CREATING THE NUCLEUS OF AN ELECTRONIC HEALTH RECORD:

BENEFITS, CHALLENGES AND SUCCESSES IN ESTABLISHING A CLIENT REGISTRY

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CREATING THE NUCLEUS OF AN ELECTRONIC HEALTH RECORD:
BENEFITS, CHALLENGES AND SUCCESSES IN ESTABLISHING
A CLIENT REGISTRY

by

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Abstract

Title: Creating the Nucleus of an Electronic Health Record: Benefits, Challenges and Successes in Establishing a Client Registry.

Background: A major challenge in the organization of an increasingly complex healthcare system is the maintenance of health records. The introduction of computers and the internet has provided a means for a significantly more efficient system of record-keeping. It has been recommended that each Canadian should have a personal electronic health record (EHR) that both they and their physician can access. EHRs have been linked with potential benefits that include more accurate and complete health records and a resultant higher standard of patient safety. Such a record is being built in Newfoundland and Labrador and across Canada. A unique personal identifier-based client registry is an essential and primary building block in the creation and implementation of the electronic record. An interoperable EHR could benefit from an overview of the challenges that are faced in the establishment of this type of registry.

Aims: This study was designed to assess the perceived benefits and challenges of the initial implementation of the client registry in the province, and to describe the opinions and experiences of those who work closely with the registry.

Methods: A questionnaire was distributed to and a focus group conducted with the Health Records Directors in the province. In addition, in-depth interviews were conducted with key individuals involved in the development and maintenance of the

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registry. Participants were chosen based on their knowledge and experience in dealing with health records, client registry output, and registry creation.

Findings: The participants agreed that the creation of the client registry in Newfoundland and Labrador is beneficial to both the government and residents of this province. Benefits discussed by participants include improved standards, cost savings and data quality. The challenges discussed include technical issues and the difficulty in establishing funding and support.

Implications and Recommendations: The findings are discussed with reference to lessons learned, and the implications for the creation of the client registry as the primary component for an interoperable EHR.

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List of Abbreviations

HIN – Health Information Network

EHR – Electronic Health Record

UPI – Unique Personal Identifier

CR – Client Registry

RIU – Registry Integrity Unit

NLCHI – Newfoundland and Labrador Centre for Health Information

BOB – "Best of Breed" solution

BDBC   Benefits Driven Business Case

DOHCS   Department of Health and Community Services

MCP   Medical Care Plan

VS   Vital Statistics

NCTRF – Newfoundland and Labrador Cancer Treatment and Research Foundation

Other Terms:

Active – Uses the client registry (UPI screen) as a source to register patients and to make queries (look-up demographic information in the client registry); this process involves active, real-time look up capability as opposed to just computer to computer transfer of information.

Passive – information gets fed into the client registry from stakeholders without any modifications to registration procedures; this is a computer to computer transfer of information, and does not allow for queries of the client registry.

Chapter 1
Introduction

1.1   <u>Background</u>

The delivery of healthcare in Canada is a complex and detailed operation that involves almost 400,000 general practitioners, local pharmacists and nurses, more than 700 hospitals, and numerous community care centres (Canada Health Infoway, n.d.). The current information technology environment has enabled the sharing of data across these points of care. Canada and several other nations have undertaken the creation of an Electronic Health Record (EHR), which promises tangible benefits that include cost savings, improved service and a superior patient care experience. An independent study done in 2001 found that 82% of Canadians supported the notion of an EHR (Martin, 2001).

The goal of the pan-Canadian approach undertaken by the federal government through Canada Health Infoway (Infoway) is to ensure that health records are built with consistent standards that will enable interoperability across jurisdictions. This interoperability would eliminate redundancy and encourage cooperation among jurisdictions during the future movement toward a Canada-wide patient index. The basis of a successful EHR is a patient registry that has quality data and processes that adhere to superior standards. The rationale for a pan-Canadian EHR is that this health information record for each resident of the nation would be available electronically to health care providers anywhere in the country and at any time (Neville, Keough, Barron, MacDonald, Gates, Tucker, Cotton, Farrell, Hoekman, Bornstein & O'Reilly, 2004). Individuals not only move from town to town in their own province or territory,

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Canadians are also moving between provinces; a national EHR would enable care across this divide.

Historically, the approach to maintaining patient records has been paper-based, non-standardized, and inefficient. Healthcare professionals and health records managers have had to face the challenges and unknowns that have permeated this system of record keeping. The fundamental problems that have been identified include inaccessible paper files and the absence of universal data standards for managing and linking health information. Problems such as these have been identified as "a key barrier in developing the national health information infrastructure" (Alvarez & Zelmer, 1998). Issues that have been prevalent in this area include registration entry errors, absence of standard registration procedures, and ultimately, lack of awareness among registration clerks of the importance of accurate data entry and absence of data maintenance procedures. These issues affect data quality and are important to address when looking at how to build a successful client registry, as the registry is the core of an electronic health record. Non-standardized registries and an overall lack of standards in health records keeping has been a challenge. As jurisdictions move forward with change management there will be new challenges. The issue of record standards has been discussed in different areas of health care (e.g., Pullen & Louden, 2006). The registry that will be discussed throughout the findings of this thesis is the initial client registry database created in Newfoundland and Labrador, which consists of names and demographic information on all residents of the Province.

In the Royal Commission report on health care, *Building on Values: The Future of Health Care in Canada* (known as the Romanow report), released in November of 2002,

it was recommended that each Canadian should have a personal electronic health record that both they and their physicians can access (Romanow, 2002). An electronic system would put an end to the time-consuming and inadequate paper files that currently exist, and would provide more accurate and accessible information for decision-making. Not only would it remove the need for patients to remember their entire health history, the availability of accurate and complete information would ensure that patients are provided with quality and safe health care by their providers.

Figure 1. Illustration of EHR Data Linkage
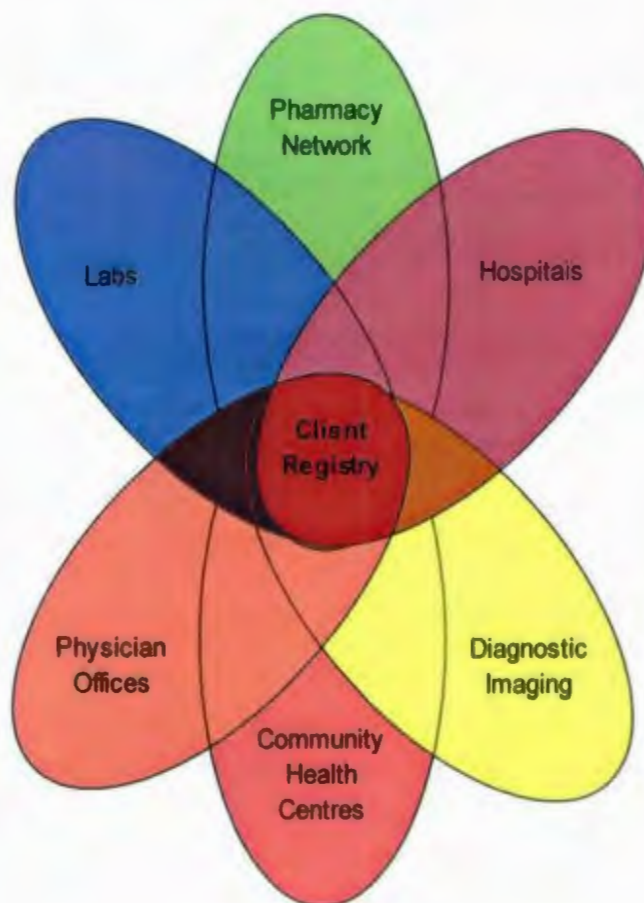
Implementation of an electronic health record requires the creation of several essential building blocks (see Figure 1) including client registry (directory of patients), provider registry (directory of participating authorized health care providers), diagnostic (i.e., x-ray and ultrasound), laboratory and pharmacy systems. These are essential components in the EHR infostructure, as together, they can provide a comprehensive overview of a patient's health data and history. Figure 1 depicts how an EHR brings together health information from multiple provider systems and points of care. The client registry is the central identifying component that ensures an accurate patient record. There are various studies that demonstrate the positive impact that an EHR can have on the quality, efficiency and level of safety in the healthcare that a patient would receive (e.g., Chaudhry, Wang, Wu, Maglione, Mojca, Roth, Morton and Shekelle (2006), Kaelber & Bates (2007), and Pullen & Louden (2006)).

The Health Information Taskforce in Newfoundland and Labrador recommended in their July 1995 final report, that an entity be created to develop strategic plans for the implementation of a quality-based information system for the residents of the Province (Health System Information Taskforce, 1995). In 1997 the Newfoundland and Labrador Centre for Health Information (NLCHI) was created, and the following year the centre was mandated to establish a scope for a unique personal identifier/client registry (UPI/CR) and the components that were to follow (i.e., laboratory and pharmacy). A unique personal identifier (UPI) is, as its name implies, an identifier unique to each person. It is also the first building block of an EHR, which will, as a whole, enable person-specific health and clinical information to be united from various sources. The gold standard client registry is an information system that holds accurate demographic

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information about all people using provincial health services at various points of care; in other words, a directory of people being served within the health care system. The UPI Scope (Newfoundland and Labrador Centre for Health Information, 2000) proposed that the UPI/CR would be able to provide a solid foundation for future components of an EHR.

During the summer of 1999 it was announced that work on the first phase of Newfoundland and Labrador's EHR was commencing. In an effort to ensure that all stakeholders were involved in the decision and planning process, representatives from NLCHI met with over 2,000 Newfoundlanders and Labradorians prior to implementing the initial UPI/CR (Shaw, 2001). This allowed any potential concerns to be voiced and taken into account when creating the new system. In addition, potential benefits were explored. It was hypothesized that the unique personal identifier would serve to enhance the capacity of the health system to evaluate outcomes and resource usage (Government of Newfoundland and Labrador, August 20, 1999). When the UPI/CR was implemented in 2001, Newfoundland and Labrador (NL) became the first province with an operational provincial client registry.

To capture the population within the Registry, the data from the Provinces Medical Care Plan (MCP) database was used. The MCP is the provincial entity that controls and tracks who in the province is entitled to province-funded health care, for example residents and students. The MCP is, according to the official MCP website, (Government of Newfoundland and Labrador – Medical Care Plan) a comprehensive plan of medical insurance that covers the cost of medical services for bona fide residents of the Province. The services covered include visits to physicians, diagnostic procedures,

lab procedures, surgeries, maternity care and a host of other services. The MCP has existed since 1969 and is funded by the Government of Newfoundland and Labrador. The rationale for using this MCP database was that it was thought to be the best catchall for residents of the Province that present for medical services.

Since the mid-1990's, Health Canada has been working towards the vision of a pan-Canadian approach to health infostructure (Western Healthcare Information Collaborative, March 2002). As well, Health Infostructure Atlantic (HIA), representing the Atlantic provinces of Prince Edward Island, New Brunswick, Nova Scotia and Newfoundland and Labrador, seeks to improve the use of technology in the Atlantic region by working together to find common solutions to common goals (Sierra Systems Consultants Inc., July 31, 2000). Several priorities for how best to proceed with the development of EHRs were identified during discussions that took place among Canada's Atlantic Provinces in a 2002 CHI Stakeholder Forum. Some of these include:

- Develop a common client registry;
- Focus on outcomes improved care; and,
- Address issues related to privacy and security rigorously but pragmatically.

Representatives of the Atlantic Provinces also made suggestions at the Forum for early successes that would help to build momentum and establish a solid foundation (Canada Health Infoway, 2002). These were threefold:

- Keep focused on one-person/one-record as a goal;
- Build awareness and knowledge; promote and market successes; and,

- Build on current projects, help move them to the next level and devise best practices.

A common vision among the stakeholders (Infoway, Health Canada, HIA, NLCHI and the Government of Newfoundland and Labrador) was to build on existing knowledge and technology and move towards a beneficial and innovative health information system.

In support of this pan-Canadian movement towards a national EHR, Canada Health Infoway has taken on hundreds of projects that work toward interoperable solutions to the core elements of an EHR. The progress of Canada's nation-wide EHR approach is discussed within Canada Health Infoway, 2007-08. The report notes that 254 projects have been complete or are actively underway at the end of the 2007-08 fiscal year. Further, Canada Health Infoway anticipates that by 2010, three of the thirteen jurisdictions in Canada will have fully interoperable EHR infostructure in place; these first three jurisdictions make up approximately 50% of Canadians (Canada Health Infoway, n.d.). Looking even further into the future, all Canadians are expected to have an EHR by the year 2016 (Canada Health Infoway, Spring/Summer 2008).

At the time this study was conducted, there were two health regions in the province that had been chosen as test areas to commence active connection between care providers and the registry. The majority of the regions in the province maintained their passive means of information transfer (Note: the eight Institutional Health Boards and six community Health Regions mentioned were reduced to four Regional Integrated Health Authorities in 2006). The passive mode of access to the client registry involves information transfer after patient registration, without direct action by a registration clerk. For example, a registration clerk in a hospital in NL updates the mailing address of a

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patient who is registering for care; this update into the hospital's own registry of patients, feeds automatically into the client registry. Active mode, however, allows for queries to be performed using the client registry to identify the person registering. For example, if that same patient had presented for care at a health care facility that was piloting the active connection to the client registry, the registration clerk would have looked up the patient directly in the client registry, not in their own facility registry system. The client registry is a nucleus system that information from many stakeholders feeds into. The registry did not have the same impact on all areas, which is why key informants from both active and passive regions were interviewed for this study. Since 2002, the Newfoundland and Labrador UPI/CR has been used by all hospitals, Health and Community Services regions, long-term care and MCP facilities in the province.

The client registry in Newfoundland and Labrador, as it existed in the Fall of 2003 when this study was undertaken, was preparing to move toward an upgraded system that could better provide the anticipated benefits. At that time it used custom-developed interfaces to exchange information with Meditech (current regional health care registry system in 2003) systems, but this arrangement presented challenges for maintenance and long-term sustainability. Areas in need of upgrade were identified through meetings organized by NLCHI with stakeholders such as the Department of Health and Community Services (DOHCS), Vital Statistics (VS) and the Newfoundland and Labrador Medical Care Plan (MCP). Necessary levels of registry connectivity were then implemented for the various stakeholders in Newfoundland and Labrador (NL); some with passive, some with active, others with "look-up" capability (the ability of certain

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stakeholders to search information on the client registry but without the flow of information).

Figure 2 depicts the main stakeholders involved in the Newfoundland and Labrador client registry and the directionality of information flow to and from the registry (Newfoundland and Labrador Centre for Health Information, 2000). Getting the provincial registry up and running was a goal that necessitated having a great deal of support, especially from the stakeholders, as it is ultimately their health information needs and expectations that are at the forefront. The flow of health information between the UPI/client registry and various stakeholders is depicted.

Figure 2. Stakeholders of the Client Registry and Flow of Information to and from the Registry
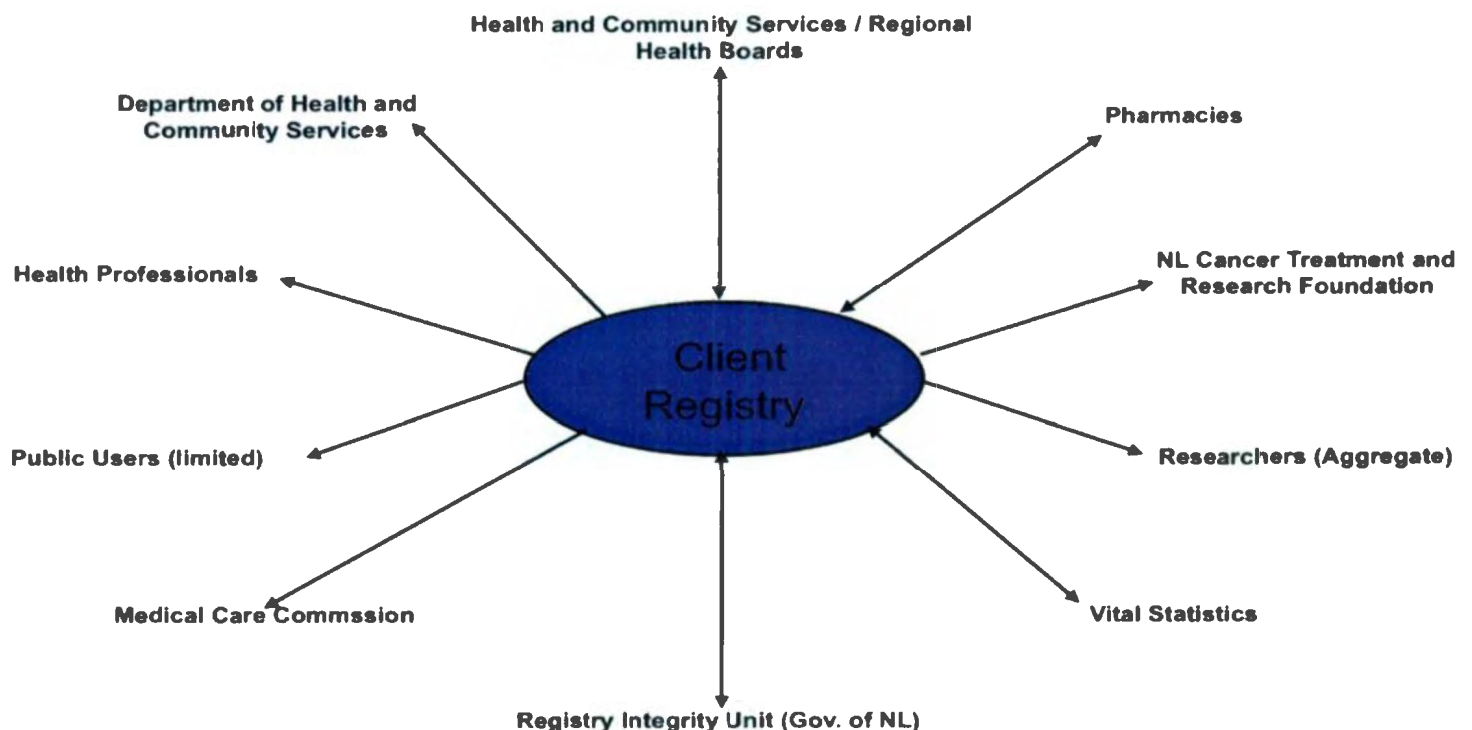
The need to develop a UPI and client registry has been identified as an essential primary component for an EHR by jurisdictions across Canada and across the world, in countries such as Australia, New Zealand and the United Kingdom (F/P/T Advisory Committee on Health Infostructure, 2001; Canada Health Infoway, n.d.; Robbins, 1999; Detmer & Steen, 2006). These nations have made significant progress in their goal of establishing an electronic health record for their residents. There is, however, a need for research that explores, evaluates and documents the development of a client registry. To build an interoperable client registry it is important to identify "best practices" and "lessons learned" from those directly involved with the development of the client registries that exist.

By 2003, efforts to pave the way to successfully creating a province-wide registry were recognized by Canada Health Infoway, which, like NLCHI, had been mandated to work toward the development of electronic health information systems. Infoway contributed significant funding to NLCHI to improve the original UPI/CR that the current study focuses on. The province then began to expedite implementation of interoperable (information that can be exchanged) registries, in line with Infoway's goals.

In February of 2005, Canada Health Infoway partnered with the Government of Newfoundland and Labrador to create an upgraded client registry in the Province, one that was reusable and could be shared with other jurisdictions across Canada. Neville, MacDonald and Gates (June 2005) evaluated the new and upgraded registry that was made up of "Best of Breed" components, or what has worked best in other jurisdictions to date. Their evaluation was mainly to ensure accountability for the funding dollars received to upgrade the registry, and also, to ensure that the knowledge gained would be

highlighted to aid other jurisdictions. Neville et. al, used a pre/post methodology, that consisted of scoping documents that provided pre-implementation details, and then, very similar to the methodology of the current study, conducted key informant interviews and secondary analysis of relevant documents to achieve their post implementation data. Key findings that the authors identified included benefits, barriers and facilitators. Benefits identified included improvements in data quality and access, while concepts such as leadership and teamwork were identified as facilitators in the project. Key barriers to successful registry implementation involved changes to project scope, human resource constraints, as well as timing of the registry implementation. The authors also concluded from their study that the province had successfully, with the help of Infoway, created a reusable client registry, complete with a tool-kit that could be used by other jurisdictions. This study differs from the current study in that the objectives of the current study focus mainly on the perceived benefits and challenges that were identified by key informants, while providing detailed exploration of opinions and comments provided by the participants. The current study enables a comprehensive look at whether the client registry is deemed a successful base for an electronic health record.

