to capture the particularities of all that, and to ensure that when people are looking at this information that they're a) able to access it; b) they're able to understand it; and c) that they're able to... you know, that there's that intervention piece to provide them with what they need to understand it.

Participant: Right, because personal health information is covered by the Health Information Act. You should know there is a Health Information Act which is on its way to... making its way to the Cabinet system, and the irony is that we have a Health Information Centre, which we (laughs) pre-suppose is a Health Information Act, and so, you know, the... I think that, you know, in the next year or so we'll see this in place.

Others stated that ATIPP, being more general in nature, did not attempt to specifically address personal health information. As well, a health information act would be better suited since there is a difference in application to public and private bodies.

Participant: This didn't attempt... this Bill did not attempt to deal specifically with personal health information of the nature that you're talking about that... of legislation that exists in other provinces. This... that wasn't the objective with this legislation. This is not a personal health act - that wasn't the focus. It was much more general in nature and was just... it was designed to, basically, update the Freedom of Information Act, as it existed, and to introduce protection of privacy.

Participant: It would be to allow for personal health information legislation, which would actually deal specifically with personal health information... you know, there is unique... there is a lot of unique factors, I guess, that you're having to deal with from a health information perspective in terms of research, allowing custodians to share information with one another, and it would probably be best suited to that piece of legislation as opposed to Access to Information, which is a more general piece of legislation which deals with personal information in general; and, as well if you're doing the research - the Access to Information Act only applies to public bodies. It doesn't actually apply to private entities. So there's a little bit of a gap there as well. So in terms of like pharmacies, you know, private individuals... so, you know, won't be... it would be difficult to have a whole bunch of different rules going on.

It was also mentioned that there was a lack of readiness and that the government wanted to give people more time to get comfortable with the existing legislation before putting something more into place.

Participant: I think it was a readiness or a lack of readiness to deal with it, which is a very substantial part and a very sensitive part; and from that perspective, it is a sort of a new approach by departments, by agencies that would be covered by the legislation. So it's just taking more time for people to get comfortable with the intent and then with the mechanics of allowing the legislation to be fully enacted; and until there's... that comfort is there and the resources are in place to let... you know, that provision will not be ready to be enacted.

The point was made that if health care workers strictly abided by ATIPP, they would not be able to properly deliver services.

Participant: I think in terms of health care, if you were to abide by the restrictions of ATIPP you could not manage. You could not deliver services. You would deny access - timely access; and in health care, you have to have a certain amount of to and fro and sharing of information. Can you imagine, for example, that you got an x-ray done but you can't release it to your family doctor until you come in and sign a release form? That doesn't even make sense most of the time.

4.4.6 Personal Health Legislation for Newfoundland and Labrador

When asked whether Newfoundland and Labrador needed legislation dealing specifically with personal health information, all participants agreed that it did. Most said that it was due, others that it was on its way, and moreover some said that there had already been some initial drafting at the departmental level.

Participant: We are planning for such an Act. We need separate legislation. That's why we're planning for such an Act. This information is so significant, so important that it needs separate protection - separate clear protection - absolutely.

Participant: We feel here at the department that the case has been made for that and we've consulted internally and within government and, I think, have general agreement that we should do that. We have had some consultations with the health care provider service delivery network in the province, who would certainly suggest that; and in light of the federal legislation and our... and some of the deficiencies there for us, as well as ATIPP, we feel that this would be appropriate. So, in fact, we have drafted... we have preliminary drafting done to go... to move in that direction - certainly, at the department level. The question is for us now - will the provincial cabinet also accept that premise - and that's something we'll know in the... hopefully, in the near future.

On another note, a participant stated that this legislation would help establish borders and give transparency to what government does with this very sensitive personal information.

Participant: I would be positively supportive of it. I think it would establish... the reasons I think it would be needed probably are different than what everyone would expect. Legislation is about standing... is about establishing borders. It's also about communicating those borders to the people who represent the public. It's also about... and in terms of legislation like ATIPPA, that... it's imposing requirements on ourselves as

a bureaucracy or in the government - respectful of the rights of the citizens to... in this case, there is individual privacy and the way those rights are abrogated. Is it a good sentinel - and I put to you in sort of question format - that government is doing the right thing. I think personal health information legislation, where it's been brought into place, is a good sentinel for that. You know, it shows in a clear way what government is doing with very sensitive information and for what purposes and context, and what things can happen.

Some participants went further to explain what they thought the objective of this personal health information legislation should be, and many different ideas and recommendations emerged. Several spoke of protecting the integrity of individuals' personal health information, and the importance of striking a balance between respecting individuals' privacy and the public good.

Participant: To protect the integrity of personal health information and to allow for its sharing in proper circumstances with the informed consent of the providers of the information - the person to whom the information belongs - mainly, the patient or the research subject, or whatever.

Participant: It's making sure that we respect... we strike that balance between respecting the individual's privacy, but making sure that there are mechanisms to share that information when it must be shared and sometimes, you know, in the health world, I think that's going to mean that a certain piece of information may have to be shared despite what someone wants. You know, we have communicable disease legislation which... you know, certain diseases - you know, the fact that you have them that must be shared with certain authorities - period.

An added point here was that any new legislation should be flexible enough so it does not adversely affect patient care and that privacy should not be used as an excuse not to deliver good care. Also, the proposed act should be able to address health research as well.

Particpant: You have the... there's not a whole lot covering personal health information under the regional boards, for example, and yet they're going to be largely responsible for handling a lot of the information to their Meditech systems and so on. Then there's the research component. Then there's also the stats component like NLCHI, so they got... you got many tiers in the game; and in addition to making sure that you have privacy and confidentiality protected, legislation should also be flexible enough to ensure that you don't use that to create bottlenecks where you can't deliver care. You've got to be able to

find that balanced approach to it. I mean, otherwise, privacy controls everything and people's health care denied. So that's... and my concern is that if you don't have a good legislation in place, then you will get people who are so zealous or so ambitious in the protection of their own work... and if they're looking at privacy, they're going to deny access to useful information to do things, and I've see that already.
So you need a good legislation to find that balance - the balance between providing reasonable... reasonable privacy, confidentiality, but yet the ability to not impinge upon good service delivery. One shouldn't... you know, it... privacy should not be used as an excuse not to deliver good care.

Participant: I guess, there'll be a dual-pronged approach there. First of all, you want to protect people's health information from being, you know, accessed from someone who shouldn't be accessing it. You want the privacy interests of the individual, but you also want to be cognizant that there are certain people who need to see health information. They need to actually get information; and also, your... just your health researchers need to get information as well, you know, in terms of doing health research, you know - for instance, diseases in a specific area or whatever.

One participant said that the legislation should focus very specifically on personal health information, including having patients know exactly what information is being collected and how and by whom it can be accessed. As a result, health care providers would clearly understand the basis on which they should be collecting this information; this will provide both confidence and protection to all parties.

Participant: I think in terms of what it should be is that it is focused on personal health information, so it's very specific to the subject matter; that the... that both the, (chuckles) shall we say, the individual/patient clearly knows and understands what information is being collected - and, basically, which is being collected and stored and accessed; and those who need or want or request access - they know the basis in which it can and cannot be used and... or accessed. So it's very specific. I think it will lend a greater comfort and confidence in the health care delivery system if those people who are using and benefiting from the system clearly understand why and on what basis their personal health information is being collected and stored and used and the limitations that should be put on that, and that's certainly true for the health care provider as well, so he or she clearly understands the basis on which they should be collecting information, the basis on which they can and cannot use it and that would lend greater certainty and protection for all parties.

Another participant built on this point by saying that this legislation should have two objectives. One would be to give people access and rights to their health information

in a way that they can understand, thus helping to empower the individual, and the second objective is that the institutions holding this information should be accountable and transparent.

Participant: I think there's two objectives. I think 1) it should be to promote people getting access to their own health information - that they're informed consumers of the health care system. Oftentimes, people have this experience of coming away from the health care system, knowing something is wrong, not fully understanding the implications of it and feeling disempowered in their own lives and in their own personal processes, and that then impacts on how they're able to deal with the health care system in the future and deal with their own healing and processes, and that should... you know, the well-being of the individual should always come first. And secondly, and I would say almost equally importantly, 2) is the accountability of the institutions that are providing health care and the people who... sometimes it's institutions, sometimes it's people - if you talk about a physician in private practice or, you know, a midwife or a pharmacist or whatever, there needs to be an accountability and transparency piece there too because the kinds of information they're providing, as I said earlier, oftentimes it's in code and doesn't make sense to people, and so they can't be informed consumers about their own bodies and their own health; and if you can't even feel like you have control over your own body and your own health because you can't get the information, how are you supposed to cope? We have caregivers who are trying to understand, extended families and so on and so forth, who are trying to care for somebody; and if they can't understand the implications of what's happening in this person's life, how can they possibly provide care, which then puts a larger burden on the health care system.
Let's give them the information, let's give it to them in a clear fashion and let's tell them they have rights to have that information.

4.5 Newfoundland and Labrador Government Practices Regarding Exchange of Information with Relevant Stakeholder Groups on Privacy and Personal Health Information Legislation Issues

When making legislation, the exchange of information between government and stakeholder groups is very important as it could have a significant impact on how people or organizations conduct their daily work. Many aspects of this topic were discussed with the participants and several themes emerged.

4.5.1 Working Relationships Between Stakeholder Groups and Government

All participants stated that government does indeed consult and work with stakeholder groups on issues associated with privacy legislation and legislation governing personal health information. Additionally, all agreed that there was a very strong working partnership with NLCHI in place and that even though groups may not feel that they have a direct line to government, their concerns are taken into account.

Participant: All the time. The... you know, I know that stakeholders probably feel they don't have a direct line to government for... on the Health Information Act. But we consult with Health Information... the Centre for Health Information, and they've actually been here in the Department of Justice and done any number of presentations, and Lucy McDonald has been over on a number of occasions with presentations so... and I'm sure on many more occasions, been to the Department of Health.

One said that consulting with stakeholders usually works very well; stakeholder groups are treated as partners and hopefully, health regions and boards recognized this.

Participant: We've always worked with other information groups, I think, you know, fairly well. You know, the limitation that we've all had in the relationship is our time and the resources and so on but, you know, the... I suppose, always the best of intentions. I think we've done fairly well. I think, to a large extent... and, you know, with the health boards and health system, and I hope that they would at least recognize our efforts in this regard. I mean, we... we've... I've always looked to them as our clients and partners on all issues, you know, including privacy and so on and it hasn't been so much, well, that's their issue kind of thing. It's all our issue.

Others were expecting a larger relationship in the future but, although government always talks with groups that may be impacted by legislation (health professional associations etc.), there were limits to this in the area of resources.

Participant: We're anticipating a much larger partnership. Now, having said that, there will be certain limits placed on that by virtue of the fact that we will only have so many resources in the office, and so certain pieces will be assigned to certain people and so on. However, when we talk about implementing Privacy Provisions or implementing the Health Information Act, what we're talking about is going to those organizations that are impacted, okay, and the personal information coordinator probably, or another resource,

to be that agent of change within the organization and to do the assessments that need to be done.
Well, we talk about the management - the Health Information Act. You're talking about all the professional associations because you'd have to work with them. There's no way that this office could contact every single physician in the land. You know, so you're talking about physicians associations, pharmacists associations, nurses associations - all of those groups - and then you're talking about the actual public bodies who are on the ground, right? So then you have your hospitals; you have your clinics - you have all of that.

Others maintain that this consultation is simply a part of the way they do business.

Participant: The answer is yes we have, yes we do and yes we will; and so that's a mainstay of how we do business here at the department on all key public policy initiatives.

One individual mentioned that government decides on a case-by-case basis as to which groups are consulted and the level of consultation they want.

Participant: The government decides on a piece by... on legislation, you know, piece-by-piece, case-by-case basis, as to the level of consultation that it wants to conduct and then when those decisions are made, that consultation is done.

Participants were asked if they were encouraged to work with stakeholder groups on legislation, and, once again, everyone agreed that this was the case. One individual said that occasionally they would share their information directly with the group that the legislation would influence. Another participant stated that they always work this way and that it is a natural aspect of their work.

Participant: Absolutely, and we often share, depending on the stakeholder group that the information... that the legislation influences. We... you know, we don't have a problem with that.