Research into data quality improvement has to be an integral part of the health care system. There is no universal method for matching client health records, yet as technology expands, so too does the ability to use new and better matching methods. To be able to accurately and safely share health information in a timely manner, standardized processes and systems must exist.

The business of health care and the technologies that are utilized in modern record keeping and decision-making are rapidly changing. A need has been identified to closely

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monitor the opportunities and challenges involved in the implementation of patient records systems, such that other provinces and jurisdictions can learn from these. The current study undertook a detailed investigation of the processes and operations involved in establishing a client registry system in Newfoundland and Labrador.

1.2   Purpose of Study

The overall aim of this study was to describe the challenges associated with implementing a client registry, and to outline the perceived benefits associated with the creation of this registry. Also, one of the anticipated implications of this work, is to illustrate and report on the lessons learned during the creation process. The study begins by assessing the existing systems and practices of various jurisdictions, discusses the challenges in developing a registry that can be implemented on a pan-Canadian basis, and considers the successes of the Newfoundland and Labrador UPI/CR.

Objectives

There are several distinct objectives associated with the current study:

Primary:

- To identify the perceived benefits of the client registry;
- To identify the perceived challenges encountered during the creation and maintenance of the client registry;
- To analyze, synthesize and describe opinions and experiences of those who work closely with the registry;
- To evaluate the client registry as a base for an electronic health record.

Secondary:

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- To compare experiences between passive and active systems of connectivity;
- To identify the level of staff and resources required to develop and maintain a client registry, particularly for a dedicated Registry Integrity Unit (RIU).

1.3   Significance of Study

This evaluation aims to document both the experiences of those involved in the creation of the registry as well as the resources needed to build and maintain the primary element of an electronic health record. The benefits that key individuals associated with the implementation of the registry as well as the challenges that they each experienced will be clarified. The end result will be an overview of the planning and initial roll-out phase of the registry as the primary component of an electronic record. Detailed accounts from the various participants will add to the existing literature available on registry creation and maintenance. It is intended that other jurisdictions can use the findings of this research to aid them in creating their own registries.

Chapter 2
Review of Literature

There is continuing debate internationally about the potential benefits of implementing electronic health records (EHRs). Researchers and organizations have discussed the need for EHRs and the various challenges that jurisdictions face when developing and implementing them. Much of the literature pertaining specifically to client registries as a component of an EHR has been generated by researchers in those nations leading the way in EHR development, namely Australia, New Zealand, Canada and the United Kingdom.

The current review of literature sought to unearth studies that identified benefits and challenges of client registry creation and maintenance; as well as uncover previous evaluations of client registries as a primary component of an electronic health record. In addition, the review included commentary on the various methods of data collection used in the different studies.

To maximize access to the existing literature, several online search engines and databases were used. Since much of this research is not published in academic journals several sources including CINAHL, Pubmed, and Google/Google Scholar were searched for information. Numerous terms and phrases were entered into the searches, including, but not limited to, the following and combinations of the following: medical record, electronic, patient identification, systems, computerized, evaluation, client registry, master patient, master client, index, element, building block, electronic health record, Canada Health Infoway, standards, health records, interview, focus group, benefit, challenge, qualitative, content analysis, thematic analysis, unique patient identifier,

unique personal identifier and health information. All literature uncovered through these searches was reviewed for relevance, comparability and essential information.

2.1   Why Create an Electronic Health Record?

Healthcare systems today are undergoing major change, and the introduction of technology is part of that change. A client registry acts as the base directory of patients that will ultimately be linked to various repositories of information from health care providers within a jurisdiction. According to the Romanow report, assurance is needed that "healthcare providers have access to complete information", and the EHR appears to be the tool to make that possible (Romanow, 2002). The possibility of the electronic health record is one that has been discussed for decades, and some countries and jurisdictions have already taken steps toward its introduction.

As Protti and Catz (2002) have noted, people die from medical errors on a regular basis. Aside from huge financial savings for the healthcare system, an EHR could potentially help reduce the consequence of such errors. Protti and Catz emphasized that although many organizations like to put dollar figures on the savings that a Health Information System brings, the main concern should be the improvement in patient safety. Kaelber and Bates (2007) have also argued that one of the largest advantages that could come out of the electronic exchange of health information is improved patient safety. These authors note that as many as 70% of adverse drug events could be eliminated if the right information was available to healthcare providers at the right time. Their study details the various ways in which patient safety could be improved with a health information system such as an EHR, including improved medication, laboratory

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and radiology information processing. The challenge is to develop a system that is capable of processing and utilizing this information.

A landmark study by Baker et al. (2004) provided an estimate of adverse medical events on a national scale within Canada, which they discuss as an indicator of patient safety. They found that of the estimated 2.5 million annual hospital admissions in Canada, about 185,000 experiences an adverse event, and of those, an estimated 70,000 are potentially preventable. It can be rationalized that an EHR could help to reduce adverse events in healthcare, with the core of an EHR being made up of client and provider registries that serve to link current patient information.

The introduction of the EHR is designed to promote more accurate and reliable health information that will lead to better and more informed healthcare, which will, ultimately, ensure greater patient safety through the reduction of human error. There is increasing use of EHRs internationally; however the methods of development differ across jurisdictions and nations.

2.1.1 Global Electronic Health Record Developments
New Zealand, Australia, and the United Kingdom all have national health information systems in place or in development (F/P/T Advisory Committee on Health Infostructure, 2001). Detmer & Steen (2006) conducted an in-depth review of approaches to and developments in EHRs within England, New Zealand, Australia, Canada and the United States. They noted that Canada's approach to EHR development has been similar to Australia's, with a national framework guiding the implementation of the EHR components at the provincial (or state) level. England has taken a different approach, with a centralized system whose implementation is coordinated by regional

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health authorities. The United States' framework for an EHR is still in development, and will pose a different set of challenges due to the private sector aspects of health care in that country. There is a national strategy in New Zealand, but the systems for an EHR are being implemented in varying ways, sometimes, nationally, sometimes regionally or locally.

Two main methods of EHR development identified by Canada Health Infoway (Canada Health Infoway, n.d.) are the "Hub and Spoke Repository" and the "Point-to-Point Information Exchange". Jurisdictions such as Canada, the UK, and the US Department of Veterans' Affairs, use the "Hub and Spoke" approach which consists of a main repository for the health information that is accessible in real time by health care providers. Alternatively, nations such as Australia and New Zealand have taken the "Point-to-Point" approach, which means that each jurisdiction within these nations has its own independent database of electronic health information, and shares elements of this database with the other jurisdictions as the information is requested (Canada Health Infoway, n.d.). The "Point-to-Point" approach does not allow for real-time or on-demand access to patient information, but it is faster to implement than the "Hub and Spoke" approach. Canada Health Infoway also noted in their *Vision 2015* report that New Zealand and Australia are moving toward adapting their existing systems to the repository "Hub and Spoke" model.

Detmer and Steen (2006) discussed progress these nations have made in developing and implementing their EHRs. Canada, Australia, New Zealand and England have all articulated their strategy well, while the United States is in the process of putting their strategy together. Also, while development and implementation of an EHR is well

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underway in England and Canada, it is still in the early stages of progress for Australia and New Zealand.

2.2   Why Create a Client Registry?

In order for the EHR to fully serve its purpose it has to have some means of integrating personal health information in such a way that it can be shared between regions or jurisdictions. The Western Health Information Collaborative (WHIC) white paper on client registries summed up the purpose of the client registry when it stated that "a common client registry is a fundamental building block towards the realization of an EHR and enables the accurate, consistent, unique identification of clients" (Western Health Information Collaborative, 2002). In addition, the registry addresses and alleviates many of the challenges encountered with the regional and organization level registries. Thus, the challenges of duplicate data, limited linkage and lack of standards can be minimized with a successful CR built on agreed principles and guidelines.

When looking at the end goal of an operative EHR, jurisdictions need to assess what will sustain the systems and offer benefits in the long-term to patients. As was discussed by Nazi (2003), in the *Journey to e-health*, in order to create and sustain such high-reaching goals it is critical to focus on a limited number of initiatives, so that resources are targeted. For example, to concentrate on the foundation of the EHR, which is the client registry, to ensure data integrity, interoperability and security, is to ensure a solid base from which to grow and build an effective system.

As the central component of an EHR, the client registry will ultimately give health professionals the ability to access patient demographics and health history, enabling the provision of healthcare even when a patient is not physically present or is

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unconscious and unable to communicate to the provider (Protti, 1998). The unique personal identifier and client registry provide the accurate and unique identification that is necessary to eventually link patients' data.

Unique identification is critical as a component of electronic health information compilation and exchange, but it is only a part of the base element needed for a successful electronic record. The client registry is needed to house health information adequately and efficiently, and this piece coupled with the standards that are forced by housing all data from different facilities and regions, is thought to produce an effective primary step in the development of the electronic health record (Freriks, 2000). It was recognized in the strategy of the Northern Territory Health and Community Services in Australia, that a database with integrated and updated information, such as the client registry, would be pivotal to the success of an electronic health record system (Robbins, 1999).

The Newfoundland and Labrador Centre for Health Information (NLCHI) conducted substantial preliminary scoping research in the 1990s to determine the need for, and potential outcomes of, a client registry. According to the *Benefits Driven Business Case (BDBC)* (NLCHI, 1998) and the *Updated BDBC Benefits* (NLCHI, 1999), the anticipated positive outcomes associated with the person-centered client registry, include reduced delays in services, better data quality, enhanced privacy, improved integrity and completeness of the held information and facilitated research. Also identified, was the need to create and maintain an accurate unique personal identifier/client registry, which would require dedicated staff (RIU) and resources who would be tasked with maintaining an accurate and up-to-date registry.

2.2.1 Benefits of a Client Registry

With a registry system in place that can manage client information and provide accurate and accessible identification data for an entire jurisdiction, there is a foundation from which to build an EHR system. The registry provides the mechanisms that will enable unique identification within systems, institutions, regions and throughout the province. There are expected advantages from the implementation of this first element, including clinical and administrative benefits (Western Health Information Collaborative, 2002). The creation of a registry can also serve to drive change in health and health information systems (i.e. standards and data quality).

The benefits that were expected as a result of the creation of the CR in Newfoundland and Labrador, as identified in the updated *BDBC* were broken down into immediate and future benefits. The immediate benefits anticipated included (NLCHI, 1999):

- The CR will permit coordination among multiple service providers caring for the same groups of clients – reducing costly duplication in services and freeing up resources;

- The CR will produce Death Reports that will help clean up stakeholder databases; and

- The CR will avoid duplication of diagnostic tests.

The available literature demonstrates that a client registry would provide the capacity for unique patient identification, along with numerous benefits such as standardized procedures and accurate information, while making use of ever-changing technology to provide better and more accessible healthcare. A variety of systems have been proposed and implemented within Newfoundland and Labrador, Canada, and

internationally to address the need for accuracy and accessibility in healthcare information.

2.3   Client Registry Project in Newfoundland and Labrador

Newfoundland and Labrador began the process of creating its own EHR with the establishment of NLCHI, an organization dedicated to the creation and facilitation of the many distinct EHR components. With clear goals in place, and the overriding need for access to quality information, NLCHI's Health Information Network Team took on the first task at hand - the need for unique patient identification. Patient identification is an important component of any health system. It enables the tracking of patients and their care, and since legacy and multiple systems often exist within a jurisdiction, "a plan ought to be in place in order to support their incorporation in a single ID domain in a standardized way" (Katehakis, Kostomanolakis, Tsiknakis & Orphanoudakis, 2002). Newfoundland and Labrador's solution for this was to create a unique personal identifier client registry (UPI/CR). Not all jurisdictions start with this component (e.g., the Western Australian Health Services linked databases) but others have (e.g., the Manitoba Population Health Information System) (D'Arcy, Holman, Bass, Rouse & Hobbs, 1999). Interest in client registries or master patient indexes has been increasing in the past two decades, and is expected to increase further as jurisdictions search for ways to improve healthcare delivery. The American Health Information Management Association MPI Taskforce (2004) discussed some of the reasons for the shift to master patient index use. They cite customer-centric focus, consolidation of healthcare organizations and implementation of EHRs.

The rationale for the creation of an Electronic Health Record includes, among other things, a need for accurate and accessible health data and a need for enhanced patient safety. More specifically, there is no universal approach to standards, so data has been consistently compiled in varying ways, producing an unreliable source for health information. Potential duplicate numbers (individuals registered in the system more than once) were discussed by Neville, Gates and MacDonald (2005). They identified levels of duplicates at different points in time, from the original client registry, as it existed in March of 2003, through to implementation of the updated registry in January 2005. More specifically, Neville et al., reported that the number of potential duplicates was reduced from 214,682 in March 2003 to 78,699 in March of 2004. With the implementation of the BOB client registry in January of 2005, the number of potential duplicates jumped to 421,534 with the increased ability of the registry to detect data quality issues.

The vision of the Health Information Network (HIN), as described in the *Client Registry Project – "Best of Breed (BOB)" Solution* (NLCHI, 2002), is to "improve the quality of health services in the province, through the provision of accurate and timely information to the appropriate care-delivery and decision-making stakeholders and to the public." Old interfaces posed many challenges for maintenance and sustainability of the system, so by updating the stakeholder interfaces and the software in 2003-2004, NLCHI, with the help of Infoway, was able to create an optimal client registry system. This Infoway-funded update was rolled out in Newfoundland and Labrador after the completion of the data collection for the current study. In November 2007 there was another upgrade to the NL client registry (NLCHI, May 2008). This new upgrade will enable the client registry to connect to and interact with the pharmacy network, which

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will be operational in early 2009. Other provinces and territories in Canada adopted different procedures. These are described in the next section.

2.4   Client Registries in Canada

Canada Health Infoway, the force behind the development and optimization of the Electronic Health Record in Canada, has certain goals for the future Canadian client registry. These goals, according to the authors of the blueprint for a nationwide master patient index, include establishment of a nationwide master patient identity solution, provision of provincial client registries, the possibility for inter-provincial communication and sharing of patient identifiers, and support of a national view of patients (Dorrel, Fernandes & Laskoski, 2004). Work currently being done in Canada is considered innovative and as the country moves toward having half of the country using interoperable EHR systems in this decade, the experiences and developments are being watched by other countries for guidance and direction. The December 2005 *Privacy Impact Assessment* completed by NLCHI states that they provided Canada Health Infoway with more than 90 documents to use as part of a client registry Toolkit to help other jurisdictions benefit from best practices and lessons learned from improvements made on the client registry as it existed during the current study.

Infoway and healthcare stakeholders are currently undertaking a series of projects, such as BOB (Best of Breed project described above), in order to create and solidify EHR solutions. One of the main objectives of such projects is to develop deliverables that facilitate inter-operability and that can be used by other jurisdictions. According to the NLCHI *Backbone* published in January of 2005, Infoway had invested $5.4 million along with $3.6 million from the Department of Health in NL, to enhance the CR system.

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making it the best of its kind (NLCHI, 2005). Canada Health Infoway is also investing in the creation of re-usable components across Canada that together will produce interoperable EHR systems.

As of March 31, 2009, Canada Health Infoway has been involved in client registry projects in all of Canada's provinces and Territories (Canada Health Infoway, 2008-09). More specifically, by March 31, 2009, 76 percent of client registries across the nation have been completed and the remaining 24 per cent (Quebec, Yukon and Nunavut) are in the implementation stage. As of March 31, 2008, Infoway had invested more than $88 million into client registry projects across Canada (Canada Health Infoway, 2007-08).

2.4.1 Alberta (AB)

In the spring of 2004 Alberta's Enterprise Master Person Index went live. This client registry has the ability to cross-reference the millions of individual patient records from systems across the Capital Health Region (Edmonton and area). It has sophisticated search and selection tools and has been deemed a Best of Breed (BOB) patient registration system by Infoway which invested $1.8 million in the project. The government of Alberta reports on its "Alberta Netcare EHR" website that Alberta has a common set of registries in place for unique identification of clients and providers (Government of Alberta, n.d.). Capital Health has worked closely with the province to develop a strategy for a provincial CR (Capital Health, 2004). Within 18 months of implementation of Capital Health's EHR system known as netCARE, they recorded a 50 per cent reduction in lab requests alone (Canada Health Infoway, n.d.). In 2006 Capital Health partnered with Infoway, and netCARE, which is able to provide comprehensive

service to some 1.6 million residents in and around the Edmonton area, was set up to become the basis of Alberta's provincial EHR. This provincial record database will link patient information across all nine of Alberta's health regions (Canada Health Infoway, 2006-07).

2.4.2 British Columbia (BC)

In 2003, a client registry was one of several EHR components for BC that was in the works. Since then, the province has been able to implement a CR based on the Infoway toolkit created by Newfoundland and Labrador, and Capital Health in Alberta. The province was able to save valuable time and financial resources by creating a replica of the BOB solution (Canada Health Infoway, 2004-2005). Infoway has identified in their *2015* vision report that BC will likely have all components of the EHR in place by the end of 2010 and that it will need that extra time to implement the laboratory database and to reach the point of becoming an interoperable EHR.

2.4.3 Manitoba (MB)

Manitoba Health and the Regional Health Authorities, with Infoway, have worked towards the implementation of a CR. The province has been focusing on the creation of a provider registry, and has worked closely with Infoway to develop a reusable solution (Canada Health Infoway, 2004-05). Infoway has reported that Manitoba will not have a complete interoperable EHR in 2010 but that it will have completed client and provider registries as well as diagnostic imaging databases in place by 2010 (Canada Health Infoway, n.d.).

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2.4.4   New Brunswick (NB)

As in many of the other Canadian provinces, New Brunswick is in the midst of laying out the plan and vision for the rollout of their EHR. In that regard, the creation of a client registry is one of the priorities of this province. NB is a part of Health Infostructure Atlantic (HIA), a group made up of representatives from all four Atlantic provinces. HIA provides a means for the Atlantic provinces to share ideas on technology initiatives and to benefit from the practices of the other jurisdictions. NB was also involved in a project with Infoway to work toward the implementation of a CR (Canada Health Infoway, 2004-05). Infoway reports that New Brunswick that as of March 31, 2009, the client and provider registry projects are complete (Canada Health Infoway, 2008-09).

2.4.5   Newfoundland and Labrador (NL)

Similar to Saskatchewan, NL will not have a complete interoperable EHR by 2010 but will be well on their way. Registry and diagnostic components are complete, and in 2009 the drug network will be complete and linked to the client registry. Infoway worked with Newfoundland and Labrador to create a Best of Breed client registry and were able to create a tool-kit from this partnership that would benefit other jurisdictions in Canada during their own creation and implementation stages of a client registry. The province will require further funding to be able to complete the Laboratory information component and will only achieve partial completion on this in 2010 (Canada Health Infoway, n.d.).

2.4.6   Northwest Territories (NT)

In 2005, records indicated that the Northwest Territories did not yet have a client registry system in place, and the vastness of this Territory would present challenges for

the development of a successful EHR and its components (Canada Health Infoway, 2004-05). Since then, Infoway has helped the Territory partner with Capital Health in Edmonton to share service agreements. With a population just over 40,000, the Northwest Territories has the potential to piggy-back the forward momentum of the larger and better-equipped province of Alberta (Canada Health Infoway, n.d.). It is important to note that a partnership already existed with Capital Health and the Department of Health in the NT, as patients from the north frequently visit Edmonton for medical tests and procedures that are not available in Yellowknife or other northern communities. As of March 31, 2009 the client registry for the Northwest Territories was complete (Canada Health Infoway, 2008-09).

2.4.7   Nova Scotia (NS)

Nova Scotia has implemented a unique patient identifier in support of future implementation of a provincial EHR. As with the majority of the other provinces and territories, Nova Scotia worked on a CR project with Infoway (Canada Health Infoway, 2004-05). Infoway has identified that as of March 31, 2009, the client and provider registries are complete (Canada Health Infoway, 2008-09), however, like NB, NS has not begun work on the drug domain to link with the registries (Canada Health Infoway, n.d.).