Participant: As I said, we adopt that as a manner of practice, as a manner of doing business so.

Yet another said that is how government creates and manages policy, which has to work for all involved; otherwise, no one will abide by it. It was also mentioned that a

goal of government was to build trust between groups. This was followed by a detailed explanation of the type of positive relationships government wants to build with stakeholder groups.

Participant: Oh yeah, all the time. I mean, the very nature of what we do, we have to work with stakeholders. I mean, we're... we create and manage policy, but policy has got to work for all players; and if you create policy that no one is going to abide by, then you're wasting your time. So you got to get people to buy into what you're doing.

Participant: Absolutely. And it all revolves around the question of information and how you make decisions. The goal is... in government, the goal is always to get the best information possible to back up your decision-making; and the only way you get that information is by going out to the stakeholders and asking, and building a relationship of trust so that people are comfortable speaking and feel that their comments will make a difference, will be taken into account. It's one thing to say, well, we'll consult but it's very easy to then turn around and do whatever you want to do after that, right? The goal in government is always to conduct - how can I say it - the highest quality consultations so that not only are you gleaning the best information possible, but you're fostering a relationship with stakeholders so that the next time you go to consultation people feel it's worth participating and giving the info, but that you also encourage the relationship of continuous feedback so that you don't have to wait until consultation time, that you can go back to people where feedback is coming in.

One participant firmly stated that there would never be a legislative policy done without consultation.

Participant: Absolutely. I mean, it depends on... very much on... I mean, some legislation has just a public nature about it. It affects everybody! So, in that regard, consultations would be directed by executive as to who... who they would want to consult. On more specific legislation, if it's a piece of legislation that deals with a governing body or a particular group, obviously, those stakeholders are extremely involved because they have a very special, particular interest in the legislation;
I would... you know, if I'm doing legislation that deals with Memorial or that deals with a group, I mean, there would never...there would never be a legislative policy developed without consultation.

4.5.2 Benefits of Consulting with Stakeholders

The benefits and difficulties of consulting with stakeholders were also discussed in-depth. One recurrent theme was that consultation helped bring ideas and

considerations to the forefront before and during the implementation stage of legislation. As well, frontline workers would be able to provide very important insight into the realities of health care. The point was raised that information garnered in this way would be more accurate, up-to-date, and comprehensive.

Participant: If you consult with these folks, you can get little gotchya's and other considerations and wrinkles at the... implementation phase. You just... I mean, at the end of the day legislation has to be... and the whole regime has to be a living and breathing thing, and all these people are parts of bringing it to life.

Participant: Ensuring that your information... that your information base is accurate enough to date. It is important to... make sure that stakeholder groups are given an opportunity to bring their concerns to decision-makers and... so that decision-makers can... can prepare a legislative regime that reflects provincial realities and best information that's available on these issues.

Also, by tapping into the knowledge of diverse groups, it will help shape policy that will serve not only the government but also the public. It was felt that if there is strong endorsement from stakeholder groups, the legislation will be more legitimate and widely accepted.

Participant: One is... we would be tapping into the knowledge of diverse stakeholders in terms of their perspective. So if we're dealing with the... a research community, we can get their perspective; if we're dealing with the academic teaching world, we can get... we can get their insights; if we're dealing with the service provider, we can get their perspectives - all to inform and help shape public policy that serves not only the government of the day but the society as a whole, and that's generally been our approach: getting as many diverse views, achieving consensus - but not always consensus but trying, certainly, to achieve consensus on the main features of any piece of legislation;
And once we go to implement, if there is a strong endorsement through a consultation process of the principles and the provisions of a piece of legislation such as personal health information or access to information, then the legitimacy of the legislation will be endorsed or widely accepted by the population and the users of it and so, to me, it's a basic premise of policy and legislative-making that we should encourage.

Conversely, an insular approach without consultation will result in non-compliance.

Participant: The benefits is entirely opposite of the risk of not doing so. If you don't consult with them, you usually take an insular approach of things, and no person is so wise and knowledgeable that they have the answers to all the questions. In addition, quite often, the people who are impacted are the people who are out on the ground doing the work; and if you don't take into consideration their issues, you know, then you... that isolation will create problems with them and they will not be able to do their work. So it only makes sense that we have to consult with the people. We do it all the time. We do it with all our policies.
I've spent half my time going around the province meeting with groups talking... we're doing it right now. I just came back last week and we were... we're looking at a policy around a certain issue, and we bring all that back and we learn from that and we adjust our direction based upon that feedback. It's a... it's a people's issue for the province, and we got to get it right.

One individual summed it up by saying that consultation results in a better product, one that is workable and respectful of the values of all concerned. With consensus there is greater buy-in to the legislation or policy.

Participant: You get a better product. I mean, you end up with, materialistically, something that's workable, that respects the values... and that of all persons. You reach a consensus. You have buy-in. You have... you know, you avoid hurdles and pitfalls and barriers and so on.

4.5.3 Difficulties of Consulting with Stakeholders

The difficulties of consulting with stakeholders also brought forth a wealth of responses. One participant stated that there were no difficulties involved since consulting does not necessarily mean implementing what stakeholders say.

Participant: There are no difficulties involved... I mean, the process of engaging with stakeholders in dialogue is always one of give and take, so it's part of the normal process. Remember, consulting with stakeholders doesn't always mean that you do what stakeholders want you to do. In any legislative process, you might have a myriad of different views, and government is charged often with the task of reconciling those different views and moving forward but one hopes that where views are not accepted, they're not accepted on an informed basis, after rational discussion and dialogue and, you know, full review.

Another said that although there was no apparent difficulty, government departments are in charge of their own consultations so they would not be aware of problems that other departments have or have had with consultation.

Participant: I don't know that there's any difficulty in consulting. I mean, you're just... you're talking about consulting and getting people's views. I mean, there could be difficulties sometimes though individual departments are in charge of their own consultations.

Participants listed several difficulties which might arise: different and possibly conflicting perspectives (i.e. researcher vs. frontline worker), lack of time and resources, and the necessity of making sure the right people with knowledge and experience in the field are involved in the consultations because without this they may not be able to solve the issue that they had originally set out to.

Participant: Well, you've got different perspectives. You know, the researcher versus the frontline. The care provider has different interests. Folks may not have thought through, you know, what their perspective is.

Participant: One is time - ensuring you get the right people (chuckles) and the right people in the sense that those have the knowledge and experience to bring to the table so you can get access to them, and the other would be, obviously, reaching consensus to allow you to move forth; and managing that process is a very particular skill and, if that's not there you can run into a host of problems, and the one being you don't achieve the goal you set out to do.

Also, groups could have unrealistic expectations although this did not mean that they or the public were not astute; only possibly uniformed.

Participant: One of the difficulties is that the people you're consulting with may not understand the topic well enough, and therefore takes some time just to bring them up to speed. Another difficulty is the time it takes to do it. It's a lot easier to sit down and write a document than it is to draft a template and then do a consultation. It takes time. It takes resources. It takes funding. And there is a risk, of course, that you can raise unnecessary... or unrealistic expectations. People often... they read into something you say a little differently than what you intended.

There are always those with personal interests that may, you know, temper a response, but people are generally astute. You have to give people credit for, you know, being able to think for themselves; and, as one person said to me recently - the public is not stupid. They may be uninformed but they're not stupid. You know, give them a chance and they'll give you good feedback.

One participant took this point further by saying that this could create problems as these groups may not be willing to participate in the future because their ideas or recommendations were not acted on by government despite the fact that the government is trying to do the greatest good for the greatest number of people.

Participant: I could anticipate that... there's always the what I'll call the aftermath pieces where people have come to a consultation and have voiced strong opinions and somehow that opinion did not change the outcome, and there was a hope created that it would, so there's that disappointment and then how do you keep them participating in the process after that. That's a challenge. And the other challenge- I think the biggest challenge is that it does create an expectation and you cannot always meet that expectation because what you're trying to do is make... do the greatest good for the greatest amount of people, hopefully; and that always means that there are people who are not going to be pleased with the outcome.

Another participant felt that consultation involved tremendous challenges in getting people informed and trained, a process involving human resources, finances and technical capacity as well as public awareness.

Participant: Anytime you're bringing in a regime and you're setting up rules... I mean, they're not discretionary. You know, you have to follow the rules of the game. There are certain latitudes built in, but they are rules. So besides the whole notion of getting agreement on what those rules should be, which is the first hurdle for any legislation introduced... you have the hurdle of the capacity to inform and train. After the fact, you have aspects in the system: human resource, financially wise , technical wise. Does it have the capacity to do it? I mean, if your rules of consent require explicit consent in areas where in the past you've only had implied consent, there's a cost to that. Even getting down to the printing of consent forms. So there's a tremendous challenge in terms of looking at the balance of it. There's tremendous challenges... in the beginning you're looking at implementation issues such as training, awareness issues for public awareness.

Discussion

The purpose of this qualitative study was to gain a better understanding of governmental decision-makers' views and concerns regarding privacy and confidentiality issues surrounding personal information, personal health information, and electronic health records. To that end, observations on the governmental decision-makers' comments were made from a researcher's perspective. This study contributes to the literature in that there has not been a similar study done in Newfoundland and Labrador. It provides insights and observations of a group that plays a key role in the development and establishment of privacy legislation and discusses the tensions between privacy and patient care and health research.

Throughout the interviews it was evident that the participants had a great deal of experience with the issues surrounding privacy and confidentiality in the context of personal information, personal health information, and the *Access To Information and Protection of Privacy Act* (ATIPP). They provided many insights and raised numerous points that will be discussed further in this section.

5.1 Definitions of Terms

With respect to their knowledge of the terms involved, all participants demonstrated a very thorough understanding of privacy, confidentiality, and security of personal information. They gave very detailed responses and also brought up different issues surrounding these definitions, thereby confirming their experience and training in these areas. For example, when the issue of safety of personal health information in the form of electronic records was mentioned, all participants did believe that this information was safe. Because the technical environment is continuously changing,

however, they expressed a need to remain constantly vigilant and to use best practices to continue to improve their methods for keeping this information safe. Comparisons were made to the banking sector and how it has long been successful in using electronic records containing sensitive information. It was mentioned that the health care system can learn many lessons in this area from the banking sector. It was also recognized that although electronic records do create opportunities for errors and breaches, according to the participants these were no more frequent than when paper records were kept. These and other responses appear to reflect a wide range understanding of the issues involved with electronic health records and that the participants do appropriately address the benefits and pitfalls.

5.2 Current Legislative and Technical Environment

When asked whether the current legislation and technical environment provided enough protection for personal information associated with electronic health records, governmental decision-makers made some interesting comments. It was stated that the Newfoundland and Labrador government had a good history of protecting personal health information and that changing the medium of storage to an EHR was not an insurmountable step in continuing to protect this information. In addition, it was mentioned that privacy and confidentiality issues in this area were more of a concern for government than for the individual or patient. Though there is a logical link between Newfoundland and Labrador's positive history of protecting personal information and having the same protection with an EHR, the statement regarding privacy and confidentiality issues being of greater concern to government than to citizens or patients may not necessarily be valid. Since there are no studies in Newfoundland and Labrador

to confirm or deny this, the statement should be considered an assumption. Another important concern involved the need for a separate piece of health legislation, since many participants felt that Part IV of ATIPP was not adequate for health information. Others said, however, that many types of legislation that involve some type of information technology will always be playing a game of catch-up with technology itself.

Several participants believed that security and protection of personal health information were not really big issues in Newfoundland and Labrador because of its 'trusting culture'. This statement also seems to be an unproven assumption. Would there be any difference in trust within cultures between residents of provinces with somewhat similar population sizes, such as, for example New Brunswick? Without concrete research evidence this cannot be proven. It seems like this statement could be and possibly is used as an excuse for why things do or do not occur in this area.

5.3 Protection of Personal Health Information and Patient Care

Participants gave their thoughts on what the protection of personal health information would mean for patient care. Some suggested that it would require a higher level of administration, possibly resulting in somewhat less effective patient care However, there has not been indications of this in other provinces that have passed personal health information legislation (Government of Alberta, 2006). Others felt that there would only be minor improvement if any, but that it would provide confidence to the public that their personal health information is being protected. There is much to be said for this statement. As previously mentioned, health care in Canada is treated as a public good. Since government administers this good, it is the duty of government to provide a legislative and regulatory environment to protect personal information, whether

it is used for health care delivery, administration, planning, or research purposes. In addition, government should be transparent in how it will protect this information (by legislative means or otherwise), which in turn would affirm the public's confidence that their personal information is being properly safeguarded.