2.4.8   Nunavut Territory (NU)

A client registry was created in Nunavut in its first year as a Territory in 1999. The registry has since been discontinued due in large part to technology and confidentiality issues. The Territory is in the process of replacing the old system with a more effective infrastructure. NU also participates in the WHIC along with Canada's western provinces and the NT. Infoway (Canada Health Infoway, n.d.) reported that as of

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spring 2008, there were no Infoway-partnered registry projects in progress in Nunavut. Infoway (Canada Health Infoway, 2008-09) later reported that the client and provider registries are in the implementation stage in the Territory.

2.4.9 Ontario (ON)

E-Health in Ontario is a very high priority. The province has also made use of the Infoway CR toolkit to help them create a CR that they call an Enterprise Master Patient Index. Patient records from local hospitals are added to the provincial client registry and patient records can be linked (Government of Ontario, September 19, 2006; Electronic Patient Record, n.d.) As of March 31, 2009, Ontario has completed their client registry, and expects to see completion of their provider registry in the near future as it is currently in the implementation stage (Canada Health Infoway, 2008-09).

2.4.10 Prince Edward Island (PE)

Prince Edward Island has moved forward much the same as Newfoundland and Labrador with the vision of an EHR. The social services system of this province has been guided by the development of an EHR. PEI has addressed registries as key components of a successful Health Information Network and has worked with Health Infostructure Atlantic and Infoway to create a common CR. They developed a unique personal identifier based upon standards, and the registry has complete demographics to form a critical building block for an EHR (Canada Health Infoway, 2004-05; Health Infostructure Atlantic, February 2002). As of March 31, 2009, Prince Edward Island has all EHR components in place (Canada Health Infoway, 2008-09).

2.4.11 Quebec (QC)

Quebec was able to utilize the CR toolkit from Infoway to help them in the implementation of their patient registry (Canada Health Infoway, 2004-05). As of March 31, 2009, Quebec's client registry is still in the implementation stage, however their provider registry is complete (Canada Health Infoway, 2008-09).

2.4.12 Saskatchewan (SK)

All regions in Saskatchewan are connected to a universal network. The past emphasis for the province has been to establish the core health network infrastructure, part of which is a central data centre. The province undertook a CR project with the support of Infoway, called the Shared Client Index. This registry project provides the automatic matching of identifiers and demographics from various provincial and regional health sources. The province actively participates in the Western Health Information Collaborative, partnering with other Western Canadian Jurisdictions, and it is making the client registry an area of focus (Canada Health Infoway, 2004-05; Government of Saskatchewan, 2003). As with most other regions of Canada, as of March 31, 2009, Saskatchewan had a client registry system in place (Canada Health Infoway, 2008-09).

2.4.13 Yukon Territory (YT)

The Yukon Health and Social Services participates in the Western Health Information Collaborative. The Territory has made use of the Infoway toolkit to work towards the implementation of a territorial CR. According to the minutes of a September 2005 meeting of the Yukon Health and Social Services, two proposals put in to Infoway were turned down, so the Territory has decided to independently develop a CR (Canada Health Infoway, 2004-05). As of spring 2008, the Yukon Territory was in discussions with Alberta and British Columbia to share in their service arrangement. It is expected

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that the Territory will require a significant amount of time and resources to move forward

with plans to achieve their EHR (Canada Health Infoway, n.d.). As of March 31, 2009

the territories client registry was still in the implementation stage (Canada Health

Infoway, 2008-09).

2.4.14 Summary

It is apparent that some provinces are more advanced than others in the

development of client registry initiatives. This provides an opportunity for less

developed provinces to learn from progress in other provinces such as NL and AB.

2.5   Client Registries in Australia the UK

Prompted by a government action plan, the state of New South Wales in Australia

set out to develop a system that would enable the linking of patient's health information

(McAlpin, 2003). This resulted in a project named the "New South Wales Health Unique

Patient Identifier Project." Initially, as in Newfoundland and Labrador, the health and

demographic information was held in separate systems across the jurisdiction, and in

multiple health settings. Also, very similar to the approach in NL, their strategy was to

retain local patient identifiers and to have these all mapped to a central or primary area

unique identifier and to a statewide unique identifier. The tiered plan and architecture of

this new Australian system required the implementation of software that would function

in passive mode (not real-time). As with the registry in NL, the integration of residents'

demographic information was to be based upon real-time Health Level 7 (HL7)

messaging. HL7 messaging is an American National Standards Institute (ANSI)

accredited standard for healthcare specific data exchange between computer applications

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(Health Level 7, www.hl7.org). This New South Wales UPI application was scheduled

for completion in late 2003 (McAlpin, 2003). Pilot EHRs began in various places in

Australia in 2002, and in 2004 the pilot projects expanded to include more regions,

including New South Wales. Australia anticipates having all regions connected to the

EHR by the year 2014 (Canada Health Infoway, March 2005).

In the United Kingdom, BMI Healthcare, the largest independent acute care

hospital in the country, originally had standalone systems that led to substantial

duplication. As in NL, the lack of standardized processes in the legacy systems meant a

lower quality of patient information and hence, patient care (Agilisys, n.d.). In 2005,

BMI healthcare started the ball rolling on implementation of an Enterprise Master Patient

Index (EMPI) via a group of software developers and service providers (Fairey, 2006;

Agilisys, n.d.). BMI Healthcare and several provinces within Canada use the same

Initiate software for the EMPI or CR. Several benefits were identified for BMI

Healthcare with implementation of the EMPI, and include improved availability of

patient information, better quality information, standardized processes in all hospitals in

line with the best known practices, and the change to an EMPI for BMI will reportedly

make their systems compliant with the National Electronic Record (Agilisys, n.d.).

2.6   Challenges in Establishing a Client Registry

In planning and developing a health information system that can address these

apparent and documented inadequacies in healthcare, there are several main issues that

need to be addressed, including privacy, technology, leadership, and standards (all of

which will be discussed in later sections of the current study). All underlying

components of a system must come together in order for it to be successful; therefore,

identifying up front exactly what must be accomplished is important. It is apparent that "leaders must take an active role in developing strategic information system plans that address the unique challenges of establishing an ... information network" (Wager, Heda & Austin, 1997). Positive and experienced leadership in the creation of an EHR and its components (i.e., client registry and provider registry) is essential to ensure continued movement toward goals, and to ensure that the necessary issues and challenges are being worked through. It makes sense then, to have those individuals who will be actively involved in the final product, or system, to be involved from the very beginning to ensure that the end result is a successful one.

Researchers and policy makers have also identified the need to understand and ensure privacy in the realm of electronic data storage, linkage, and usage. Risks to privacy could come from both authorized and unauthorized users, and to show and maintain accountability for the protection of individuals' personal information strict guidelines have to be followed. Steps taken to ensure the protection of information housed in Newfoundland and Labrador's client registry will be explored further in the discussion section.

The creation of an EHR or a client registry also means looking at broader social issues such as security, confidentiality, and public acceptance. Many jurisdictions approach their goal of creating a successful and sustainable electronic health system in varying ways, yet all need to consider similar social issues during the process. In addition, there will also be limitations and challenges such as the cost of creating the system, the issue of privacy, and the need for the EHR and its components to be understood by a large group of individuals and stakeholders sharing a common vision.

Different approaches may be both challenging and successful, depending on the systems and infrastructure (such as Newfoundland and Labrador's HIN) that are already in place. Larger jurisdictions will face the need to address and "understand each participating organization's individual and common business objectives, and evaluate their critical success factors" (Wager et al., 1997). However, although business objectives are vital, a perfect solution to all of the potential issues and challenges associated with creating an EHR or any of its elements is likely not plausible at this or perhaps any stage.

2.7   Evaluating a Client Registry

There is a need to conduct a detailed and comprehensive evaluation of the processes involved in creating the Newfoundland and Labrador Unique Personal Identifier/Client Registry, and to identify the benefits and challenges associated with implementation of this primary component. The process of planning such an evaluation involves a number of steps very similar to those outlined by UK Institute of Health Informatics for the NHS Information Authority, March 2001:

1. Agree why evaluation is needed
2. Agree when to evaluate
3. Agree what to evaluate
4. Agree how to evaluate
5. Analyze and report
6. Assess recommendations and decide on actions

There are any number of reasons that justify doing an evaluation of computer systems and processes as they relate to health information. Heathfield and Pitty (1998)

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identified two reasons for doing an evaluation: to determine efficiency of computer systems and their component processes; and to gain explanatory insights into implementing computer systems into clinical environments.

An evaluation of regional communication network initiatives in the United States by Inova as discussed by Wager et al. (1997) included interviews conducted with Health Information Network managers and executives who were involved in the installation processes. A total of ten interviews were conducted in that study and the information received in these interviews provided evaluators with "significant insight" into issues that needed to be addressed. In particular, the results showed that the key issues that needed to be addressed included structural and political issues such as applications, confidentiality, data sharing and acceptance among users. The authors of that study concluded that proper systems' planning is the key to success.

A pilot study was conducted in Scotland to reveal key points on users' opinions on the Diabetes Audits Research Tayside Project (DARTS) 2000, a project whose goal was to create an interactive web-based source for diabetes data (Pagliari, Hunter, Clark, Boyle, Cunningham & Morris, 2003), a registry of sorts. The study used a mixed methods approach, including survey and semi-structured interviews with staff from a healthcare cooperative, including general practitioners, nurses and practice administrators. The feedback that was received revealed important information around attitudes, experiences, perceptions and perceived barriers to implementation of the data source. In the end, the qualitative feedback proved to be instrumental in developing future strategy for implementation, and ultimately, evaluation.

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Implementation of a hospital information system failed in the Limpopo province of South Africa at the beginning of this decade. An evaluation was conducted to identify the reasons for this failure. A survey of members of ten stakeholder groups was conducted, followed by workshop discussions with the same groups to obtain feedback. The goal of these combined methods of data collection was to determine how best to design an evaluation framework (Littlejohns, Wyatt & Garvican, 2003). These methods provided the researchers with viable feedback from individuals who were considered potential users of the system.

Evaluation is increasingly recognized by organizations and jurisdictions interested in implementing electronic health information systems as an essential component of the final product and vision. As described in the 2001 UK Institute of Health Informatics report, standards or appropriateness of an evaluation can be determined by the utility, feasibility, propriety, and accuracy of the intended evaluation plan. The review and documentation of experiences, successes and challenges in the area of health information sharing and the process by which this sharing is conducted is a useful practice, and one that could benefit many people. Ultimately, it is important to recognize the importance of reviewing the progress (Jayasuriya, 1997; Wager et al., 1997; and Healthfield, & Pitty, 1998) and processes of information systems.

The above-noted studies used some combination of survey, interview and analysis to identify relevant information for their evaluations. They illustrate the benefits of using a variety of different methods of data collection.

2.8   What we know - and how it Guides the Current Evaluation

The literature that was reviewed for this study identified several key themes:

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a) client registry initiatives are happening across Canada and the World;

b) the level of benefits that can be recognized with a client registry;

c) the challenges and issues that come with the creation of a client registry;

d) the implications of putting a client registry in place as a building block for an EHR; and,

e) the need to learn from the implementation of client registries in different jurisdictions through careful review and evaluation.

There is a need for ongoing research and evaluation at all stages in the development of EHR systems. There is a need to learn from the experiences of the key individuals who are involved in the many detailed processes of registry creation. Such information would help other jurisdictions achieve similar goals.

Previous research demonstrated that a mixed approach to evaluation using both quantitative and qualitative methods can potentially provide a comprehensive identification and assessment of the actual and perceived benefits and challenges that are inherent in the creation of the electronic health record/client registry.

The aim of this study is to clarify the challenges and successes identified in the early stages of the establishment of an electronic health record/client registry in the province of Newfoundland and Labrador.

Chapter 3
Methodology

3.1   Study Design

The study used a cross-sectional mixed-methods design that incorporated a

questionnaire survey, a focus group and a series of individual interviews. This approach

allowed for different forms of data collection and consequently, a more comprehensive

set of findings. The questionnaire provided data in the form of percentages of

respondents who felt a particular way about various aspects of the unique personal

identifier and client registry. The qualitative methods allowed participants to be involved

in in-depth discussions, guided by the research questions, which served to provide this

study with a more thorough understanding of relevant experiences. Together, these

methods of data collection enabled the various objectives of the current study to be

addressed, eliciting information on benefits, challenges, experiences, opinions, processes

and resources associated with the creation of a client registry as the primary component

of an electronic health record.

The supplementation of questionnaires with interviews is a method often used by

researchers. For example, a recent literature review on research concerning the success

of inpatient clinical information systems noted the value of a mixed approach (Van der

Meijden, Tange, Troost, & Hasman, 2003). These and other authors have noted that

integration of quantitative and qualitative methods of data collection provides an

improved quality of results through a process of triangulation (Patton, 2002; Flick, 2002).

Using a focus group as a means of data collection not only allows for more views

to be explored and expanded upon at the same time, it also capitalizes on communication

between participants that is directly related to common experiences. Another advantage

of the group setting is that it can encourage participation from reluctant participants. For some participants a focus group may be either more or less comfortable than one-on-one interviews. Potential disadvantages to this method that need also to be considered include the possibility of opposing views being silenced by the view of the majority, the compromise of confidentiality, and the restriction of discussion or personal views on sensitive topics (Kitzinger, 1995).

The focus group and interviews conducted gave voice to the key individuals who were critical in the development of an operational client registry. Purposive sampling (non-random, with a particular group of people in mind) was conducted, with specific key individuals identified and approached to be a part of this study. The individuals interviewed maintained very different roles and provided knowledge, support and guidance on varying levels within the agency.

To prepare accurate and effective measures for data collection, guidance was sought from key individuals involved in all aspects of the client registry. When preparing the questions asked in the questionnaire, focus group and interviews, advice from key staff members at NLCHI was taken into account regarding what information would be valuable to gain from participants. However, the main drivers for the questions were the objectives of the study. The need to evaluate the first phase (pre Best of Breed Phase completion) of the UPI/CR, with a particular emphasis on what benefits and challenges were associated with every part of the planning and actual creation of a functioning master registry for the province, guided the majority of the question content.

With respect to the current study, evaluation is purposeful, in that it seeks to gain and highlight knowledge passed on by individuals that have the ability to explain

processes important to the development of the client registry. Evaluation for knowledge

is described by Heathfield and Pitty, (1998), as the "acquisition of a more profound

understanding in some specific area or field." Notable or noteworthy responses and

recurring themes within the qualitative data were identified, analyzed and then

interpreted. Figure 3 summarizes the flow of the methodology utilized for data

collection.

Figure 3. Flow of Study Methodology
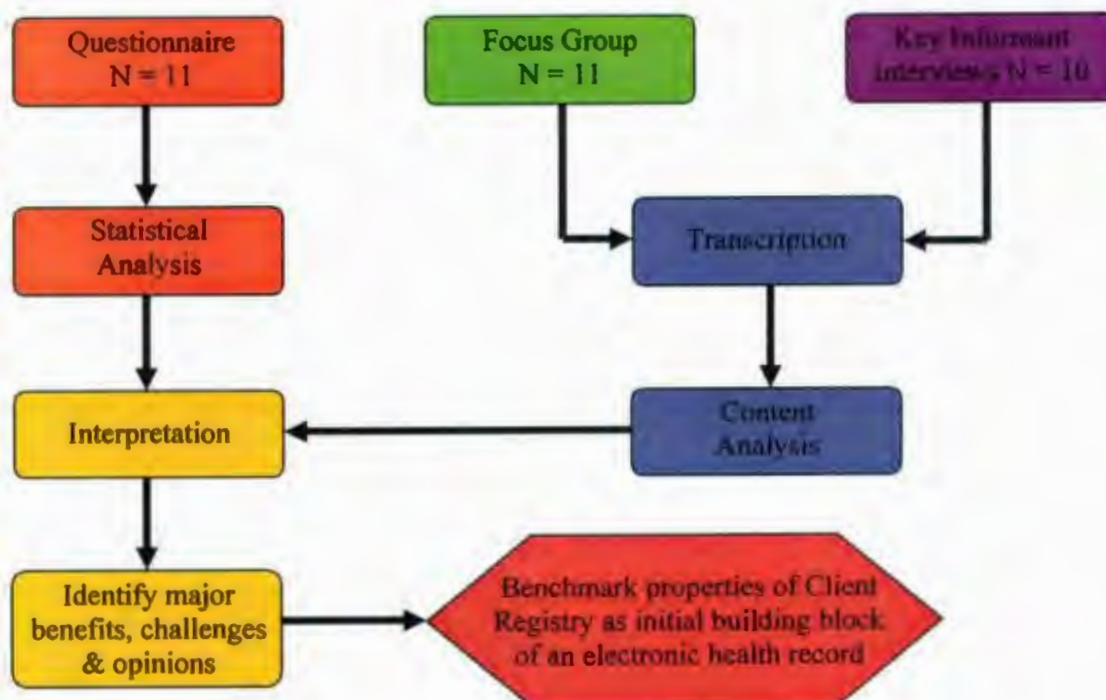
3.2 Questionnaire Component

3.2.1 Participants

The questionnaire (Appendix G) was distributed electronically to all 13 Health

Records Directors in Newfoundland and Labrador in September of 2003. Of the 13

Health Directors contacted, 11 participated in the survey.

3.2.2 Questionnaire Content

The questionnaire was designed to elicit opinions from Health Records Directors

on the CR, its development, and its processes. It included questions relating to specific

elements of the registry, its usefulness and its processes. More specifically, participants

were presented with a series of statements that they could agree or disagree with on a

Likert scale of one through nine, one being strongly disagree, and nine being strongly

agree. In addition, questions were asked regarding the perceived benefits and challenges

of the client registry and of the use of the UPI. The majority of the questions/statements

were aimed at creating a picture of the feedback received by Health Records Directors

from front-line workers in the regions (i.e. health records and registration staff), opinions

on the unique personal identifier and client registry as a primary element in the larger

vision of an electronic health record, and opinions on the changes in processes for those

that work with the new registry.

3.2.3 Procedure

An introductory letter (Appendix H) describing the study as well as a letter

requesting consent (Appendix I) accompanied the questionnaires sent to each Director.

Questionnaires and consent forms were anonymously returned to the investigator by the

directors. who placed their completed questionnaires in an envelope provided during the

focus group that took place at a later time so that responses would remain anonymous.

3.2.4 Method of Analysis

Questionnaire data were keyed into a database. SPSS was used to conduct

statistical analyses and to calculate frequencies of responses to each question. This

provided a numerical breakdown of the opinions of the respondents.

3.3 Focus Group Component

3.3.1 Participants

As with the questionnaire. 11 of the 13 Health Records Directors in

Newfoundland and Labrador were able to participate in the focus group. As the

questionnaires were anonymous. it cannot be reported whether the same 11 of the 13

Health Records Directors took place in the focus group. The average number of years the

participants worked as Health Records Directors, as shown in Table 1, was 11.0, with a

range between 2 years and 24 years (N – 11).

Table 1 Number of Years Focus Group Participants Worked as a Health Record Director

Number of Years	Frequency
2	2
3	1
6	1
7	1
10	1
14	2
17	1
22	1
24	1

Mean Years Worked = 11

At the time of data collection, most of the participants worked in regions where the UPI client registry was passive (Table 2).

Table 2 Frequency of Focus Group Participants Working in an Active or Passive Region

Level of Activity	Frequency	Percent
Active	3	27.3
Passive	8	72.7

3.3.2 Focus Group Content

The participants were provided with the opportunity in the focus group to expand on responses given in the questionnaire. Specifically, the questions presented to the group (Appendix J) were broad and enabled the Health Record Directors to discuss and provide commentary around passive versus active regions, data sets, potential benefits and challenges, and business processes. The process also allowed the Health Records Directors to discuss any other elements of the client registry they wished to speak to. The focus group lasted approximately two hours.

3.3.3 Procedure

Permission was granted by the Chair of the Health Records Directors meetings to allow utilization of this quantity of time from one of their regular quarterly meetings, provided the directors wished to participate. Written consent (Appendix K) to participate in these focus groups was sought well in advance to allow for the investigator/group facilitator to plan the focus group around the Health Records Directors quarterly meeting.

The group was facilitated and tape recorded by the primary investigator in September of 2003. Content areas were introduced for discussion by the facilitator in the form of broad questions noted in the Focus Group Content section above. An additional researcher was present for the focus group and the notes from both the facilitator and other researcher were compared to ensure more accurate transcription. Comparison of both sets of notes taken at the focus group confirmed the major points set forth by the directors.

The reasons for including all participants in a single focus group were both practical and also methodological. The number of possible focus groups was limited by the fact that only three of these individuals worked in active/live registry regions, and limited secondly by the number of individuals that held the required knowledge. In addition, it was felt that it would be beneficial to the study to have all Health Records Directors attend the same focus group, to allow experiences to be equally drawn out and addressed.