5.4 Protection of Personal Health Information and Health Research

All participants agreed that the protection of personal health information would have a significant impact on health research. Most believed that it would be a good thing as long as health research was considered from the beginning, but the possibility of having more consent requirements leading to less people willing to participate was mentioned. As well, several spoke about how it would help researchers study specific diseases that occur in Newfoundland and Labrador's population. The participant stated that this would be accomplished by collecting and using information based on current information, which could allow for a more informed and resourced research community that could help to achieve better daily health outcomes in the short and the long term for the people of Newfoundland and Labrador. Furthermore, it would help clarify the researcher's role, which at times can be cloudy. Another participant concluded that it was really about finding the right balance between an individual's privacy and the public good. The comment about clarifying the researcher's role is very important, as this could have a major impact on health research. If the rules and regulations are too stringent in the opinion of health researchers, research in this province could be severely impeded. If they are set appropriately in concert with consultations with relevant parties, then this could actually be very beneficial for researchers. They would not be hampered by uncertainty over access to pertinent information; the boundaries would be known and all

sides could carry on with their work while following the designated best practices, whatever they are identified to be. Again, it is important to note the need for stakeholder consultation in the process of developing specific health information. An example of legislation that hindered research is the Advance Healthcare Directives Act which: (a) was implemented without adequate consultation among the health research community, and (b) it effectively curtailed certain research on vulnerable populations until the legislation was amended.

5.5 Information Used Regarding Privacy and Confidentiality Issues

Another objective of this study was to gain insight to what information governmental decision-makers' are given and use concerning privacy and confidentiality surrounding personal information, personal health information, and privacy legislation (ATIPP). Respondents generally reported that they received almost all their information from internal documents, cabinet reports, and through other senior officials. In addition, they would at times be given legal advice from their respective legal department or the Department of Justice; they would also review government publications from other jurisdictions, and engage in inter-department consultations across Canada. Some participants stated that they attempted to keep up-to-date via continuing legal education, by following relevant court case decisions and through working closely with the Newfoundland and Labrador Centre for Health Information (NLCHI). It appears as though these government officials are doing a thorough job of gathering and seeking out resources for information on these topics. A strong working relationship with NLCHI would be very sensible considering NLCHI works specifically on many of these issues. A possible project for future research would be to interview senior staff at NLCHI to

determine if there is indeed such a strong working relationship between the two. Furthermore, it could be established how much of their shared information those NLCHI employees feel government actually does take into account.

One participant raised a concern with regard to the matter of interdepartmental collaboration in the context of working on legislation. This person's impression is that often the various departments of government appear to be on different pages from one another. Is it a possibility that departments are receiving different information from different sources and that there is little communication between departments? This question was not asked during the interview process utilized in this study; however, upon examination of these research results, it is evident that this information would be helpful to know. One could propose that it would be more efficient and beneficial for the various departments to have individuals in charge of coordinating these tasks and exchanging information. This would reduce the time and resources that different departments spend searching for similar information.

5.6 Information Used During the Creation of ATIPP

In terms of ATIPP development, all participants said that there was an extensive review of similar legislation from other provinces and around the world, and that they were trying both to identify best practices in this area and to determine where legislation stood on key points. Several mentioned that they were actually given more information than they could process. This indicates that governmental decision-makers have completed detailed background work and have followed a logical course for clarifying the important issues in order to prepare legislation that is similar in scope and nature to that of other provinces. The participants stated that before and since ATIPP has been in

force, ATIPP coordinators have played a major role in collecting information and informing their respective departments. From the information gathered in the interviews, it seems like the ATIPP coordinators from other departments do interact and share information and ideas which would be a reasonable approach to maximizing efficiency, and that there is more coordination than in other areas. It is important to note that every department in government does have a Freedom of Information coordinator so that there is knowledge in this area though the same is not true of privacy.

5.7 Privacy Legislation and ATIPP

One study objective was to better understand governmental decision-makers' perceptions of various factors that might influence the development and enactment of certain types of legislation, specifically ATIPP. Another objective was to gain perspective on reasons why Newfoundland and Labrador was one of the last provinces to enact this type of legislation. Many respondents' comments suggested that privacy was apparently not considered a priority by the government of the day. Some participants thought that, once again, Newfoundland and Labrador embodied a more trusting culture than other provinces. This point has come up in several places and as mentioned earlier, it is most likely an unexamined assumption; however, it is an assumption that might influence the sense of urgency about proceeding with more legislation in this regard. Others mentioned a lack of resources to get this accomplished. Several participants noted that although Newfoundland and Labrador still does not have such legislation enacted, this province was at one time a leader in this area of legislation, and despite the fact that technically Newfoundland and Labrador is the last province, it is still not far behind the others. In should also be said that the Federal Privacy Act has been considered by many

to be clearly outdated and does not reflect the principles of privacy, and that even though Newfoundland and Labrador is the last jurisdiction to proclaim privacy legislation, the federal government is still very far behind in this regard.

5.8 ATIPP Privacy Provisions

Additional discussion was initiated on the topic of why the privacy provisions of ATIPP had yet to be enacted. A general consensus emerged that the main reason for the delay was a lack of bureaucratic and operational readiness. Because of the great number of municipalities, each with their own method of maintaining privacy and confidentiality (in one example, a shoebox was being used to store files), government wanted to ensure that all groups involved would be prepared for the implementation of the new legislation. Though this comment appears to make sense, government could have also used this as a crutch or an excuse as to why implementation took as long as it did. Most participants stated that there would be little point to enact such legislation unless everyone was ready for it and able to abide by it. This would be an obvious conclusion, although it is not clear exactly what level of priority ATIPP was given at that time or how many resources were put into training, raising awareness etc. Do these factors point to a lack of government planning for ATIPP and the accompanying privacy provisions? It is difficult to say, although one participant did shed light on this question by stating that government considers many items to be priorities, but these priorities must still compete for scarce resources. Conversely, it was learned during this study that in the Department of Justice, the position of ATIPP coordinator sat empty for over one year, despite the fact that ATIPP activities were ongoing. If the government was fully committed to ATIPP, to being prepared for its implementation (i.e. training) and to setting aside adequate

resources, then why was this allowed to happen? This could be taken as evidence of inadequate planning on the part of government and also that privacy legislation is not a high priority. It also seems contrary to the idea of 'we need to be prepared before we move ahead' that government has put forward if key positions that would supposedly be responsible for ensuring such preparedness are left unfilled.

Also, during the period of time when government was taking steps to ensure that it would be prepared, were stakeholder groups contacted and told why the proclamation was taking so long? Did government explain what it was doing to reach a stage of readiness? Did it offer a timeline for completion? A future study could address these important questions. The findings could provide valuable information and insight from which government and stakeholder groups could learn for the future. This insight could help expedite a transition such as this, while establishing clear guidelines to reduce confusion.

All participants agreed that the ATIPP privacy provisions would definitely come into force. A common theme was that they were confident because government has already committed the necessary staff and resources and that there is a real desire from government and the public to make it happen. When the governmental decision-makers were asked if they thought there should be any amendments, most felt that because we live in a continually changing environment, legislation should be constantly reviewed and updated. In the particular case of ATIPP, participants stated that the legislation should be applied first and see how it works and then make any necessary and appropriate changes can be made in the future. It should be noted that ATIPP does have a mandatory

requirement for review five years after enactment. This provision allows for a reasonable time frame in which to study ATIPP's effectiveness.

5.9 Personal Health Information and ATIPP

Much was learned when discussion centred on why personal health information was not specifically addressed in ATIPP. At the same time, participants were asked if they thought that Newfoundland and Labrador needed legislation that explicitly dealt with personal health information. In terms of ATIPP, one participant stated that it was properly designed for its intended purpose, was general in nature and did not attempt to specifically address personal health information. All believed, however, that Newfoundland and Labrador did need a statute specifically governing personal health information. Many said that the need for separate health legislation was recognized early on; they spoke of a 2001 committee which released a report called 'Striking the Balance'. This report explained how personal health information was different from personal information, that it should be handled separately and gave several reasons as to why a separate personal health information act was needed (Striking the Balance Committee, 2001). Most participants agreed that such a personal health information act was overdue, and several participants stated that such an act is on its way. One participant mentioned that because a difference exists in application to public and private bodies, a health information act would be better suited and of great value. Another believed that if health care workers abided strictly by the present ATIPP, they would be unable to manage and deliver care effectively.

One question raised by these results is why a personal health information statute was not being created and brought in at the same as the new privacy legislation. These

seem to be intrinsically linked domains; having them enacted simultaneously would minimize confusion for health care providers and health researchers in terms of what one could and could not do with personal health information. If the government's intent from the beginning was to stagger the implementation of the two pieces of legislation, what was their rationale? Who would really benefit from this? It would be interesting to know whether or not government informed health care workers and health researchers during the discussion of ATIPP that separate health information legislation was planned for sometime in the future.

5.10 Objectives of a Personal Health Information Act

Given that there is now a personal health information act on the way, the participants were asked what they thought the objective of this legislation should be. This question brought about many important issues. Many said that it should protect the integrity of an individual's personal health information, and provide a balance between respecting the individual's privacy and the public good. A key point raised by several participants came from the perspective of patient care. In this area, the new legislation should be flexible enough to avoid negatively affecting patient care; also, privacy should not be used as an excuse for failure to deliver good care. One participant stated that the statute should focus specifically on personal health information. Patients should know what information is being collected and health care providers should understand the basis on which they should be collecting this information. The participant felt that these considerations should relieve patients of their worries. Another participant added to this point, saying that patients should be given access and rights to their health information in a way that they can understand. In the end, this would help empower the individual.

Furthermore, institutions holding this information should be accountable and transparent. Finally, participants emphasized that the legislation should be able to address health research concerns as well.

It is apparent that these governmental officials have a comprehensive understanding of both the issues involved with personal health information and the objectives which should be taken into consideration when instituting personal health information legislation. It is imperative that these issues and objectives are addressed during the creation of such an act. It would be interesting to know if any of these individuals have been approached for their input for the proposed legislation. Additionally, if some of these objectives are not addressed in the initial drafts of legislation, would these individuals have the opportunity to voice their concerns and would those concerns actually be taken into account?

5.11 The Legislative Process in Newfoundland and Labrador and ATIPP

Another objective of this study was to discover more about the legislative process in Newfoundland and Labrador, with emphasis on the creation of ATIPP. Much was learned in this respect. First, this researcher received a thorough step-by-step account of the actual process of drafting legislation. Subsequent questions revealed concerns that were raised during the development of ATIPP. Finally, discussion centered on the issue of stakeholder consultation.

A common theme was that government had decided that the previous access to information privacy legislation was outdated and that changes were needed. Subsequently, ATIPP was developed by the Department of Justice. Participants stated that during the creation of ATIPP, there were many concerns raised surrounding

implications for patient care and health research, and that government was aware from previous experiences with other legislation that it would be a sensitive issue for health providers and the research community. A key comment was that the Department of Justice made a presentation of ATIPP to Memorial University (MUN) after the fact (same as they did with all public bodies), generating many concerns from academics. This approach appears to be backward. It seems as though any presentation outlining possible implications for health research should have been given to MUN while ATIPP was still being formed. If any issues were raised, they could have then been discussed by government before ATIPP was completed. Another issue with ATIPP is that in certain respects it appears as though it was really meant as an 'Access' act and that privacy was add-on inasmuch as only a small number of the provisions of the act are privacy provisions. If the legislation did not have an appropriate amount of focus designated to privacy, it is possible that this created problems and delays for health care providers and health researchers if there was no direction on implementation.

This study asked questions to learn if and how stakeholder groups to be affected by ATIPP were consulted or involved in its development. All participants agreed that they were. Open public forums were held across the province, and stakeholder groups were approached, all of which helped to facilitate discussion regarding separate legislation for personal health information. One participant said that it is a normal process to automatically discuss and consult with identified stakeholder groups before any legislation impacting health care workers is being created. If this is indeed accurate, this would be evidence of sound and responsible practices during the creation of legislation. However, it does appear that health researchers did not take full advantage of

expressing their views while ATIPP was being considered by the Review Committee on the Freedom of Information Act or during the committee stage of the legislative process. With that being said, it could also be argued that government should have more actively involved health researchers during the process.