The idea of conducting a focus group with the public was considered, but after preliminary consultations, it was decided that the general public possessed neither knowledge nor awareness of the unique personal identifier/client registry project in Newfoundland and Labrador.

3.3.4   Method of Analysis

The focus group was transcribed verbatim by a professional transcriber and then fully reviewed and edited by the facilitator/investigator. Content was analyzed and open-coded for emerging themes (Appendix L) and key points relating to the planning, development and maintenance processes of the client registry. Main themes were categorized based on the objective of the questions asked and content areas presented,

and with analysis, further themes emerged. This qualitative method is known as thematic analysis (Braun, & Clarke, 2006).

3.4   Interviews

3.4.1   Participants
A series of ten interviews was conducted with key individuals involved in the development and maintenance of the unique personal identifier and client registry.

The participants included the following:

a) The Director of Privacy and Communications at NLCHI. This person was responsible for preparing communications tools and project scopes.

b) The former CEO of NLCHI. This person has a number of responsibilities, which included the initial necessity of getting NLCHI up and running, the need to create a mutual goal within the organization, orienting the board, creating a mission statement, and ultimately getting the organization of NLCHI to work together on the registry.

c) The Health Information Network Project Leader. This person was responsible for the development of requests for proposals "that contained the detailed functional requirements of what our business challenge was." This individual maintained a leadership role in the development of the registry throughout, ensuring that the appropriate "mechanisms were in place to iron out any particular bugs from the human perspective." In addition, the role of the Project Leader was to ensure that at the end of the day the value was still there for the project and that those involved didn't lose sight of the end goal and why they were working towards it.

d) The Past Chair of the Board of NLCHI. As Chair this person held the role of encouraging the board to think about the concepts involved in the creation of the registry

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and engaging the considerable talent that made up the Board. This individual also had to keep the board moving toward the project's goals.

e) The Standards Director at NLCHI. This person maintained the role of leading discussions with the Health Records and Registration Directors to determine elements to be captured in the registry, developing it and helping it evolve, and determining how the information was going to be shared back and forth. In addition, the Standards Director had the responsibility of establishing the Registry Integrity Unit (RIU) - the individuals involved in maintaining the database, and the Director continues to hold a supervisory role with the RIU.

f) The Manager of Public Services and Administration - Audit and Claims Integrity Unit of the Department of Health and Community Services. This department was "extensively involved in the first look at the databases", and this person was in a position to provide feedback as a very significant stakeholder. Also, because the MCP database fed into the registry on a regular basis, there was a vested interest in the potential benefits that the registry could provide, specifically, better capability of determining MCP eligibility.

g) A Government Official from the Department of Health. Their role was to champion it within the department to get the executive support and the minister of the day. This individual also sat on the Project Steering Committee and was involved in managing the implementation of the client registry.

h) A physician representative of the medical association (NLMA). The medical association had been extensively consulted by the Health Information Network at NLCHI around the establishment of the CR.

i) The staff of the RIU maintain the data in the registry, concentrating on cleaning, updating and merging the demographic information. In order to get an accurate picture of what is required of an RIU, detailed interviews took place separately, with two of the three staff members of the RIU in the province.

3.4.2 Interview Content

Three separate interview guides were utilized, and though geared for the different, individually-interviewed participants, each contained questions that sought relevant information on the roles and responsibilities that the informants held in the CR implementation process. In addition, participants were asked to identify potential benefits and challenges from their diverse perspectives. These interviews also contained questions that addressed the processes involved in the actual planning and development of the registry, privacy, and resulting implications. The three different interview scripts that were used for these key informant interviews included:

a) One for the Registry Integrity Unit (RIU) staff (Appendix M). Questions were related in particular to their roles and responsibilities, and also, what proportion of their time was spent doing particular tasks;

b) One for the Standards Director at NLCHI (Appendix N), to get an accurate picture of the guiding principles of creating a UPI. It included questions to ascertain what processes took place in the planning and implementation phases of the unique personal identifier and client registry, and;

c) One for the remaining key informant interviews (Appendix O), to obtain diverse views from a variety of stakeholders. Questions posed related in particular to what was involved in moving the concept of the registry, as the initial building block of

an electronic health record, forward, as well as what perceived and apparent benefits, challenges and implications are associated with the registry itself.

The study objectives addressed in the interviews include those given above, as addressed by the questionnaire and the focus group, with the addition of addressing the level of staff and resources needed for a Registry Integrity Unit.

3.4.3 Procedure

All interviews were conducted by the researcher in the participant's place of work between October of 2003 and February of 2004. All interviews were tape-recorded. Prior to conducting the interviews, consent forms (Appendices P, Q and R) were signed.

Elaborate accounts were encouraged of the informants so that very detailed explanations, descriptions and recommendations could be obtained. A potential disadvantage or limit of any study that depends on participant's personal discussion is that the agenda of the interviewee may also come through. Thus, as in any study that collects subjective data, care will be taken in any conclusions drawn.

3.4.4 Method of Analysis

The tape-recorded interviews were transcribed verbatim and a content analysis was completed. Emerging themes (Appendices S and T) and key points were noted. Analysis of interview data was done independently of analysis of focus group data. As with the data for the focus group, recurring topics or themes were noted and compared. As all interviewees were involved in differing areas of registry development, key points that each interviewee made on their own experience with the registry were noted and will also be explored in the results section.

3.5   Participant Recruitment and Procedure Rationale

Overall, the informants were identified for the current study because they enabled exploration of particular elements of the EHR process in Newfoundland and Labrador. Health Records Directors were chosen for participation in this study because of the knowledge and experience they possess in dealing with both health records and client registry output. These individuals were chosen in lieu of registration clerks at health care facilities because these individuals are on the front line and may not be aware, at this early phase of registry implementation, of the benefits and challenges associated with the registry or its components. In some cases, registration clerks may not have been aware that they were using any particular system or interface, thus were deemed not to be the best ones to go to for feedback. The RIU was utilized because they are the only ones who have complete hands on system experience with the registry. They were capable of providing valuable feedback with regard to both the client registry and use of the UPI within this registry. With inclusion of the additional interview participants, the goal was to achieve a diverse data set from individuals that were heavily involved in the client registry project on varying levels.

3.6   Ethical Considerations

Approval from the Human Investigative Committee (HIC) at Memorial University was sought and obtained for the current study prior to the commencement of any data collection (Appendices A, C, D, E and F). All participants received introductory letters prior to the start of data collection, and were required to read and sign a consent form (Appendices I, K, P, Q and R). Health Records Directors and RIU staff were first approached regarding participation by the Standards Director and Chair of the Health

Records Directors meetings, and then by the investigator. Prior to the investigator contacting the key informants they received a letter from the CEO of NLCHI informing them of NLCHI's support of the study (Appendix U). Every measure was undertaken to ensure complete privacy protection and anonymity for the participants. All participants agreed to be referred to by title, so participant names were never included in investigation material or subsequent transcripts of the interviews or focus group.

3.7   Summary of Methods

To effectively evaluate the introduction of a client registry as a foundation for an EHR; to identify the perceived benefits and challenges that arose from the creation and maintenance of the client registry; and to evaluate the UPI as a base for the client registry, a combined use of focus group, individual interviews and a questionnaire survey with key individuals was utilized. This was identified as an appropriate and comprehensive approach to collect data from a distinct group of individuals involved in the various elements of the client registry project in Newfoundland and Labrador. The ability to triangulate data obtained using different methods strengthens the findings.

Chapter 4
Findings

When asked the question, "Why create a client registry?", one individual summed it up well with the response, "this province wanted to create a comprehensive electronic health record…and the basic building block to achieving that functionality was to tie in the identification of clients on a province-wide basis…the client registry is considered to be the main building block." This chapter provides substantial more detail on what this individual and other informants thought were the benefits and challenges in introducing the client registry. The results of the questionnaire, the focus group and the interviews are presented below. Participants' experiences, opinions and other key findings are also explored.

4.1   Key Themes

Particular themes were identified within the findings and are briefly summarized here. These key findings are explored fully in the next sections. Perceived benefits that were identified include Unique Identification, Standardized Registration Procedures, Reporting and Data Linkage, Data Quality and Integrity, Awareness and Realization, Active (real-time) Connectivity and Cost Savings. The following perceived challenges were also discussed by participants: Finding the Resources, Education and Awareness, Accepting Change, Technical Problems, Under-developed Computer Skills, Non-uniformity of Registration Procedures, Human Error, Privacy and Accountability, Building Support and Direction and Guidance.

A variety of opinions and experiences were identified in the findings, and range from positive participant accounts of working together with others to achieve a common

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goal, to accounts of ambivalence on the newly acquired expansiveness of the patient data that the registry provides access to. The majority of the opinions that were given provided a positive picture of the usefulness of the client registry. The Unique Personal Identifier/Client Registry was deemed an effective building block for an Electronic Health Record by many participant accounts.

It was apparent that participants' experiences were shaped by their access to the registry on either a passive or active level. Those regions that were utilizing the client registry in real-time were those that were acting as the pilot regions, and thus were able to provide insight on different challenges. The participants also detail the fundamental component of resources within the findings. The challenge of securing human and financial resources to build the client registry is expanded upon through a variety of participant accounts.

4.2   Benefits of the Registry

4.2.1   Questionnaire
Unique Identification

One of the guiding factors in the creation of the registry was the need to have a means of uniquely identifying patients in the province of Newfoundland and Labrador.

When asked whether the unique personal identifier client registry was an effective building block for an EHR, the directors' responses were similar. Table 3 shows that the majority of the respondents felt (strongly agreed or agreed) that the UPI/client registry was an effective building block although one of the respondents disagreed.

Table 3 The UPI/Client Registry is an Effective Building Block for an Electronic Health

Record

(Scale of 1-9, 1 Being Strongly Disagree, 9 Being Strongly Agree)

Level of Agreement	Frequency	Percent
1 – 2	0	0
3	1	9.1
4 – 6	0	0
7	1	9.1
8	3	27.3
9	6	54.5

Standardized Registration Procedures

When asked in the questionnaire whether there were any notable changes to

business processes as a result of the Registry, 10 or 11 respondents indicated that there

were. The remaining participant did not respond to this question.

Reporting and Data Linkage

The client registry has the capability to produce a number of reports that provide

registration staff and health records directors with a specific picture of the patients in the

database at a given time. Participants described several reports that are generated from

the client registry, by the Registry Integrity Unit, on a regular basis. For instance, deaths

in the Province are periodically compiled into a listing that is sent to all regions so that

regional client lists can be updated. Respondents were asked how useful some of these

reports are to their daily operations. Their responses indicate that the identified reports

are beneficial to their daily business processes, thus demonstrating that the client registry,

by itself, has the capacity to be useful in reporting and health records processes.

As Table 4 illustrates, the majority (72.7%) of respondents found the potential duplicate report to be extremely useful. The remaining three participants responded differently, one felt the potential duplicate report was useful, one felt unsure or indifferent, and one chose not to respond.

Table 4 Usefulness of Specific Registry Reports

(Scale of 1-5, 1 being Not at all Useful, 5 being Extremely Useful)

	Birth		Death		Alias		Potential Duplicates	
Usefulness	Freq.	Percent	Freq.	Percent	Freq.	Percent	Freq.	Percent
1	0	0	0	0	0	0	0	0
2	2	18.2	0	0	3	27.3	0	0
3	3	27.3	0	0	2	18.2	1	9.1
4	3	27.3	3	27.3	2	18.2	1	9.1
5	1	9.1	7	63.6	3	27.3	8	72.7
Missing	2	18.2	1	9.1	1	9.1	1	9.1

The birth report produced very different results, with only 9.1% of the respondents finding it extremely useful (Table 4). Equal numbers of the Health Records Directors found the birth report either useful or were indifferent at 27.3%. In addition, 18.2% did not find the birth report very useful, with the same percentage not responding to this question.

The Death listing appeared to be one of the most beneficial or useful reports, with 63.6% of the respondents labeling it extremely useful, and 27.3% labeling it useful (Table 4).

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The alias report is the last of the reports that were reviewed in the questionnaire, and its usefulness, as identified by the respondents, varied greatly. Apart from the one respondent who did not respond on the usefulness of the alias report, an equal number of the Health Record Directors (27.3%) found this report to either be not very useful, or, conversely, extremely useful. A total of 18.2% described it as useful and another 18.2% were indifferent or unsure (Table 4).

Table 5 shows that seven of ten questionnaire respondents felt that the need was not present to have additional reports created from the registry.

Table 5 Need for Generation of Additional Reports

Response	Frequency	Percent
Yes	3	27.3
No	7	63.6
Missing	1	9.1

Of the remaining participants, three Health Records Directors did feel that the registry should be further utilized, and identified the following potential reports: catchment, children by date of birth residing in a region with current demographic information, healthcare number field error, and name field error.

4.2.2   Focus Group
Unique Identification

Participants noted that the registry allowed for "appropriate identification of individuals in the health system." Duplicate control and the ability to uniquely identify

patients were identified as key issues in relation to data quality. As one participant said,

"If we don't have duplicate control then we get lots of people that are dead still in

the system...So it just controls the number of records in the client registry and we

have a better handle on the actual use of the system by individuals."

Data Quality and Integrity

One of the recurrent themes in the data was the overall benefit of having a

provincial database that was accurate and reliable. Typical comments included: "The

duplicate report was certainly a benefit for cleaning up our database", and "...if we had

not had regions that were in active mode, a lot of the issues that came out of it would not

have been known."

Though having the integrity of the data tested was a challenge, it was felt to be an

enormous benefit to the client registry and its stakeholders. As one participant said:

"I sometimes think about...that most of us have had clients about 10 years... and

considering the volume of work and things that have gone into addressing some

of the issues that have been raised in this type of initiative...what will the state of

your system be in 15 years...force the issue and then that integrity issue stops

being there."

Standardized Registration Procedures

Standard registration procedures were described by participants as an essential

step in the process and were deemed as necessary if the database was to maintain the

integrity that was required. A common method of registering an individual or querying an

individual in the database which could be utilized by all regions in the province was

found to be a necessary step in maintaining the accuracy of the registry. Proper names

were important; as one participant described, "I think we've heightened the awareness of the importance of a proper name, a proper address."

The standardization of registration was another substantial change to the usual business processes of the registration staff, but the need for this difficult undertaking was understood as being a necessary hardship. As one participant said: "I think we've all been on the receiving end...here's the solution, make it fit how you're going to work." Similarly another said: "It was no good to clean it up if you were going to go back and make all the same mistakes over again."

Awareness and Realization

As registration staff (both Health Records Directors and front line workers) learned more about the client registry as a provincial entity, they gained an appreciation for the importance of quality control and standards in the registration process. For example, "...we realize the impact that a small change can make....", and they indicated, "...giving the registration staff added value." This follows directly from the previously identified benefit of standardized procedures. It seemed that the registry had created an awareness of the need for quality information at every level.

Despite the technological problems voiced for the active interface, it was stressed by several participants that having the active system made registration personnel able to see the benefit of having access to the demographics. It was explained that some registration personnel were able to realize that there was a "bigger picture" and that they "were now involved with a provincial database" and as a result, were more diligent in ensuring accuracy of data entered into their systems. Awareness seemed to be a key to the buy-in of the new system by front-line workers.

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The focus group discussion provided an opportunity for the participants to take a step back and take a look at what had changed for them and what it had meant for their jobs and business processes. Many health records directors cited that the biggest change was that their involvement in creating the client registry had served to heighten their "awareness of the importance" of the new registry.

Active, Real-time Connectivity

In addition to the benefit of the actual capability of live interaction with the registry, another benefit of this set-up, identified by health records directors, was that it also aided in creating much needed awareness of the provincial picture. For example, one participant said: "Having the active system made you see the benefit of being able to access the demographics from the provincial point of view." A real-time connection enabled stakeholders to get more out of the system and in a more efficient way.

Reporting and Data Linkage

Additional details on the benefits the reports provided were given in the focus group. Several participants stressed the value of the death listing. One individual stated,

"We usually have two benefits from the death listing. One is that it allows us to update our database for any clients who we may have lost touch with…it allows us then to control …inactive files and which ones we take out for storage. The other thing that it does for us is that it…identifies which of these clients will no longer be needing a (long-term care) room."

4.2.3 Interviews
Unique Identification

Duplicate control was thought to contribute to the avoidance of errors and mistaken identity because the registry has one record per person. While some of the participants brought attention to the large number of duplicates in the MCP database, not all felt that the duplicate problem within MCP was as great as it seemed. As one participant said,

> "[the] database was only set up as the means of identifying and paying services for people who were entitled to services. It really was irrelevant...for the past 35 years if you were registered two or three separate times. The idea was that you were entitled to services." (P1)

It was felt by most that the removal of duplicates would benefit the province greatly. The following comment expressed here by an individual involved in the creation of the registry on a high level was typical:

> "...for every illegitimate number that's out there that we can take out of the system, it means that somebody who might have the intent of saying, 'I'm living in Ontario and paying taxes in Ontario and taking advantage of Newfoundland's poverty stricken health care system'...having denied these people that access once, it's a permanent thing." (P3)

According to the interviewees, the main role of the Registry Integrity Unit (RIU) is to:

> "...maintain the database for the client registry and...make sure that the data that we get is the most accurate, up-to-date and current information on each

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client…and then making sure one person has one number throughout the island."

(P10)

Participants discussed the idea that the unique personal identifier would allow for true unique identification of individuals that access the health care system in Newfoundland and Labrador.

Data Quality and Integrity

As was identified previously, the main role of the RIU is to ensure data quality, and this is done in many different ways according to RIU staff. Their primary responsibilities include cleaning, updating and merging data, and also creating reports on the data that is stored in the client registry. One individual expressed "…basically, I check all data that comes in to see if it's correct…" (P5) and "…we clean data to the best of our ability." (P5) Two of the RIU participants identified that cleaning the data is a constant responsibility that involves running algorithms on a computer to determine what data in the systems is duplicate data or potentially duplicate data. This process also involves a substantial amount of time spent in contact between the RIU and the stakeholders; as one participant indicated, "a lot of investigation work" (P10) is often necessary to ensure that the registry houses the most recent and accurate data that exists for a patient. Cleaning the data also involves changing data already in the system, such as changing all initials into the full names, and changing abbreviations, "every time I go and see NF, I put in NL." (P5) One participant noted,

"The protocol says that you can't use nicknames. So everybody agreed…that was a change to registration clerks, who are used to registering if a person comes up and says my name is Suzy, that they would put in Suzy. There was nothing

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wrong with that. But now there's a process that they ask 'what is your name' and if they say 'Suzy', they say 'is that Suzanne or Susan', or something like Mary, and I just go by Suzy. It happens. So we've definitely had a change in business processes. I would say as the client registry evolves we are seeing more changes and the need for more changes…" (P2)

It was important to the interviewed stakeholders who have a vested interest in the accuracy of the data in the registry to maintain these standards in the information that they feed into the system.

Active, Real-time Connectivity

The registry was described as an entity that stakeholders can interact with and query when an active connection is set up. As one participant said,

"It will enable more timely provision of key information to health care providers…Now the beauty of the model allows real-time change of information on the fly. It's not static. So it self-cleanses." (P8)

The active connection was also described as beneficial by another respondent who stated that the active interface "gave them (registration personnel) feedback". (P10) Active and passive connectivity are explored later in this section.

Reporting and Data Linkage

It was noted by some participants that to track usage of health care and to do any data linkage, the registry was an updated and integrated means of doing so. For example:

"…if I understand it correctly, this information could be gathered as statistical information and sharing information…I see that as being positive because while you are gathering valuable statistical information for research and all of that,

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you're not, as I see it anyway, you're not really infringing on anybody's rights or

identifying you with this particular disease…you're just dealing with numbers and

what should be accurate statistical information." (P1)

The data available to researchers would be aggregate data, so confidentiality and privacy

issues would be less of a concern. One participant said that "The existence of this

database will definitely facilitate much better and much more frequent research in the

province down the road." (P3)

Cost-Savings

The actual savings was never discussed in terms of definitive dollar figures, but it

was anticipated by several key informants that the monetary resources that fueled the

registry creation would be recouped within 2-3 years. One participant said:

"We think the savings are bigger than what we initially identified. Savings

initially identified were done on a very conservative basis…this is more of a

hearsay thing – from what we are told, the identified savings are probably double

what we identified to date." (P8)

The business case (Newfoundland and Labrador Centre for Health Information

1998 & 1999) created for this project was considered by those closely involved in the

planning and building of the registry, to be conservative, but very close to the truth.

Savings, in particular, is something that is difficult to measure, which is why there are

differing opinions as to whether the business case was accurate or not. Some of the

interviewees suggested that the actual savings were bigger than potential savings outlined

in the business case. One participant felt that the benefits could not be fully captured, as

the registry did not have the capability of identifying all ineligible claims.

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"I think it was a major success. It was delivered on time. It was delivered on budget. A little disappointing that we couldn't go full gamut and get the full benefits. You know...I think we were trying to avoid the province having to incur costs by issuing a new card..." (P4)

One interviewee ascribed the term "appropriate" (P3) to the business case in lieu of using the term accurate. Though it was felt that the way the registry was developed was valid and realistic, and that the conceptual framework had not changed, there was an acceptance that it might not be possible to give an accurate financial estimate:

"...you never get accuracy in forecasting budgets. You only get accuracy in the actual results. So I think that as time goes on and as the experience dictates, the budget will be refined and...but I think still the global aspect of how it was done is quite valid and it remains so." (P3)

Several participants referred to the issue of former residents of the province returning for a visit and taking advantage of the free care available through the holding of an MCP card. This trend was identified as a problem in that it was estimated that millions of dollars were being paid out by the province each year for services for individuals that no longer reside or pay taxes there. It was pointed out by several participants that this, sometimes unintentional action, was costing the province considerably and the registry has been able to help alleviate the problem. The challenge of addressing this issue was mentioned by one participant:

"The client registry hasn't completely resolved that issue and they may have to look at actually issuing new cards...with expiry dates on them. And the problem is that...other hospitals outside of Newfoundland – in doctors' offices outside

Newfoundland   have no access to our client registry so they take the card in

good faith and they have no way to determine that it's no longer a valid card."

(P4)

In addition, it was identified by one of the interviewees that there has been talk of MCP

cards being sold on the black market to individuals in the United States, who use the

cards to get free health care. This practice was not discussed by other participants during

data collection.

Many of the interviewees noted that it was the financial driver of the quantifiable

savings in out-of-province expenditure on health care services that was the most

important factor in obtaining stakeholder support. One of the participants quoted a figure

of "a minimum of $2 million dollars" (P4) as the approximate annual loss from false out-

of-province claims to the Newfoundland and Labrador Health Care System.

Stakeholders were shown the potential benefits that could result from the client

registry and future projects, and as was discussed by some of the interviewees, it was

possible to bring them onside because the benefits could often be quantified. For

instance, stakeholders "knew how much money they were spending (on out-of-province

claims), but they didn't know if they were spending it inappropriately." (P6)

Another participant referred to the added savings that the Province would see

once the pharmacy, laboratory and diagnostic components are added to the registry

demographic base: "...I think a lot of the cost savings and the financial benefits are going

to be when the clinical components are added on top of it." (P4)

4.3   Challenges of Registry Creation

In addition to the many benefits associated with the registry, participants also identified many challenges that they had to contend with during development and implementation.

4.3.1   Questionnaire
Finding the Resources

Health Records Directors were also asked to determine how much time per week regions spent in contact with the RIU. Table 6 summarizes the results. Four of the respondents' regions were in contact with the RIU on average 0-15 minutes each week, two were in contact an estimated 16-30 minutes per week, and another two were in contact with the RIU between 31 and 45 minutes each week. One Health Record Director indicated that their region was in contact with the RIU between 46-60 minutes per week, and the final two respondents did not provide an answer for this question.

Table 6 Average Time Health Records Directors Spent in Contact with the Registry

Integrity Unit

Time	Frequency	Percent
0-15 Minutes	4	36.4
16-30 Minutes	2	18.2
31-45 Minutes	2	18.2
46-60 Minutes	1	9.1
Missing	2	18.2

Accepting Change

An item on the questionnaire asked whether there were changes to business processes as a result of the data and reports received from the RIU. Apart from the one participant who did not respond to this question, all health records directors indicated that there were indeed changes in business processes in all regions. When asked what specific changes had been made to their business processes, a recurring answer, from 8 of the 11 respondents, was that registration protocols had been altered for a more standard protocol.

4.3.2   Focus Group
Finding the Resources

When discussing the impacts that the client registry had for the participants, one health record director noted that,

"…number one obviously, was the time and resources that we all put into it.

Duplicate patient reports took mega-time resources – money. That was certainly

an impact."

For the health record directors alone, the registry project required a significant amount of time and effort to make the project work. One director noted, "I mean, it was every week for a while that we had conference calls."

Education and Awareness

The importance of education and awareness regarding the client registry and what it meant both for clients and those working with the registry, was discussed. Some participants had been asked by members of the general public to provide them with more information on the registry and what it would mean for them. It was felt that educating

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the public would be a significant and imperative task. One participant emphasized that: "Education will be the key…and I think it's going to have to be handled very well, very diplomatically."

It was agreed by many focus group participants that those in charge of disseminating information to the public, would have to be open and transparent in what details are given and how the registry and EHR are explained. In addition to simply pointing out that this large scale education of the public is necessary, it was also stated that "the public needs to be educated about this before they ever get to that person who is initiating services with them." Health records directors felt that the responsibility of informing the public should not rest on the shoulders of registration clerks or doctors, but that awareness should be ensured much sooner, for all relevant groups, including the public, the stakeholders and the front-line health records and registration workers.

One of the main concerns disclosed was that the general public and health professionals alike did not understand the client registry and its elements. There was the concern that the community was not seeing the benefits and successes of the registry, potentially as a result of lack of interest or awareness in the process and how it would affect them. As one health record director expressed, "…my concern is that people don't know that it's there and what is does."

Technical Problems

Participants identified the existence of a variety of technical issues. One specific challenge discussed was that if an error was made by a registration clerk with passive connectivity and they realized after that they had made the mistake, they would not only have to change it in their own system, but also call the RIU to ensure that it was changed

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in the provincial registry as well. One health record director noted, "…the technical problems did taint the whole thing I think. Yeah, it took…it certainly diminished the usefulness." Another stated,

"Some people had no problems with it. Other people did and you would actually go there and they could recreate the problem for you… I think it certainly would have made a better impression definitely, had it run a lot smoother, having gone that route, once it comes back again, is it going to be more difficult for us because of all these technical problems to sell it again."

Although it was expressed during the focus group that the processes of registration needed to be standardized, and that moving to active mode of data transfer and query would help achieve that, it was also expressed that,

"…we need to ensure before it goes out to the various regions that all the technical bugs are worked through before it's actually implemented in the various sites…most times I'm getting frustration on the part of the staff, which was with respect to all the technical issues…and we did have a lot of technical difficulties."

A few participants were concerned that having to query a larger provincial database would significantly slow things down at the point of registration. In addition, technical problems with the new registry system (e.g., registry not always easy to access, active interface issues) sometimes resulted in sporadic access. This participant described the frustration that most regions had identified, "We've had a nice bit of complications with this system. We're going to upgrade and get a new one, so that's hopefully going to alleviate it."

Under-developed Computer Skills

As an extension to the identified technical issues, feedback received by the health records directors from regional registration clerks indicated that there were varying levels of computer skills amongst front-line workers. Those individuals that had limited computer skills were not as well-equipped as those with higher levels of computer skills, to address issues with the new interfaces that stem from active interaction with the registry. One participant spoke for his colleagues when he said:

> "There were some areas that people found extremely difficult and I would have to say again that most people that found it difficult were people that were not very skilled in PC environments and those that were very comfortable with using a mouse and with PC skills were very keen."

It was not clear how much participants attributed some of the technical difficulty to the fact that not all front-line workers were equally equipped with computer skills. However, it was apparent that along with the newly standardized registration procedures, many of the health record directors felt that standard computer education was essential.

Non-uniformity of Registration Procedures

Historically, the various health regions in Newfoundland and Labrador had different ways of collecting and entering information during registrations. As one participant said: "There's been years and years of different ways of gathering information – not uniform at all. That is a big challenge." The health records directors worked to set up a standard registration system that all registration clerks would use. The challenge that was described by most participants at the time was that data had been "entered in by untrained persons" in the past and that when some registrations were being completed, "a

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lot of information was missing." This inconsistency was an ongoing concern for many of the participants who tried to explain their frustration. One health record director noted,

"Yeah, it's impacted the orientation processes for us. You know, it sort of changed the flow or...some of the significant pieces. I think we've heightened the awareness of the importance of a proper name, a proper address, I mean, name, address, phone number, how mundane can you be...but we realize the impact that a small change can make...and...this really opened the discussion around that but we've got to see they're not taken for granted."

The entries at the time of registration are time/date stamped and the changes made to the file override any previously existing information. So if a representative from one of the stakeholders were to input some updated info for a client/patient and that person was to go to a different health centre to report for care, and the registration clerk did not take the time to fully register the person and enter proper data in all fields, the useful and complete data that was entered by the previous stakeholder would be deleted permanently. This was a consistent challenge identified in our data. One director recalled a key example of this:

"So we were using the mother's first name (field) as next of kin...for whatever reason at the time, when we implemented, that seemed to be the best...Nothing to compare it to and that seemed the best. Why did we want to see the mother's first name for? We didn't want to see it. So, of course, when we went live with the UPI, we had the next of kin there. Everyone else was using for mother's first name. So every time we had a registration and we put it in as "Michael – Father", it went into the system and wiped what everyone else had as Jean as mother's first

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name…we had to change our whole system. We stripped it and took everything out of that field…so now our registration clerks are gone back to square one and have to ask every person that comes in 'what's your mother's first name'."

Human Error

Information is fed into the registry from various sources, and this has been identified as a major concern for some stakeholders, as some interviewees reported that data continues to be entered incorrectly on occasion and human error is still a reality. One individual reported, "I'm not sure at this point in time that all the stakeholders fully appreciate everybody else's role in this." As mentioned previously, any new information entered into the system will replace previous information entered, so if incorrect demographic data is keyed in carelessly at the point of registration, this new, incorrect information, is what others accessing the system will have available to them. Another participant confirmed this concern about accuracy: "Our biggest challenge is getting the stakeholders to take accurate, clean data from the person when they present (for health care)."

Accepting Change

There was an obvious growing realization of just how significantly the business processes of many of the regions, both passive and active, had changed with the awareness of the importance of clean data. One participant said:

"My business processes have really (changed) because we're focusing more now on appropriate registration protocols, which we should've been all along, but we weren't, simply because provincial ones (registries) didn't exist."

Overall, the majority of the participants appeared to have developed an acceptance of the vast changes to the everyday operations and many even seemed to embrace the changes to their business processes as a necessary evil that would see them realize the shared goal of a successful electronic health record.

Privacy and Accountability

Though the majority of the participants did not voice major concerns around privacy with regard to the registry, it became apparent that several individuals seemed apprehensive about having access to so much more information. One participant said: "I have reservations around…all of the privacy issues that are inherent in that." For instance, the fact that all regions receive a death listing of those individuals that had died in the Province over a certain period of time was bothersome to some. As one Director put it:

> "…there are some privacy issues that kind of bother me a little bit around that and…I have a real concern around the death listing because the listing is everybody in the Province. It's not just people that I have records for…I almost feel like, gee, I'm not supposed to have this."

The issue of privacy around death listings (reports) did move the focus group into a discussion around the fact that death notices are regularly published in the newspapers, and that perhaps there would be more issues instead, around the birth listings. In particular, it was briefly discussed that having the ability to access the information on all children in the province may infringe on the privacy of families trying to maintain anonymity in abuse situations, or those trying to protect their identities. Overall, privacy was not a focal point of much discussion amongst the directors and the general picture

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that was portrayed from their standpoint was that pros and cons exist with the client

registry. It was suggested that privacy issues would be less of a concern to the public if

they maintained some control of their own information, or involvement in the control of

their identity and health information. One director commented,

> "...the privacy legislation is going to require people to be informed with what's
>
> going to happen with their information and, obviously, this is one of the things
>
> that's going to happen."

Another director added their opinion that,

> "...I think people would have to have some sense of control or some feeling of
>
> involvement and control – that it is their information and that there may be some
>
> things that they will have to have some choice in because I don't think anybody
>
> will agree to give up total, unrestricted...control of their identity to anybody..."

4.3.3   Interviews
Finding the Resources

Participant accounts in the interviews indicated that a significant amount of time

was spent cleaning the data for the initial registry set-up, which is relevant to the fact that

the efficacy of the client registry depends on the cleanliness or accuracy of the data in the

registry. To avoid the challenge of having to clean the data all at once at the beginning of

a registry project, it was recommended by one participant that jurisdictions should:

> "...clean the data before actually compiling it into one major databank...On the
>
> stakeholder side of it, if they had their data cleaned up, it would help a lot." (P5)

It was stated by another participant that,

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"...three people running the RIU is not enough...I think when this was initially set up, I think it was 7 or 8 employees were recommended to run the RIU...and three were funded by the government...so you definitely have to have adequate staff." (P10)

It was also recommended that as far as an RIU goes, the provision of job-specific training over a period of time would be of value to the project. The RIU staff identified the fact that their role of merging duplicate files would move to overall data quality once the duplicates were down to a small and manageable number.

In addition to the RIU resources required for the registry project, it was felt that the initiative added more human resources challenges to the Medical Care Plan (MCP) staff. For example one participant said:

"...the client registry feeds information to the MCP staff (via duplicate reports) but it doesn't automatically update the MCP database, so then they (MCP staff) have to, it's extra work...so basically they have to try to fit it into their workday."
(P4)

Even before the registry project started, a steering committee and board had to be formed to identify the goals and then guide the roll-out of the project. The NLCHI board was described as being made up of:

"...a great cross-section of people from the private sector and the health care sector and the government. I think, as a group, it brought all these strengths from their various backgrounds to the table...all this voluntary effort was really amazing to watch...people with regular daytime jobs which were pressure jobs...they all stepped up to the plate and did a marvelous job." (P3)

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Overall, the feeling from many participants was that the NLCHI board and steering committees were deemed successful, though it required a lot of planning and dedication from "like-minded" (P3) individuals to serve as a driving force for the registry project. To some interviewees, the biggest challenge was "Getting the money. Getting the go-ahead from government on a timely basis to move forward with it." (P3)

Building Support

According to the participants, it was a challenge to get the client registry beyond the concept stage. However, several of them indicated that they felt confident that with support, consultation, proper direction, credibility and the involvement of a group of like-minded individuals, the concept could be realized. Gaining the much-needed support of the government meant, according to one participant, having to:

"...go through all these hoops to show them each step along the way and it just increases your credibility as you do it...you're building on what you've said to them in the past. You now go and do what you said you'd do." (P3)

Another individual described the need to obtain support:

"There was a groundswell of support for doing a unique identifier from both the research community and the clinical community. The people who needed to be sold on it were the funders because...until we pointed out to them that they were losing millions of dollars in out-of-province claims, they didn't have any motivation to do it." (P6)

By breaking down the project into workable pieces, some interviewees said they felt they were able to illustrate the future health and health system benefits that would be realized, not just the immediate benefits.

The intricate progression of the project involved getting the Department of Health (DOH) on side, given that they were the entity with, as one participant described, "the authority to allocate the funds."(P3) Once the DOH was in full support and the Project Steering Committee had gained the support of the Treasury Board, the project was then brought forth to the Minister of Health for approval. One interview describes how this process was by no means a short and painless one:

"This is over a period of months and, well, a couple of years, really – to educate everybody about what was being done here and to really listen to their point of view and to learn from what they were saying...it was a 2-way street...It was sometimes a very dynamic process that we went through." (P3)

Another interviewee likened the process to "fighting all the way up stream." (P7) However, the general feeling among participants was that the end product of this complex development stage was the strategic piece in building an EHR, an integral first step in identification and linking.

Direction and Guidance

Without a lot of evidential material to provide to the stakeholders and funding bodies, it was reported that the steering committee and NLCHI had to rely mainly on their own research and findings to guide them through each step of the registry project. One interviewee stated:

"...I was responsible for the development of a request for proposal that contained the detailed functional requirements of what our business challenge was essentially...that also included a buy-build analysis. Was there something out

there that we could just buy and put in or is this something that we have to

develop from scratch and maintain after the fact." (P8)

One participant described that the development of the registry involved taking the

concepts and ideas that had been discussed for decades prior and turning them into

reality. One interviewee recalled, "…that was something that had been bandied about for

like…well, at least 20 years in Newfoundland…" (P6) A large part of the effort was

provided without direction from other jurisdictions; as one key individual put it,

"We couldn't go to Finland or Alberta or Florida and say, 'well, show us what

you did'. We said 'we know the slate is clean right across the board'." (P3)

There was a sense of pride among some of the interviewees at having started from scratch

and built something that had such potential to benefit the people of the province of

Newfoundland and Labrador.

Non-uniformity of Registration Procedures

It was noted more than once that health records directors province-wide were key

to making the registry project work,

"They weren't superstars, they weren't the ones up for… Treasury Board, but it

was going to live or die based on whether they did their job in terms of specifying

what needed to change and implementing changes." (P6)

The task of setting up universal registration procedures to be adhered to by all registration

clerks across the province was a substantial challenge that was identified throughout the

data.

Privacy and Accountability

A consistent finding in the data was that privacy was not a big concern at the client registry stage of the project, but that privacy would become more of an obstacle and more of an issue as future components of the EHR, such as the Pharmacy Network and medical information, are added. One of the interviewees noted,

"The design of the client registry is such that it contains little data other than demographics, but most of that is straightforward but...if you really wanted to find out you could probably find out all the information so the privacy issue hasn't been a big concern." (P7)

Similar comments were made by many of the participants. One interviewee noted:

"In terms of the privacy issues for the client registry, I don't really see a whole lot of them with that entity itself. It's what that entity will allow to happen in the future – that's where the privacy concern happens." (P6)

Several of the informants indicated that stakeholders had been assured that the project would not move forward until privacy issues and proper guidelines were taken care of. It was also re-iterated by many of the respondents that the intent going forward was that there would be some "legislation" (P7) or "proper guidelines" (P3) in place to address situations while maintaining the patient's confidentiality and right to privacy. One respondent noted:

"Because you had a unique identifier, you can link records...when we did our cross-province consultation, my God, back in 1998, myself and (two others), we talked to over one thousand people about privacy and so we felt that we had a pretty good understanding about privacy...but for the most part people didn't

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have a lot of privacy concerns as long as…only the people, authorized people, would be able to access your records…" (P6)

Concerned groups that were mentioned during the interviews included those that were "diagnosed with socially undesirable diseases, including serious mental health conditions, AIDS, sexually transmitted diseases" (P6); and reasons for the concern varied. As discussed by one interviewee, some groups of individuals were concerned that insurance companies or potential employers would have access to their information. For example, one interviewee noted that cases were found where an individual suffering with a disease such as AIDS would have two General Practitioners (GP), one who saw them for their disease and another for other, minor ailments, so that when applying for health insurance the individual could get a letter of good health signed from the GP that was not aware that the individual had been diagnosed with AIDS. According to one participant,

"people suffering from chronic illness didn't want to be disadvantaged in terms of having information on their health status accessed by insurance companies or potential employers." (P6)

No details were given as to how common this practice might be. One individual even expressed concern that too much consideration had been given to privacy:

"…we've gone a little bit too far with it being concerned about not violating someone's privacy…and at the same time, that person could for all intents and purposes be abusing our health care system and availing of services they're not entitled to. And it's not so much the services; it's who pays for it. No one is going to be turned away from a hospital, but the right people should be paying…." (P1)

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This comment relates to the determination of eligibility in the MCP.

According to several of the participants, there is a general lack of knowledge amongst the public regarding what information is kept on them in the database, where the information is stored, or their right to access their information themselves. As one participant stated,

"Another privacy issue is that the information is collected without the individual knowing that it's going in this central database that is managed, well, it's owned by the Department of Health and managed by the Centre for Health Information – so they don't know that...you know, they can come and check the information that we hold about them...we're assuming that as the electronic health record is built, people become more aware of the Centre's role in it..." (P9)

Also, some participants noted that clerks at the registration level now have the ability to see information on clients that they do not see in their client base or in their region. Once the information systems are all connected this will likely become a more real issue for many people. However, because standards and best-practices are forced, it is expected of all regions that have access to the registry, to agree to meet a certain "minimum level of standards in regards to how you protect privacy and confidentiality" (P8) as one individual put it. In addition to the existent and continual obligation to protect the public, the need to have consequences for occasions where privacy was breached was also a concept addressed by a few of the participants.