5.12 Consultation between Government and Stakeholder Groups

A final study objective was to gain insight into what practices are being used to increase the exchange of information about privacy and personal health information issues between the government of Newfoundland and Labrador and relevant stakeholder groups. According to the participants, government consults regularly with the public and stakeholder groups, and several stated that this is simply the way that their department does business. It was agreed that consulting with stakeholder groups works very well; these groups are treated as partners and the participants hoped that the regional health authorities recognized this. Furthermore, numerous participants said that government had a very strong working relationship with NLCHI. One participant said that government always talks with groups that will be impacted by legislation, for example health professional associations, but occasionally a lack of resources forces limitations on this interaction. These responses would indicate that there is a healthy working relationship between government and stakeholder groups in the creation of policy and legislation and in interaction and exchange of information. It is, of course, difficult to verify this information without contacting all of these groups.

Participants all agreed that they were encouraged to work with stakeholder groups, they constantly do work with these groups, and that active consultation is a goal of government; it builds trust between groups and creates long-lasting positive

relationships. These responses portray responsible actions by government. Again, this cannot be verified without the researcher contacting the head of each identified stakeholder group. It is encouraging, however, to hear these very positive statements. They reveal that these governmental decision-makers certainly do understand the need for these relationships and how to establish them. However, recognizing a need (or paying 'lip service' to a need) does not constitute an ability to engage in the process. A similar example of this would be to ask people if they think regular exercise is important to good health. Most will agree that it is, but that does not necessarily mean that they will do it. Given the respondents comments to the effect that there has not been a sense of urgency in the area of privacy, and the previous record with the Advanced Healthcare Directives Act in which a failure to consult with health researchers resulted in a moratorium on certain kinds of research until the legislation was amended, one cannot be sure that the stated intent on the part of government decision-makers to consult with all relevant stakeholders is always or usually put into practice or how extensive and effective such consultations have been.

Participants indicated that there are many benefits to such consultations. One common theme was that it helps bring ideas and considerations into account before and during the implementation stage of legislation. People working on the frontline are able to provide valuable up-to-date information that is relevant to the proposed legislation. A participant added that speaking with many different groups will help shape policy that serves both the government and the public. If there is strong endorsement from stakeholder groups, the legislation will be considered more legitimate and thus hopefully more widely accepted. Another participant neatly summed it up by saying that

consultation results in a better product, something that is workable and respectful of the values of all persons. With consensus, the participant said, there is a real buy-in to the piece of legislation. All these comments reflect a deep understanding of the benefits of stakeholder group consultations. Once again, these comments show that the government is adhering to responsible practices.

In terms of difficulties with consultation, several points of view emerged. One participant stated that since consulting does not necessarily mean doing what the stakeholders say, there were no actual difficulties involved. If this is the case, this attitude could undermine working relationships if stakeholder groups feel that government is ignoring their concerns and not taking what they have to say into account. Another participant said that they were not aware of any difficulties, however, they continued on to say that since each governmental department is in charge of their own consultation, it may never know if any other department is having problems, or the exact nature of those problems. An observation is that perhaps there should be an exchange of this kind of information between departments in order to raise awareness of potential issues, thus helping to avoid similar problems in the future. Some other issues that were not raised were if there were conflicting opinions between stakeholder groups or a situation when stakeholders do not want any change at all.

Several participants did cite particular difficulties with consultation. Common themes of the main difficulties include locating and involving the right people with experience in the field to ensure that the issues were competently resolved. Also, stakeholder groups have had numerous and sometimes conflicting perspectives. In addition, groups may have unrealistic expectations; this comment, however, could be

seen as subjective in terms of the meaning of "unrealistic expectation". Different political ideologies, both stakeholder groups and government of the day, could have contrasting expectations. One participant believed that there were many difficulties involved with consultation, such as getting people informed and trained which involves human resources, finances, and technical capacity and public awareness. All these responses outline the various difficulties involved with consulting stakeholder groups. Nevertheless, the participant's comments do show that the benefits of consultation outweigh the risks and that such consultation should continue to play major role in the formation of public policy and legislation.

5.13 Limitations

There are several limitations of this study. One of these limitations concerns participant involvement. Two potential participants were unable to take part, one due to a busy schedule and the other for unknown reasons as the individual did not respond to any e-mails or telephone calls.

Secondly, interviews require self-reported responses, and as such, results may be subject to a socially acceptable bias. The nature of politics, government, and the manner in which legislation is impeded or enacted is complicated and may cause participants to give responses that they feel they "should" give for social, moral or ethical reasons, and which may not necessarily reflect their actual opinions or decision-making processes.

Because this study is limited to Newfoundland and Labrador, it cannot be generalized outside of this province. Governmental decision-makers involved in the privacy domain in other provinces may possibly have different views; their governments may have different legislative processes.

An additional limitation results from this study arises from interviewing only individuals in government and not in other stakeholder groups. Stakeholder groups may have different perceptions on how government operates and how much of their input is taken into consideration. As well, in order to verify the participants' statements regarding their extensive consultations with these groups, it would be necessary to contact the head of each of these groups. This provides opportunities for future studies.

Summary

6.1 Conclusions and Implications

A key finding was that the governmental decision-makers' interviewed had a thorough understanding of the terms and concepts involved with personal information, personal health information, and electronic health records. There was an overall agreement that electronic health records can be and are safe; government, however, must always remain vigilant. As well, the protection of personal health information should not hinder health care and should allow for health research. It should be noted that even though ATIPP was not created specifically to protect personal health information, there were instances in which this legislation did adversely affect health care providers and health researchers. Participants spoke of incidents where delivery of care was delayed due to certain privacy restrictions as well as health researchers being hindered due to unclear regulations imposed by ATIPP. These issues should be taken into account for the proposed personal health information act.

These governmental decision-makers use mainly internal documents. They also perform extensive searches through other jurisdictions and review similar legislation in other province and countries for information on privacy and confidentiality issues surrounding personal information, personal health information, and privacy legislation. As well, they state that a strong partnership exists with NLCHI, a relationship that has been very beneficial. An interesting and important study would be to see if members of NLCHI felt the same way.