It was indicated by one of the key informants that the UPI/client registry is "on a private network, not just a virtual private network, but an actual private network" (P9) and as a result "there are fewer privacy risks." (P9) Further, it was felt by some

participants that this was the reason that there was not a great push to address privacy for the information that the registry houses. However, it was expressed that as the project moves further, and the registry begins incorporating health, and other information, privacy may become a matter of increasing concern.

The registry will allow for tracking and surveillance of individuals through different information systems, therefore creating the possibility that information that patients would rather not have anyone know, may be available to those with access, for instance researchers or even authorized personnel. Although researchers will never have access to identifiable information, one participant pointed out the fact that because of the small size of the province, "it's not too difficult to try and put things together." (P9) Another interviewee noted,

> "...the biggest issue around privacy is not technological...The biggest problem is the people that we actually give authorized access to. They're our greatest privacy problem or potential privacy problem; and when there are user security leaks and information leaks, it typically comes from within. It doesn't come from people trying to hack into the system. It's usually a problem with somebody that you've given access to that's inappropriate. So it's always a concern. That's why you put in all of these techniques that make your employees aware that you know, we're watching the activities to make sure that their activities are only related to their jobs...the key point there is that we follow present industry practices and standards." (P8)

The sensitivities associated with the information that is accessible in the registry were also discussed briefly. The issue was brought up that although it is just

demographic information available in the registry at this time; data on the health care institutions that patients present to for care is recorded. As was described by one respondent, this could be especially worrisome for patients that have been to addictions treatment centres or other such specific health care facilities. However, the consistent finding among participants was that the registry is "demographic in nature, it didn't have the same sensitivity as personal health information." (P8)

With regard to the fact that registration personnel are able to see information on patients that are not in their own region or client base, a participant noted,

"We developed memorandums of understanding so that we force national standards and best practices for the protection of privacy through our MOU. So, in other words, in order to play ball with the client registry in another region, they have to agree to meeting a certain minimum level of standards in regards to how you protect privacy and confidentiality." (P8)

In addition to asking the interviewees what they thought the implications of the client registry would be, they were asked whether they felt the registry would be able to aid in accountability – or measuring results or efficiency. The general response to this was that by itself, the registry would not really aid in accountability. Participants stated that the registry would save the Province money and it would require that information be maintained accurately, but "where it's really going to impact on accountability is it's going to allow other things to be built on top of this...." (P6) One interviewee noted that the registry would, however, aid in accountability reporting by providing control and tracking of access to health records.

4.4   Opinions and Experiences

The data collected from the different sources contained varying opinions based on the specific experiences that the participants had with the registry creation and maintenance.

4.4.1   Questionnaire

This method of data collection did not specifically address the opinions and experiences of those involved with the registry, but one question asked to the health record directors, was whether they felt that the registry provided them with useful information. Only one respondent (9.1%) did not feel that the information the registry now provided them was useful. All other participants felt strongly that the information the registry could provide was useful.

4.4.2   Focus Group

It was clear from discussions amongst the participants that they felt the direction that was taken in regards to their involvement in the building of the registry was the right direction. As one participant commented,

"…we knew what was going on. Our opinions were sought and we had lots of

opportunity to work through and come to a consensus on a lot of issues."

With regard to having an active interface with the client registry, another director noted:

"I think it will in the long haul be very beneficial and I think it will help

standardize our process and I think, presumably, the argument is going to be to set

a daily input and so on. I'm anticipating…not so much of a learning curve but an

acceptance curve, I guess you could say."

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Several focus group participants voiced opinions on what their experience had been in having access to extra information than they were used to. The registry reports provided access to more complete and provincial data sets, and some of the health record directors did not want to have access to information on patients that were not in their health region. Participants' comments included, "…it's a real benefit getting it but still I have this little bit of ambivalence around getting it."

Several of the directors also discussed their opinion around education and awareness of the registry. One director stated,

"I don't think there's been very much public awareness or education around this initiative…and by and large, Joe Blow doesn't have a clue about this, you know."

Another director added to this by noting that,

"…the privacy legislation is going to require people be informed with what's going to happen with their information…"

During a discussion on how data quality has changed, one director made the following comment, which was followed by agreement from many of the other directors:

"I sometimes think about…that most of us have had clients about 10 years…and considering the volume of work and things that have gone into addressing some of the issues that have been raised in this type of initiative (the client registry) – and that occurs – what will the state of your system in 15 year be?"

4.4.3 Interview

The general impression was that, despite the challenges, records staff liked the new system. One participant reported:

"…what I hear through the grapevine is that people like the system. They find it

to be user friendly and it meets the expectations of a variety of users, including

the health records people…." (P6)

It was felt that staff would benefit from the registry as it would provide up-to-date

information and,

"…allow for more systematic and consistent extraction of information from the

health records, because it will allow you to link information and extract

information in a more consistent format." (P6)

Given that the interviewees had different levels of experience, a number of

different expectations were disclosed. The UPI/client registry was expected to serve as a

"virtual health enterprise" (P8), which "saved the Province money" (P6) and which

would provide updated health information. Further, there was a big expectation that with

the creation of NLCHI it would become the hub of activity for the ultimate creation of the

registry, as a first of its kind in Canada. The registry was said to have,

"…brought together a group of like-minded people…to do things that a lot of

people believe in but had not been able to articulate in the past." (P3)

In addition to being the first of its kind, the underlying expectation of the registry was to

serve as an effective core building block for an electronic health record for the province.

One participant said:

"After many government studies, many committees, the work of many, many

people, it was agreed there needed to be a better way to uniquely identify each

individual in the province." (P2)

It was briefly addressed by three of the interviewees that economic benefits, including job opportunities, may be expected in the future. This interviewee talked about the potential future economic gains,

> "Well, see, there's many ways to look at a benefit and so from economic gain they are looking for not just dollar savings but…changes in the way the things work that result in a job…so it's not an exact…direct relationship; but if you can lay off staff, if you can reduce sick time, if you can reduce length of stay, if you can reduce overtime expenditures – these are direct costs that accrue to the government or government agencies like health boards…Those are the kinds of economic gains they're looking at." (P6)

At the time of the interviews, it was unclear whether these expectations would be met.

> "So the key with the economic gain is to know whose perspective you're looking at it from…society can find all kinds of economic gains but government will be much more interested now…" (P6)

Another interviewee adds to this concept with the comment,

> "We also talk about potential for creating new jobs. I'm not sure that we've really seen that yet, but we're still early in this." (P9)

As one participant expressed,

> "Oh, economic benefits, certainly…We're leveraging a first move with a technology project…That's the biggest part of it – that we brought millions of dollars…We were able to bring money into the province that otherwise would not have been." (P8)

In order for the project to get off the ground, government support was necessary. All participants were asked why they felt the government supported the creation of the client registry, which resulted in an array of opinions. According to several of the participants, the project had the "potential for controlling expenditures from out-of-province payments for health services" (P9), which would save the province a considerable amount of money each year. In addition to the potential millions of dollars that could be saved, there was support for the concept of a unique identifier and the expected benefits it would provide for the clinical and research communities and, of course, the patient.

4.5   Unique Personal Identifier/Client Registry as EHR Foundation

4.5.1   Questionnaire

Table 7 shows that over 80% of the directors strongly agreed that the UPI is "an effective building block for an Electronic Health Record." In addition, the remaining respondents agreed, though not strongly, that the UPI was an effective building block. No one disagreed with this statement.

Table 7 UPI is an Effective Building Block for an Electronic Health Record

(Scale of 1-9, 1 Being Strongly Disagree, 9 Being Strongly Agree)

Level of Agreement	Frequency	Percent
1 – 6	0	0
7	2	18.2
8	1	9.1
9	8	72.7

Table 8 UPI/CR is an Effective Building Block for an Electronic Health Record

(Scale of 1-9, 1 Being Strongly Disagree, 9 Being Strongly Agree)

Level of Agreement	Frequency	Percent
1 – 2	0	0
3	1	9.1
4 – 6	0	0
7	1	9.1
8	3	27.3
9	6	54.5

When asked whether the UPI/Client Registry was an effective building block, the Directors responses differed slightly from their feelings on the UPI without the client registry. The majority of the respondents still felt (strongly agreed or agreed) that the UPI/Client Registry was an effective building block, but as Table 8 illustrates, one of the respondents disagreed.

4.5.2   Focus Group

The health record directors provided substantial data on the Unique Personal Identifier. Comments included:

"Well, without having a UPI, a unique personal identifier, for each person in the province, how else would you begin to like, link the information that you have."

And,

"I would think and I would hope that eventually the goal would be that the whole province would, you know, be just using that one identifier and I'm assuming that's the goal."

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One director also noted,

> "…if you're looking at provincial networks, how else are you going to communicate back and forth without the UPI."

When discussing the "bigger picture" of an Electronic Health Record, one director identified the need to have a "strong" foundation, referring to the UPI/CR they had helped create.

4.5.3 Interviews

Participants discussed how the UPI/client registry functions and provided a variety of different view points. The UPI essentially became an index of all numbers associated with an individual given to them upon receiving patient care. One of the RIU staff that was interviewed described this process:

> "Also, if a client is seen throughout the island at different institutions, it's our responsibility to try to match and put them all under one UPI, which is a unique personal identifier. So basically, that's what we're doing. It's data quality, and then making sure one person has one number throughout the island." (P10)

The registry will keep track of these numbers along with demographic data. Another participant went on to note,

> "The benefit is not to me, it is to the health system in having uniquely identified each person once and not having conflicting, multiple, information on everybody. So the prime benefit is to the stakeholder system and obviously in the bigger picture that allows the development of the electronic health network." (P2)

The option of using the MCP number as the unique number system for identification purposes was addressed by three of the interviewees. One participant described their view on this:

"My thoughts I guess...going to use MCP but then decided not to...the UPI number, as I understand it, is going to be used to keep everything tied to that person...so if I present to you in a hospital and you have my name and MCP number you should probably find me...So I guess I'm just kind of thinking, why didn't they use the MCP number instead of a UPI number. There's a very good chance that you have the right number in the registry...Yeah there were duplicates in the system but I think there's a lot of people who have come to realize they weren't duplicates in the sense that some people thought there were...the other reason that I could understand more was not everybody, not all users of health care would have an MCP number." (P1)

Other interviewees deemed the MCP number inappropriate.

"...those that had concerns with MCP did not take into account that MCP is only for those who are covered by insured services and there are many people in this province who are not." (P2)

The goal was to create a database with a link to other systems, and the decision to use the shadow number that connected all available information was considered the best alternative and was also, as one participant put it "considered the least expensive." (P3) As described above, an apparent factor in not having used the MCP number as the unique identifier was the fact that not all users of health care in the Province possess an MCP number; thereby making it ineffectual for use as a catchall for residents of the Province.

Yet another interviewee commented that the MCP was "not a very private number" (P9). They went on to say, "…the MCP is a horrible number because it gets your gender, your year of birth and the first three initials of your last name". (P9)

The few interviewees that did comment on why the MCP number was not used as the unique identifier provided a strong rationale for this. One individual noted that it was clear that those people involved in standards "didn't look at the UPI as an automation of their existing practice. They used it as a driver to change their work patterns and work problems." (P6)

The idea of implementing a UPI/CR as the base of an EHR was addressed by many of the participants. One interviewee stated that the UPI/CR project,

"was a project that we feel was…an early success, which is important for sustainability in an organization, and it was something that everybody had to work on because it had implications for standards; it had implications for privacy; it had implications for the kinds of product report that could be done, and you couldn't build an EHR without it." (P6)

The same participant went on to describe the client registry:

"…I think that major implications are that it really was a building block…it's going to be a foundation around which…the EHR succeeds…" (P6)

Another interviewee stated:

"…the biggest implication of the client registry is that it takes you to the next step of the strategic information mapping in a virtual health enterprise environment."

(P8)

4.6   Passive and Active Systems

Participants provide information on the differing experiences between the passive-connectivity regions and the active-connectivity regions in the province.

4.6.1   Questionnaire

Only three of the eleven participants (27.3%) worked in an active region at the time. The majority of questions in the questionnaire were answered by the majority of participants, indicating that their experience with either the passive or active interface did not impede their ability to provide a response. When asked whether they were capable of providing feedback for the current evaluation, 100% respondents strongly agreed that they were capable.

4.6.2   Focus Group

As expected, differing issues were identified by those participants working in passive or active regions of the province. The pilot project (active interface with the client registry) had to be rolled out in only a limited number of regions to iron out any kinks, and this difference in experience with the registry led to disparate opinions in many cases. Those that worked in regions where the active, real-time version was introduced as a pilot test had to tolerate glitches and a significant disruption to normal daily business processes, and battle a learning curve. One participant said in response to the notion of implementing an active interface in their region:

"I have really mixed feelings about whether or not I'd want it (active interface) based on, you know, past experience and just in-house kind of issues as well."

It was clear that there was a desire to have the benefit that the active interface could bring, but there was also clear trepidation at the hardships that come along with the changes and forced data integrity issues.

One of the secondary objectives of this study is to compare active and passive systems used in the health centers of Newfoundland and Labrador. Content areas and questions presented to focus group participants elicited some very in depth discussions on the benefits and challenges associated with both the passive and active systems based on differing experiences.

For those participants working in passive regions, a recurring comment voiced was that it was difficult for registration personnel to see the immediate impact of the information they logged into the system because the feedback was not live or instantaneous. Also, these personnel were not as informed on the UPI. As one Health Records Director noted,

> "...those that were using active mode are very well-versed in what it (the UPI/client registry) is...whereas all of the other people in passive have no idea – the front line person still has no real concept of what's going on and how it will work."

Participants identified that increasing the level of awareness for all workers in the health records field was considered necessary to maintain a successful registry.

The technical problems were worrisome to individuals using both the active or passive interface. Apparently there was a noted decrease in the use of the active system due to frustrations with technical problems. One director from an active region described instances where if a registration clerk was working on an active interface with the client

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registry and "their screen blacked or their field was gone, that was it – they gave up on it."

For some participants, the apparent benefit from going live with active interfaces with only two regions at first meant that not everyone had to "contend with it and work through it and deal with it." Some participants mentioned that all regions would benefit as a result of the hardship placed on a small number of pilot regions in the province and all would ultimately strive for interactivity and ultimately active/real-time capacity is the "gold standard" for them all.

4.6.3 Interviews

Three of the interviewees provided comments on active and passive operations. The RIU actively receives messages from the client registry called cloverleaf messages (a warning message that indicates there is an error detected in an individuals file). According to one participant, "Every time anyone is checked in and something differs, then they send me a message." (P5) This process apparently occurs "...actively, like there's passive and active. Well, this is actively." (P5) According to the same participant, the cloverleaf message is "a flag saying something is not quite right." (P5) This information indicates that the RIU would be notified immediately if a potential error is suspected during a registration at one of the health care facilities.

In addition, one of the interviewees discussed the existing stage that the registry was operating at.

"We have an operational client registry receiving passively transactions from all of our major stakeholder groups...Institutional, Health and Community Services, and MCP. We are testing the software for the next version and so we are in the

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throes of changing from one product to another. It is important to note we are

not talking about changing the concept or what information, rather the

technology, and with the new technology then will come the transfer back from

the client registry back to the stakeholder systems, in either an active or a passive

mode…" (P2)

The individual went on to say that passive refers to:

"…information that is being sent in the background by the computer system to the

UPI/client registry. The registration clerks do not see a difference, the persons

doing registration in Health and Community Services don't see any difference."

(P2)

Apparently not even all individuals directly involved with the registry were able

to understand all of the concepts involved. One interview participant indicated that "we

never did get active and passive." (P10)

4.7 Staff and Resources

Participants provided information on the people and financial resources that are

required for a registry creation project. Finding adequate resources was one of the major

challenges identified in an earlier section of this paper, and will be re-iterated here.

4.7.1 Questionnaire

Table 6, presented earlier in the findings, indicated the amount of time that the

Health Record Directors spent in contact with the Registry Integrity Unit to work out data

issues and possible errors in the client registry. Of the nine Directors that answered this

question, five were in contact 16 minutes or more per week. The other four respondents

indicated they were in contact 15 minutes or less each week.

4.7.2 Focus Group

Participants discussed the time spent developing the registry components, where there were "weekly conference calls" among Standards and Records Directors, as well as the time the RIU, MCP and various regions spent dealing with the duplicate records within the province; "Duplicate patient reports took mega-time resources."

4.7.3 Interviews

The interviewees noted that before the registry was operational there was a requirement for time resources from a considerable number of people. Volunteer positions on the NLCHI board and the project steering committee involved countless hours of time, one participant indicated that these individuals "stepped up to the plate and did a marvelous job." (P3) Also, the same participant commented that the voluntary involvement at this level was "really amazing to watch...Dedicated, like-minded...were willing ...lunchtime meetings...weekends...." (P3)

One participant indicated that given the changing nature of the client registry, the task of cleaning data would always exist;

"Its data and it's like an identity it's always changing, so our job is always to keep

it up-to-date and always keep it complete and always keep it accurate." (P10)

Several of the interviewees noted that the registry is an entity that will require continual maintenance for effective functioning. Also, participants indicated the need to find the resources to pay for sufficient RIU staff to clean and monitor the data in the registry. As was described in the challenges section, one participant identified that,

"...three people running the RIU is not enough...I think when this was initially

set up, I think it was 7 or 8 employees were recommended to run the RIU...and

three were funded by the government...so you definitely have to have adequate staff." (P10)

As described previously in the findings, participants indicated that securing the money for the registry project was one of the largest hurdles. This includes money to pay for development and for staff to implement the infrastructure. An interviewee involved with the registry during the planning stage was able to describe the initial process of acquiring the financial support of the government:

"We're not like Alberta or Ontario where they can just say, look, here's 200 million dollars; now go and do something with it. In our case, it's the exact reverse. We had to come up with the concept, flesh it out at a high level and then go to the government and say, '...here's what we think you want'. Then they'll send us back and say...take this further and do more analysis on it and come back to us and say '...give us a more definitive number, give us more information on what you can get out of this particular effort and so on and then we'll consider getting you funded or not'. So it's a very painful process for us or was, and I'm sure it still is - to go forward and convince government that this is a very good, sound investment." (P3)

Obtaining the money to move forward with the project was a challenge that several of the participants re-iterated.

Chapter 5
Discussion

The process of building the UPI/client registry was a complex one that involved the coordination of many individuals and groups. The data collected provided a glimpse into the history and progression of the registry, and because of the diversity of the individuals interviewed, a wide and comprehensive view is presented here. Changes that needed to occur within the existing health information systems were specified, and then these changes were implemented through the teamwork of the Health Information Network Team at NLCHI, the Health Boards, the provincial government, the RIU and other individuals and groups across the Province of Newfoundland and Labrador.

Health information systems will inherently face challenges, as has been explored in the current study and in the literature discussed. The data collected has illustrated the need for a common effort by all parties involved in the systems and their outcomes. As was discussed by Kuhn and Guise (2001), this common effort is needed to improve, implement, and evaluate the necessary concepts. The Health System Information Task Force (1995) demonstrated the need for strategic development of a client registry, and acted as a guiding force. The findings demonstrate that despite the challenges that are to be contended with in a project such as a provincial client registry, the benefits that the registry can provide, and the further implications of the registry as the foundation of an EHR, far outweigh the challenges in significance.

The chain of events leading up to the creation of the client registry is complex and some important milestones identified by participants are depicted in Figure 4. These identifiable events and benchmarks are likely to be similar for other jurisdictions undertaking the same path to implement EHR components.

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Figure 4. Planning and Development Process for the Creation of the Client Registry

5.1 Main Findings

The main findings are described with reference to the primary and secondary aims of the study.

5.1.1 Primary findings

a) Perceived benefits of the client registry;

Information provided by the participants identified the major benefits of the client registry as perceived from varying roles and involvement in the process. The benefits that were identified in all sources of data include the ability to uniquely identify patients and the ability of the registry to act as the core of a larger system that would allow for data linkage. Participants also indicated that an active, real-time connection to the registry, and the high level of data quality and integrity that the registry has achieved, are

key benefits. The health records directors from across Newfoundland and Labrador reported being able to standardize registration procedures and data fields, which allowed for a realization of the importance of this process and the people that drive it, which ultimately resulted in an awareness of the need for universal standards. In addition, participants identified the ability to access data reports through the registry, such as death and duplicate reports, to aid in day-to-day work processes of health record management. It was also reported that with the client registry, the province has seen and will continue to see cost-savings as a result of the enhanced ability to monitor out-of-province claims.

   b) Perceived challenges during the creation and maintenance of the client
      registry;

Numerous challenges were met with during the process of creating the registry and participants noted additional challenges that continue to exist with the on-going maintenance of the registry. Suggestions to avoid similar problems/challenges are also presented here.

A major challenge that was identified in all sources of data collection was the ability to find the human and money resources to complete the project; this is discussed further in a later section that addresses the specific objective of staff and resources. Participants also identified that they had to contend with technical issues, and at the same time it was reported that some of these technical issues may have stemmed from under-developed computer skills among the front line staff. Proper training and upgrading of staff prior to the roll out of the client registry would have saved the registration personnel frustration and grief and would have made trouble-shooting much easier when the actual software issues arose. Human error was also identified as a challenge and participants

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indicated that training, support and continual quality control by health records workers and health records directors could alleviate some of the data integrity issues associated with human error.

At the same time, individuals had to learn to accept the changes in work processes, as registration procedures had to be standardized across the entire province. Setting standards across multiple jurisdictions is an enormous task and the more disparate the legacy systems are between jurisdictions, the more time, human and financial resources it will take to achieve regional or national standards. It would greatly benefit provinces, territories, regions and nations, to think on a larger scale when linking systems so that components and systems that are developed are developed with interoperability in mind, as in the approach of Canada Health Infoway.

Participants discussed responsibility for educating the public and health professionals on the purpose and function of the registry, and it was clear that the challenge would be to provide this education to individuals prior to the point of registration. The challenge of education and the challenge of accepting change can be addressed in much the same way, with the continual transfer of knowledge. An individual will be more receptive to change if they are kept informed on the steps of the project as well as being reminded of how their role impacts the process. As well, at the time of the study, it was felt that there was not a sufficient level of awareness in the general public that the registry even existed, let alone the implications that are inherent in it. Every individual that receives health care is a stakeholder in the client registry project and in the EHR, and should be kept informed with pamphlets, public service announcements, television and radio advertisements, and mail outs.

Participants reported that the registry project team had the ultimate task of building support for this project with little direction and guidance from other jurisdictions, all the while contending with natural skepticism and the need to address patients' privacy. It is likely that it would have been significantly more challenging for the registry team to build support among the stakeholders in the first half of this decade than it would be today. There is now more widespread knowledge on the EHR and its components, and there is more readily available tool kits and opportunity for interoperability of EHR components than there was just five or six years ago. The option exists these days to learn from the valuable lessons that other jurisdictions have unearthed in pioneering the client registry as the centre of an EHR.

The need to safeguard patients' privacy will be an ongoing challenge in any EHR initiative, and should be addressed well in advance of registry implementation, as was done in NL. At the client registry stage, the primary challenge will be to develop and uphold a high level of accountability among the stakeholders that have access to the patients' demographic information.

c) Opinions and experiences with the registry;

Throughout the interviews participants freely offered their opinions of the registry itself and the process of creating it, as well as thoughts and ideas on the involvement that they and their colleagues had in the project. Opinions ranged from positive to negative. Participants described the processes as both painful and fulfilling, and a consistent finding was that their opinions were sought by those leading the registry implementation and they were able to work together to consensus on pending issues.

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The perceptions of the processes involved in the registry project may have been somewhat varied, but some very pertinent points were raised by participants. It was felt very strongly by some of the participants that there should have been more people hired to work at the RIU as dedicated staff, however, the resource of time became impeded by the resource of money in this case. In addition, there were varying opinions on how to prevent former residents (and holders of an MCP health card) from abusing the free health care provided by the Province.

The overall experience of being a part of the creation of the registry ranged from pride to satisfaction. A common theme in the findings was that when participants were speaking of their experiences, there was often a realization of the larger picture and an awareness of the need for quality information at every level. Participants often described the teamwork that went into the successful completion of the primary EHR element. Those stakeholders who had not yet reaped the benefits of the registry were anxious to get involved in the process.

d) Unique Personal Identifier/Client Registry as a base for an EHR:

The participants agreed that the unique personal identifier used was indeed an effective base for the registry to be built upon. Not all participants agreed that using the MCP database of healthcare users was the most effective way to create the unique identifier, however, it was deemed by most to be the best choice. The new unique number associated with every individual health user in the province allowed the demographic information for each individual to be tied to their number. The UPI number is essential in the functioning of the UPI/client registry and the number helps to maintain the integrity of the registry, which is critical to its operation and existence.

Findings suggest that a UPI based client registry was deemed a successful foundation for an Electronic Health Record. Numerous benefits and challenges were identified across data sources; however it was apparent from the participants' accounts, that the end result was an operational system that would enable a patient record to be accessed electronically across the health care continuum within the next five years.

5.1.2 Secondary findings
a) Experience with passive and active systems;

Very different experiences were described by people working in passive and active systems. Those that worked in regions where the active interface to the registry was being piloted indicated significantly more disruption to daily business processes. There was a definite learning curve in place for those in the active region, and in turn, these individuals were well versed in the process of the registry and use of the active interface. On the other hand, individuals in the majority of the regions were still operating with a passive connection to the registry. This lack of real-time connectivity for registration and health records workers meant that those in the passive regions could not see the immediate impact of their registration procedures and they tended to have a low level of awareness of the registry and its functionality. It would seem that registration clerks and health records workers in all regions should be educated on the registry and its functionality to achieve awareness and buy-in to the larger picture.

b) Staff and resources

Participants noted that only about half of the number of staff was hired to manage the RIU than were originally required and it was noted that the cleaning and updating of data would remain an ongoing cycle to maintain an accurate and reliable client registry.

There appeared to be a disconnect between the monetary resources available and the need to have more human resource available to manage the registry. It was noted by some participants that the process of cleaning up the duplicate records in the MCP database to build a reliable registry could have been accomplished in a more timely and efficient manner if the additional staff had been provided. This demonstrates the importance of the connection between funding and timelines. Perhaps more importantly, it emphasizes the need to adequately address each step of the process in developing a client registry so that the problems and delays caused by an early step such as cleaning the data is not negatively impacting progress and future capabilities.

Once the registry was up and running it was apparent that the resulting savings (financial and time) to stakeholders would be significant. When discussing the process of the UPI/client registry, many of the interviewees noted the quality working relationship between NLCHI, stakeholders, the RIU, and others involved in planning for and maintaining the client registry. It was reported that there was an impressive level of support from CEOs of health boards, health records directors, clinical and research communities, and many others. Some provided support while others became advocates.

Initially, integrating the data resulted in problems with non-uniform standards and duplicate patient records. The new registry system meant new computer programs that registration clerks had to become familiar with, and the findings identify that human-computer interaction can pose problems for efficiency and quality. In addition to these challenges, those individuals involved directly in the registration process and with health records experienced a noted change in the overall day-to-day work processes, in some cases seeming to place a strain on the available resources.

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5.2 Relating the Findings to Other Research

Searches for similar studies or research that looked specifically at the same objectives were limited.

As Heathfield and Pitty (1998), Littlejohns et al. (2003), and other authors have noted, and as has been demonstrated in the current study, the concept of review or evaluation is a fundamentally important part of the process of moving forward with current health information systems. As was discussed earlier, suggestions from representatives of the Atlantic Provinces on how to build momentum and establish a solid foundation (Canada Health Infoway, 2002) included keeping focused on one-person/one-record and building awareness and knowledge. The findings demonstrate that the registry project team was guided by similar processes.

The current study identified many benefits that are associated with a client registry, many of which were previously identified in the Benefits Driven Business Case (Newfoundland and Labrador Centre for Health Information, 1998). For instance, the registry forced a much needed standardization of data entry, allowing for increased accuracy and reliability. The lack of standards that exist in many jurisdictions is a problem (Alvarez & Zelmer, 1998) and seeing the larger picture through the creation of a client registry allows for this problem to be addressed. Further to this, the implications of the client registry, with quality, accurate data, is seen as a priority as much as a perceived benefit. The importance of the integrity of patient indexes such as the Newfoundland and Labrador client registry was also explored in Moczygemba & Biedermann (2000).

Although it has been stated that organizations should not expect to see immediate savings on investments into the elements of an electronic health record (Protti & Catz,

2002), the findings indicated that the government of Newfoundland and Labrador saw approximated savings of at least two million dollars during the first three years after the client registry was implemented. Such tangible findings as these are necessary to report, as it is important to government, funding agencies and stakeholders to achieve economic gain from the client registry project and ultimately the EHR to follow. A separate evaluation of the updated, Infoway-funded client registry in Newfoundland and Labrador, which was undertaken jointly by NLCHI, Memorial University of Newfoundland and Canada Health Infoway (Neville, Gates and MacDonald, 2005), estimated that a lost revenue of $3.95 million across all Newfoundland and Labrador health Boards in 2000 could be attributed to the non-existence of a client registry. The authors went on to estimate that, based on the lost revenue calculations, the costs for the implementation of the registry could be recouped in less than 2 ½ years.

Challenges that were encountered while developing and implementing the primary component of the EHR are clearly not unique to the Newfoundland and Labrador registry project. When identifying the biggest challenges in creating and maintaining a master patient index or client registry, individuals in different jurisdictions will respond based on their own experiences. For example, the Director of Health Information Management at Bryan LGH Medical Centre in Lincoln, Nevada in the United States, said that the biggest challenge was getting "ancillary departments and registration to understand the importance of a clean MPI (Master Patient Index) and then to ultimately hold them accountable for their performance" (Squazzo, 2003). Squazzo also notes that a Michigan MPI manager felt the greatest challenge they were faced with was the merging

of records and identifying duplicates in the system. These are all challenges that have been identified in the current findings.

A white paper by Sierra Systems identified numerous factors that affect the success of achieving an EHR as lessons learned from Canada (Gray & Pattison, 2006). Many of the success factors identified by the authors are in line with challenges identified in the current findings, namely, funding, standards and privacy. Other success factors identified were governance, which is comparable to Guidance and Direction in the current findings, and clinical will/adoption, which is comparable to both building support and accepting change in the current findings.

Best practice guidelines similar in scope to BOB, the "Best-of-Breed" re-usable registry, have also been addressed in Southern Australia. In 1999 an information management team came together to work towards continuity and best practice guidelines for healthcare registration. The end result of their goal to assess the best possible solutions to uniquely identify patients, a document titled *Best practice guidelines for patient master index maintenance* was formed (Walker, 1999). These guidelines include such fundamentals as definitions of the key patient identification elements, as well as guidelines for collecting and recording data. As in the best practices put forth in BOB, the teams involved had to identify and examine each of the key data fields and discuss the relevant and respective maintenance processes. Participants in the current study, particularly the health record directors, discussed a similar approach in identifying the key elements for the client registry.

The Computer-based Patient Record Institute (CPRI) put out a paper in 1996 detailing recommendations for adopting a unique health identifier (UHI), (Computer-

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based Patient Record Institute, 1996). Some of the suggestions were similar to the recommendations brought forth by the participants in the current study. CPRI's recommendations included the following:

- Enact legislation to fund and task the Social Services Administration to a check digit to the Social Security Number (SSN) and modify the process of issuing SSNs so that it may be used as the unique health identifier;

- Enact federal preemptive legislation to provide uniform protection of the confidentiality of health information;

- Develop and promote a public education program outlining the importance of a unique health identifier and describing how access to individually identifiable health information will be protected and controlled.

Current findings corroborate these recommendations.

Canada Health Infoway (2005) refers to the client registry as a functional component of an EHR, and discusses both quantitative and qualitative benefits associated with an EHR. The study states that "Registries allow the identification and grouping of people and places. These can be thought of as the 'white pages' for care facilities, care providers and patients." Other studies have indicated that a database such as the client registry would provide an accurate and successful base for further EHR components (ie., Freriks, 2000; Robbins, 1999; Western Health Information Collaborative, 2002). *The UPI Scope* (Newfoundland and Labrador Centre for Health Information, 2000) proposed that the UPI/CR would be able to provide a solid foundation for future components of an EHR, and the current findings corroborate this.

5.3   Limitations of the Study

During the completion of this study, numerous challenges were encountered. Initially, it was difficult to narrow down the focus of the study, as the subject is so expansive. Refining the search for literature specifically relevant to the client registry was difficult, and the literature available did not provide commentary on a study or evaluation with all of the elements of the current study. Much of the literature that was found and utilized was 'grey' literature, as the majority of the research was found in published reports from various nations, as opposed to journal articles. The ability to find literature pertinent not only to the EHR but also to the client registry as a primary component, proved to be one of the greatest challenges. However, as discussed by Spencer (2003), it may be more important for some studies to provide a detailed account of outcomes in lieu of a thorough literature review.

Once the focus of the research was determined, there was concern with the original number of participants that were to be part of the study, and the quantity of information that would result. It was at this point that additional key informant interviews were added to the sample. Although the small number of participants in this study was originally a concern and a challenge, it was organized so that the participants involved represent the majority of the individuals and groups of individuals that were responsible for the development, implementation and maintenance of the client registry in Newfoundland and Labrador. It is also important to note that given the busy schedules of the participants, data collection could not be done within a short timeframe, and in fact, took place over a five month period.

In addition, the current study has demonstrated the intensely time-consuming and demanding nature of the process of qualitative research and analysis. Mays and Pope (1995) discuss the problem of the large volume of data involved in qualitative research. It was a challenge to summarize the findings when presented with the vast amounts of data provided in the interviews and focus group, however, thematic analysis was used to categorize and prioritize the qualitative feedback received.

5.4   Suggestions for Further Research

A considerable amount of effort went into ensuring that the data collected was accurate and it was reviewed in great detail. The use of triangulation in the current methodology is considered a form of rigour (Lacey, 2001). As well, the current design and interpretation were systematic in nature. In future research, however, it would be beneficial to do a similar study when all upgrades to the Newfoundland and Labrador registry are complete. Additional processes that could be utilized to improve upon and demonstrate future rigour include but are not limited to, a) use of less systematic sampling, and b) use of computer software to facilitate analysis of data content (Mays & Pope, 1995).

It would also be worthwhile to have the participants complete new questionnaires similar to those used in the current study once each of the main components of the electronic health record are in place. This could be done upon completion of each new element (e.g., the pharmacy network, diagnostic service history, etc.) to provide a picture of perceived benefits and challenges along the way. Data collected could be useful in gauging satisfaction of the new system components and the degree to which they affect the roles and responsibilities of registration and health records personnel. It would be

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especially worthwhile to include participants from the front-line, such as health records workers and registration personnel, as their direct opinions and comments are not discussed in the current study.

A study with clear objectives of comparison and evaluation in mind would be of immense value as it would follow the progress of the EHR in Newfoundland and Labrador and eventually compare this system with similar systems in jurisdictions such as Australia and the UK. The importance of employing pre- and post- methodological design is explored by various authors in the literature reviewed (Gamm, Barsukiewicz, Dansky & Vasey, 1998; Welychka, 1997). An important future evaluation would be one that examines the affect that the registry and other EHR components will have on patient safety.

An issue that has not been widely addressed in EHR literature is that many Canadians receive alternate or complementary care, and this information would also be relevant in the prevention of adverse events such as drug interactions. As discussed in National Electronic Health Records Taskforce (2000), backgrounds of health consumers are varied, and for an EHR to be truly complete, alternate and complementary healthcare must be incorporated. It would benefit the EHR process to have future studies address the role that alternative healthcare will play in a comprehensive electronic health record. It is not apparent given the existing literature whether alternative medicine practitioners have moved toward establishing a client/patient registry with a repository of alternative care details, that can be linked in the future to an EHR.

5.5   General Discussion

The key informant interviews provided a broad data set that addressed the objectives of this study. As well, the use of the focus group with the Health Records Directors facilitated interaction between the participants, which in turn produced elaborate and enhanced data to complement the questionnaires. The integration of qualitative and quantitative components allowed more in-depth and comprehensive data to be collected. Other authors have utilized the similar positive integration of qualitative and quantitative methodologies (e.g., Van der Meijden et al., 2003). The commonality between the participants in the focus group was their shared involvement in the building of the Newfoundland and Labrador UPI and client registry and this shared goal sparked the discussions that ensued. This choice of methodology allowed for a better understanding of the participants and their agenda, as other researchers have noted (e.g., Wilkinson, 1998), and resulted in detailed insights. Use of the focus group was suited to the current study because this method enabled examination of how knowledge and ideas develop and function within a particular context, as is discussed by Kitzinger (1995).

Due to the nature of the implications that inaccurate data holds for healthcare and patient safety, the integrity of patient indexes such as the client registry should be seen as, and remain, a priority. The common solutions presented in developments such as the Best of Breed (BOB) re-usable registry, enable other jurisdictions to benefit from work already completed, which can help reduce associated costs. It has been predicted that in the near future approximately 80% of health care providers will be using computer-based patient records (Hammond, Hales, Lobach & Straube, 1997). More than a decade later – most nations and jurisdictions are still working toward that goal. It will be a challenge to

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get 100% buy-in from physician and other health care providers, yet Canada Health Infoway has indicated that all Canadians would have an EHR by the year 2016. The challenge may also exist for some jurisdictions to apply Newfoundland and Labrador's CR methodology to their regional health records or legacy systems because they may have already begun work on a registry using a different approach, and therefore may or may not have compatible methodology.

The EHR that is envisioned for Canada will integrate information from many sources to provide a clinical tool that will house a patient's demographic information (the client registry), identification of health providers, lab and diagnostic records, medication history and overall medical history (Canada Health Infoway 2005-06). It is predicted that in less than a decade, Canadians, regardless of geographical location, will have the peace of mind of knowing that their complete medical record will follow them.

As Heathfield and Pitty (1998) state: "despite its obvious moral importance, the question of quality of life appears to be relegated to a much lower priority than questions of economic gains." It is unclear as to why patient safety and quality of life for patients appear to have a less noticeable impact on decision and development processes, but possible explanations are explored here. It is only logical to assume that funding agencies such as government cannot move forward with a project as substantial and costly as an electronic health record, without being able to justify with hard facts and numbers that it would be in the best interest of the stakeholders, funding entities and public alike. The end product of an individual, and ideally, pan-Canadian, EHR, puts the focus on the future, and it would be well-suited to those governing the decisions around

projects such as this to further explore and illustrate the ways in which the patient is the fundamental beneficiary.

As discussed earlier, authors such as Protti & Catz (2002) have addressed the fact that the EHR could reduce deaths that occur all too often from medical errors. Dick and Andrew (1996) stated that the ultimate beneficiary should indeed be the patient – "who will receive higher quality of care at a lower cost, while gaining the ability to establish personal longitudinal patient records and the potential for improving their quality of life" (Dick & Andrew, 1996). Patient safety was not widely discussed in the current findings, most likely because the client registry itself, without the other fundamental EHR components, is not likely to have a significant impact a patients' safety. The ability to uniquely identify a patient, however, is of paramount importance, and thus, the UPI/client registry as the core of an EHR will enable a higher quality of care once the EHR is functional.

The current findings detail the many benefits that participants associate with the client registry alone. Potential benefits, such as quality data and cost savings, that were discussed in the *Benefits Driven Business Case* (NLCHI, 1998), and the *Updated Benefits Driven Business Case* (NLCHI, 1999), were identified by participants as having been achieved. Previously un-identified benefits were also realized in the current study, including the new level of awareness that health records workers found in relation to their day to day processes and the registry's integrity; and the usefulness of the reports that the registry could provide. In developing the foundation for an EHR, the value of its elements should be what drives the pace, as discussed by Golob & Quinn (November 1994), and the overall process.

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Participants identified that to gain government support and funding to begin building an EHR, there had to be cost-savings associated with the registry. To gain the support of the public will likely require more than numbers and dollar figures, it may require education and transparency on what the EHR holds and what it means for a patient. One of the significant challenges identified by participants was the lack of both education and awareness. One may conclude from this that providing stakeholders, including the public, with accounts of fewer adverse drug reactions, fewer medicating errors, better care due to complete health records, better outcomes due to increased data quality, and accessibility to health information, may help the project to build trust and support.

As the current findings clearly demonstrate, in order to get to the stage where accurate and up-to-date information can be accessed, the registry project must also have support and buy-in from the front-line health records workers. The data also identified that there was a distinct difference in the experience of those health records workers in an active-interface region compared to those in the passive-interface regions. Further addressing the need for education and awareness, the disparity between the active and passive interface experience could be lessened with equal orientation and explanation of the registry processes and technical components.