In terms of factors which might influence the development and enactment of privacy related legislation, most participants believed that privacy is not and has not been

a big issue in Newfoundland and Labrador for several years. They stated that this is a relatively more trusting culture and that in any case, there has been a lack of resources allocated for this area. There is evidence supporting the comment that few resources have been designated for privacy in the past, however, the reasoning regarding Newfoundland and Labrador being a more trusting culture is based on assumptions that are not supported by any literature. This line of thinking needs to be addressed if the Newfoundland and Labrador government wants to be able to straightforwardly state that privacy is now a priority. And even if indeed Newfoundland and Labrador is a more trusting culture, this may affect the kind of health privacy legislation that is enacted such that it might be possible to sustain a more research friendly environment (i.e. emphasize more the access side of the equation rather than the privacy side).

All agreed that the main reason for the delay in the implementation of ATIPP and the privacy provisions was due to a lack of government and bureaucratic readiness. What is not entirely clear is if this was due to a lack of planning, organization, and/or resources. All agreed as well that the privacy provisions would come into force because government now considers this legislation to be a priority as, according to the participants, they have realized the need update their legislation and get up to speed with the rest of the country.

Personal health information was not specifically addressed in ATIPP because it was previously recognized that it was different than personal information. However, personal health information legislation is currently being developed. What is not clear is the rationale for not simultaneously creating the personal health information statute along with ATIPP. By not doing so, this may have created undue problems and confusion as to how health care providers and health researchers were supposed to perform their duties.

The participants believed that health privacy legislation should: strike a balance between individuals' privacy rights and the greater public good; be flexible enough to work for both health care and health research; and should ensure that patients have the right of access to their information in a way that they can understand. These governmental decision-makers appear to have a comprehensive understanding of the issues involved in instituting a personal health information act. It is important that these individuals input was sought and used effectively during the creation of this act.

A great deal was learned as participants described the step-by-step process by which legislation, specifically ATIPP, was created by the provincial government. They also stated that Newfoundland and Labrador had once been a national leader in privacy legislation but has since fallen behind. Nevertheless, despite the fact that this province was technically the last to pass such legislation, it was not lagged that far behind several other provinces.

Lastly, it was found that the participants believe that stakeholder groups are generally actively consulted on privacy and personal health information issues, including ATIPP. Nevertheless, according to their accounts, it appears that health researchers as a group were not actively 'in the loop' while ATIPP was being created. Participants went on to add that consultation is a goal of this government, its officials are encouraged to consult and they have a strong understanding of both the many benefits and the difficulties involved in the process. A key implication of this observation coupled with the previous problems encountered with the Advance Health Care Directives legislation, is that government should make consultation with health researchers a priority when it moves forward with health privacy legislation.

The researcher was the only person who was involved in the analysis of the data. The conclusions drawn are his interpretation of the information which was conveyed by respondents during the interviews.

6.2 Dissemination/Research Transfer

The results of this study will be submitted as a Master's thesis. Furthermore, it is possible that results will be available to the research community through presentations and publications. In addition, participants were asked at the end of the interview if they wanted to be informed of the results of the study. Those participants who indicated an interest will receive a copy of the full project report by mail or e-mail, which ever they prefer.

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Appendix A: Interview guide

Interview Guide

☐ Review Consent Form and obtain written answers to the signature page.

To start, let me ask you some background questions:

1. What is your current position?
2. How many years have you held this position?
3. What position did you hold when the Access to Information and Protection of Privacy Act (ATIPP) was an issue for you?
4. How do you get most of your information regarding the protection of personal health information? (staff, articles, national or provincial committee's) And who creates and publishes these reports?

I'd like you to tell me a little bit more on your views of privacy and confidentiality surrounding personal health information and electronic health records.

1. Do you feel that personal health information in the form of electronic health records is safe (i.e. do you have any concerns)?
2. A follow-up question to this, does the current legislative and technical environment provide enough protection for personal information associated with the electronic health record?
3. How would you define privacy of personal information?
4. How would you define confidentiality of personal information?
5. How about security of personal information?

Now we are going to move into the part of the interview that deals with privacy legislation (ATIPP) and the process associated with it.

6. Can you tell me about the process of drafting privacy legislation? And also what your role was/is within this process?
7. During the drafting of ATIPP, did questions arise pertaining to its implications on health research?

8. What kind of information were you presented with when working on ATIPP? (i.e.) Where did this information come from? In what form were they (briefing notes, executive summaries, full reports, legislation from other provinces etc.)?
9. In the process of drafting ATIPP, were the stakeholder groups to be affected (i.e. doctors, nurses, health researchers etc.) consulted or involved?
10. * Depending on answer to previous question: If yes then, 'so ATIPP was drafted with consultation with stakeholders? Or if no then, so ATIPP was drafted before consultation with stakeholders?
11. Newfoundland and Labrador was the only province that did not have legislation in force to protect the privacy of personal information in the public sector- why do you think this was the case?
12. Why do you think the privacy provisions of ATIPP have yet to come into force (i.e. factors delaying the proclamation of the provisions)?
13. Are you confident that these provisions will come into force? Why or why not?
14. Would you like to see any amendments to the privacy provisions of the Act before they are proclaimed? If yes, what do you think needs to be added?
15. ATIPP allows for personal health information to be excluded for coverage under Part IV. Why was this?
16. As several other provinces have done (Alberta, Saskatchewan, Manitoba, and Ontario etc.), do you think that Newfoundland and Labrador also needs a statute that specifically deals with personal health information?
17. If yes, then what do you think the objective of this personal health information legislation should be?
18. What do you think the protection of personal health information will mean for patient care?
19. And how about health research?

Let's talk about working relationships.

20. Do you or other people in your department consult or work with stakeholders on issues associated with privacy legislation governing personal health information?

    Probes: Other groups being academics (MUN), NLCHI, CIHI, CIHR etc.

    Specifically, which ones would those be?
21. Are you encouraged to work with stakeholders on preparing legislation?

22. What are the benefits of consulting with stakeholders?
23. What difficulties are involved with this?
24. Do you have any other questions or comments?

Appendix B: Human Investigation Committee Application for Ethics Review and Approval Letter