Privacy was identified by participants as a challenge that exists in client registry and EHR implementation; however, the majority of the discussion surrounding privacy did not identify privacy as being a barrier to registry development because the registry contains only demographic information. When discussing the importance of the rights of the patient, it was apparent that to achieve the optimum level of privacy and

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confidentiality would require a delicate balance between patient responsibility and responsible healthcare. As mentioned previously, public cross-province consultations were conducted with numerous stakeholders over a period of three years when the registry project first started, to allow the Health Information Network team to get a grasp on what concerns existed surrounding the role of privacy in the creation of the client registry. The consultation team was able to deduce that there were few concerns overall, though participants did identify that there were groups for whom privacy was very significant concern. This issue of protecting patient's privacy is not unique to Newfoundland and Labrador. Australian Health and Community Services have determined that under their Master Patient Index, patients must authorize what information can be released from their files, and consider it of paramount importance that patients are well-informed of their options, potential outcomes and most of all, their rights (Robbins, 1999).

Current findings identified that the main issue around privacy would be putting measures in place so that authorized users are held accountable for appropriate use of the electronic health system. What is important to note from the current findings is that high level industry standards and practices are adhered to and that the need for legislation that prohibits and punishes misuse of the system has been recognized. Participants identified that NLCHI is aware of the privacy issues that exist around the creation of the UPI/CR and know who has access and for what purpose. Expectations with regard to the protection of individuals' most personal data will be high across the board -- however, with regard to the registry itself, few examples of modest concern were highlighted by the participants.

The true benefit of the UPI/client registry will surface only when the other EHR components are in place and operational, which will, according to Canada Health Infoway, be by the year 2016. For example, the pharmacy network will be one of the next elements of the health information network to be completed and is expected to result in enormous benefit to the individual through the reduction in adverse drug reactions. The laboratory and diagnostic imaging component that will be linked to the registry will also result in great benefit for the individual in that blood tests and x-rays will not have to be redone across regions, but instead the information can be transferred electronically. As the potential benefits to patients grow with the progress toward an interoperable EHR, it is important that this study illustrate that the movement forward will be limited by some of the fundamental challenges that exist, such as the potential for technical problems and the availability of funding and support along the way.

As demand for the implementation of master patient systems such as the client registry continues to grow, the role of technology in health sectors worldwide will continue to expand. Before jurisdictions move into the planning and development phases of implementation of an EHR and its components, it would be beneficial to review the successes and challenges that may result. The knowledge and implications that have been unearthed in the current study are transferable and universally valuable. Health information systems will continue to be shaped and re-shaped by evolving technologies and best practices, and the client registry in Newfoundland and Labrador is a perfect example of this.

5.6   Relevance and Implications of the Findings

5.6.1   Relevance of the Findings

Considering the suggestions and recommendations of the participants may

provide direction for future developments and implementation of a client registry or other

EHR components. The concept of consistency was discussed throughout the interviews

and focus group, and it was identified within the current findings that this concept is

something that should be considered from the point of conceiving need for a client

registry. When systems from various institutions are combined, and each has its own

methods of organization and identification, merging data and standardizing practices

becomes a tremendously complex process (Cupito, May 1998).

Standardized procedures are an essential component when trying to create a

common index of any kind. Many participants of the current study talk about the

importance of this subject, and it becomes apparent that standards serve to benefit all

aspects of health systems, not just the client registry and stakeholder procedures.

Furthermore, participants identified that practices and procedures should be standardized

among stakeholders and within jurisdictions, as was described in Lenson (1998,) and

jurisdictions that may be linked in the future. This can be carried over to say that any

jurisdiction, such as a province, that may be linked in the future, should identify and

adhere to universal standards. Further, it has been recommended in the past that

jurisdictions "clean the data before they actually compile it into one major databank"; this

would serve to put less strain on RIU resources throughout the process and has been

suggested as a course of action in the past by others (Carine & Parrent, 1999). More

recently, Sanders & Protti (2008) discuss data warehouses as technological tools that will

enable data analysis and process optimization. They define a data warehouse as a centrally managed and easily accessible copy of data collected in the transaction information systems of a corporation. The authors tie data warehousing to EHRs with the following statement: "As healthcare plans and invests in a greater computerization of workflow, particularly clinical workflow supported by an EHR, the associated transaction systems must be designed in concert with their analytical counterpart from the beginning, not as an afterthought". Their study discusses the idea that an additional benefit of an EHR to healthcare is the value they hold to research and quality.

The Registry Integrity Unit in Newfoundland and Labrador indicated during data collection that there were approximately 563,000 potential duplicate records in the MCP system (Newfoundland's healthcare database) when the first phase of the client registry was created from the MCP database in 2001. The population of the entire province is just over 500,000 people, so this number of potential duplicates within the original registry illustrates the room for data quality to improve.

As identified in the current findings duplicate records can impose challenges on time and money resources, thus, an initial step in registry development would be to obtain an accurate picture of what potential duplicates exist. The ideal scenario would see all provinces and territories in Canada utilize the same registration standards at all facilities; this would greater enable the building of a pan-Canadian EHR. Dorrel et al. (2004) discussed a National view of patients in Canada, and an EHR was recommended for Canada in Romanow, (2002). Also, as identified in an earlier chapter, Canada Health Infoway has been working with the provinces and territories of Canada to help them achieve this.

The updated registry is able to help MCP determine who is eligible for the free medical services provided by the Province to its residents. This demonstrates an important connection between the registry and the MCP database. It is important for the province to be able to identify those individuals who are not eligible so that the province is not paying for services received by individuals who are no longer residents of Newfoundland and Labrador. This ability to determine eligibility for paid services has been identified as one of the major benefits of the registry. The issue of duplicates is of great relevance to the client registry because the credibility of the registry is that it allows for unique identification; and with duplicates in the system, there is the potential to access the wrong files and therefore get a wrong or incomplete health record.

The route that was taken by the registry project team was to approach the government with smaller and more workable parts of the electronic health record, so that all were in agreement of where the concept was going and what goals were to be pursued. Hence, it was necessary to put the spotlight on future benefits, not just immediate benefits, as difficult as that might have been for investors and stakeholders. In 1996 the registry was still just a vision, but in the 5-6 years to follow, the UPI/client registry became a reality, as did many of the anticipated benefits.

The participants could be grouped broadly into the following two groups: Management, who were mainly involved in the development processes, and Technical, who worked with the Registry on a daily basis. There were notable differences between the information that these groups provided in the current study. Participants discussed the many benefits they perceived with the registry, though the management informants spoke mostly of cost savings and the implications the registry provide for unique patient

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identification; and the technical workers consistently referred to the enhanced data quality in their database, and the fact that the registry was the driver for a change to standardized registration procedures. Likewise, Management spoke more of the challenges of finding the monetary resources and guidance to build the registry, while the technical workers referenced the struggle to find the time to adhere to the new business processes and the technical/interface issues that they were faced with. Further to this, whereas management did not discuss the disparity in challenges between active and passive registry connectivity, the technical workers, the ones using the registry daily, referenced the technical issues and frustrations regularly. Participants equally provided details of both positive and negative experiences, and both broad groups were in agreement that the registry was a successful building block for an EHR. Those that work with the registry each day were able to provide a more acute sense of the finer issues at hand through functionality of the system, whereas, the management informants provided perspective at an operational level.

The ability of Health Information Network Team and the stakeholders to build an innovative tool such as this registry may have been attributable in part to the fact that the dynamics of communication and compatibility were present. As Cain & Mittman (2002) discuss in their paper *Diffusion of innovation in health care*, it is important that new technological innovations be able to co-exist with the ones that are already in place. The registration systems were linked to a larger registry while still maintaining cohesiveness among regional systems. With the client registry in place, patients can be uniquely identified, duplicate patient records can be avoided and data accuracy and billing accuracy have improved. An end result that all stakeholders can appreciate is the

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implication that this has for patient care, and ultimately, patient safety, once the other components of the EHR are linked with the registry.

5.6.2   Implications

There are certain implications of the findings of this study. These (not in order of importance or relevance) are:

- High quality data is challenging to achieve but worthwhile due to the enormous benefits;

- Control of duplicate patient records is essential on a continued basis;

- Cost-savings result from fewer valid out-of-province claims;

- Allow goals to lead process and the impact will be a higher standard of operation;

- Lessons learned and best practices identified by participants could be helpful to other jurisdictions.

5.6.3   Summary of Participant Learnings Identified in Findings

There were identifiable lessons learned and resultant recommendations in the data, and as these may be useful to other jurisdictions building a client registry, they are summarized here (not in order of importance or relevance).

1) Standardize Procedures:
- In developing a new registration system, let the business lead the technology.

- Let the goals and aims of the project guide the use of technology.

- Standardized registration procedures are essential for unification.

- Ensure consistent training and quality control.

2) Educate:

- Make it a priority to educate the public and the stakeholders about the registry to allow individuals to develop an understanding and acceptance of the project and what it will mean for them.

- All users of the health system should have knowledge of the purpose, contents and implications of a registry; this includes the public, stakeholders and health professionals.

3) Maintain Accurate Data at all Sources:

- It is important to the stakeholders who have a vested interest in the accuracy of the data in the registry to maintain these standards in the information that they feed into the system.

4) Address Technical Issues:

- Determine first whether issues are related to software or to under-developed computer skills.

- Strive to contend with these problems as they arise and look to the future outcome that the current hardship will ensure.

5) Determine Resources (Time and Money) Required:

- Compile data in a single registry only once the data has been cleaned.

- As communication is key to the success of any initiative of this magnitude, constant and continued discussion and problem-solving is necessary between those involved in both the registry creation and maintenance.

- Anticipate and identify monetary and human resources required to create and maintain a client registry based on the size of your jurisdiction, and be prepared to

acquire additional resources. Ensure that adequate funding is available to cover

the human resources required.

6) **Develop Computer Skills**:

- It will be beneficial to identify the level of computer skill required and address

  deficiencies early.

- Provide consistent and quality training to alleviate frustrations of those dealing

  with new interfaces.

7) **Address privacy issues**:

- Consult with the public and stakeholders to identify concerns or potential issues.

- Have enforceable policies in place to address the potential for misuse of registry

  data.

8) **Prepare for natural skepticism from supporters**:

- Demonstrate immediate and future benefits to build on existing credibility.

- Provide comprehensive information to all stakeholders and members of the public

  to promote understanding and support.

9) **Utilize direction and guidance available**:

- Toolkits currently exist through Canada Health Infoway that will aid jurisdictions

  in implementing a client registry.

- Involve those individuals with the greatest experience in health records and

  standards in the development and guidance processes.

- Identify and apply lessons learned by other jurisdictions to aid in development

  and implementation of a client registry.

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Appendix A
Human Investigative Committee (HIC) Application

HUMAN INVESTIGATION COMMITTEE – APPLICATION FORM

One copy of the completed checklist must be attached to each copy of your application.
Please ensure all items are marked either X or NA

[X] Latest copy of application form <u>has</u> been used (2002-11). (Check website or call HIC Office 777-6974)

[X] Application is typed or in clear, legible handwriting.

[X] All questions have been answered **in the space provided on the form or in the number of lines allowed.** (Do not say "See attached" or "See Protocol").

[X] One copy of full protocol, signed by local investigator, is attached, if relevant.

[X] Copies of the budget are attached to *each* copy of the application.

[X] One copy of the application is signed by supervisor, if student application (undergraduate, graduate, postgraduate)

[X] One copy of the application is signed by applicant.

[X] One copy of a current curriculum vitae attached (principal investigator or student supervisor) if first time applicant to HIC.

[X] Questionnaires and chart audit forms are attached to each copy of the application. (If standard questionnaires such as the SF36 or EROTC are used, list titles where requested and ensure one copy for the primary reviewer is included in the full protocol.)

[X] Interview guides, interview scripts, covering letters, introductory scripts etc. are attached to each copy of the application. Educational videotapes or audiotapes, copies of posters or advertisements are included in the package.

[X] I have read "Guidelines for Preparation of a Standard Consent Form"

[X] Latest version of the Consent document is attached (2002/11) (written consent, script for verbal consent) to each copy of application.

[X] Consent document follows the Guidelines.

[ ] Tissue/DNA storage component is included in consent.

[X] Consent has been assessed at a reading level of *Gr.8(SMOG)*(**must be <u>less</u> than grade 9**).

[X] I have verified that the above information is correct:

Name of Principal Investigator: Michelle Rees
Signature of Principal Investigator:

HUMAN INVESTIGATION COMMITTEE
Application Form
November 2002

Memorial University; Faculty of Medicine; School of Nursing; School of Pharmacy;
Health Care Corporation of St. John's; NF Cancer Treatment and Research Foundation

Please complete the application in **bold** or a font which can be easily distinguished from the application form.

Forward <u>one</u> copy of the checklist, application, budget, consent form and any other documents (questionnaires, scripts, etc.) for screening to the Human Investigation Committee Office, Room 1755/57, Health Sciences Centre, Phone: 777-6974. *Please consult application guidelines.* <u>Twenty-four copies</u> (**submitted in sets**) will be required when application has been screened and allowed to proceed to review.

1.   Investigators:

- Please name **Principal Investigator: Michelle Rees**

    (a) Faculty [ ]   (b) Graduate Student [X]
    (c) Undergraduate Student [ ]   (d) Postgraduate Student [ ]
    (e) Employee of HCCSJ [ ]   (f) Other: [*please specify*]

- Mailing Address:**404 Elizabeth Ave., St. John's, NL, A1B 1V2 Email: rees_michelle@hotmail.com**
- Telephone Number: **(709) 757-2420 wk), (709) 722-7871 (hm)**

Co-investigators:
- Local contact (name and contact information) if principal investigator is external:

- Research Coordinator (if relevant)   Email:
- Telephone Number:

- If a student, indicate the program and name of supervisor:
  Program: **Masters of Science, Faculty of Medicine, Division of community Health**
  Supervisor: **Dr. Michael Murray**
  Supervisor telephone number: **(709) 777-6213**

2.   Title of study: *[with protocol number and date, if relevant]*

Evaluation Framework of the Newfoundland and Labrador Unique Personal Identifier and Client Registry

3. Study timeline:

- Proposed start date *[at least 4 weeks from date of submission]*: **09/01/03**
- Anticipated completion date: **04/01/04**
- Deadline for HIC approval: **09/01/03**
  Indicate below if:
  - [ ] competitive enrollment
  - [ ] course project

4. Setting of study and data sources:

- Setting – Please **specify** the institutions and/or communities involved:

- Check relevant data sources:
  - (a) Patients [ ]
  - (b) Residents in Community [X]
  - (c) Students [ ]
  - (d) Health Providers [ ]
  - (e) Clinical Records [ ]
  - (f) Archived Specimens [ ]
  - (g) Pre-existing Dataset [ ]
  - (h) Other: [X] – **Registry Integrity Unit and Health Records Directors from Health and Community Services and Integrated Health Boards and Institutional Boards in Newfoundland and Labrador**

5. Objectives:

Provide a numbered list of the **main** research objectives of the study in plain language *[no more than 15 lines]*

1) **To identify the perceived benefits of the common Client Registry**
2) **To identify the perceived challenges faced with the current Client Registries**
3) **To benchmark opinions and experiences of those who work closely with the Registry**
4) **To compare passive and active systems**
5) **To benchmark the minimum staff and resources needed for a Registry Integrity Unit**
6) **To get a detailed look at first-hand involvement in the development of a Unique Personal Identifier-based system**
7) **To evaluate the Unique Personal Identifier as a building block for a complete Health Information Network**

6. Introduction to the study:

- What previous work has been done in this area? Summarize previous human studies *[no more than 20 lines]*

Little work has been done in the field of evaluating processes used to implement a Health Information Network (HIN). The use of a unique personal identifier as a fundamental building block to build an HIN is not unique to Newfoundland and Labrador. Other jurisdictions, such as Australia, implemented a unique personal identifier (UPI) several years ago, and have, thus far, deemed it an effective starting point in creating electronic health records. Also, several provinces across Canada have implemented a Unique Personal Identifier as a building block for the creation of an HIN. The Unique identifier to be used in Newfoundland and Labrador is the (Medical Care Plan) MCP number. In order to make MCP numbers a viable option an integrity unit is necessary to clean up files, assuring that there is only one number for any one individual. Thus the ideal Client Registry would see each resident of Newfoundland and Labrador with a unique number regardless of what region the health care was sought. An evaluation of the Unique Personal Identifier and Client Registry is an important undertaking in that it will identify any challenges that faced at the various stages of development, use and implementation of this system. The Newfoundland and Labrador Centre for Health Information (NLCHI) was mandated in 1998 to establish a plan for a UPI/Client Registry and numerous components which would ultimately follow, such as the Pharmacy Network. NLCHI produced the UPI/Client Registry Scope Project in 2000 and outlined the anticipated benefits of a UPI/Client Registry. An active (requiring human involvement) UPI system has been implemented in two regions in Newfoundland and Labrador and will be implemented in the remaining regions when upgrades following Phase I and Phase II evaluation have been made to the system.

- What is the rationale for this study, i.e., why are you doing this study?
To evaluate the Unique Personal Identifier as an essential and effective building block for a complete Health Information Network (HIN), one that will provide health, economic and financial benefits for Newfoundlanders and Labradorians, and to determine the benefits and potential problems of the current common Client Registry.

- Why is this research important? What contributions could it make?
This research is important in that e-health records are indeed the way of the future, and Newfoundland and Labrador is leading the way. Specifically, an evaluation of the UPI/Client Registry could show the benefits of the UPI system at an early stage in its implementation and identify problems in its development and implementation that can be remedied. The contribution of an HIN will be enormous. The ultimate goal is to have a complete electronic health record, and this includes electronic physician records, prescription records and hospital records. The availability of all of this information to a health professional will benefit the care patients receive.

7. Blood or other tissue sampling which is part of the study: Not Applicable [X]

- List samples to be taken from participants, the frequency of sampling and the amount of sample.
- Will any samples be kept after the completion of this study?   Yes [ ]   No [ ]

[If yes, you must include "Storage of Tissue" in the consent form]

- Can participants withdraw their blood, tissue or other sample?   Yes [ ]   No [ ]

- Will any samples now archived by a health care institution be used in the study?
  Yes [ ]   No [ ]

[If yes, indicate below how consent will be obtained to use such material]

8.   Research interventions and/or modes of data collection:

- List any procedures or tests to be administered to participants – imaging, special diets, ECGs, height and weight measures, etc. In the case of patients, list only those that are **not** part of normal patient management.

- List questionnaires, information sheets, covering letters, telephone or face to face interview scripts/outlines or chart audit forms to be used. Include copies of each with each copy of the application; if standard questionnaires are being used – SF36, EROTC, etc. *[see list on HIC website]* include one copy only.

  *Questionnaire for Health Records Directors
  *Content areas for focus groups with Health Records Directors
  *Script for interviews with Registry Integrity Unit

9.   For clinical trials: Not Applicable [X]

- What treatment do **you** now use for patients who would meet the inclusion criteria for this study, i.e., how would you manage these patients if they did **not** go into this study?

- What clinical trial phase is this study?

- What is the design of this trial, e.g., double-blind, parallel, cross-over, factorial?

10.   Description of study:

Give a brief description of the study, including interventions and outcome measures in plain language *[**no more than 20 lines**]*.   Attach one copy of the protocol if relevant.

To assess what challenges currently face those who work closely with the Client Registry, questionnaires will be distributed to Health Records Directors. In addition, focus groups will be conducted with the Health Records Directors to provide context around the same topics addressed in the questionnaires. Interviews will be conducted with two Registry Integrity Unit (RIU) team members to allow us to get a detailed look at first-hand involvement with the UPI system. The main goal of this study is to validate the UPI as an important and effective base for the development of a complete Health Information Network. It is important for future phases of the HIN implementation to establish what the Directors and RIU personnel perceive as the benefits and challenges of the UPI/Client Registry.

There are currently passive (not using the UPI Client Registry) and active (using the UPI Client Registry) systems in Newfoundland and Labrador. The study will both assess and compare these systems, specifically the benefits and challenges associated. Active systems are currently operating in Carbonear and Grand-Falls, both on the island portion of the Province. An active system uses the current Client Registry when an individual presents at, for instance, a hospital in Grand-Falls. When a registry clerk initiates the registering process, it is not the meditech screen they see (as in passive systems), but the UPI Registry. The registry that appears to those in passive regions when a patient presents for health care, is not the provincial UPI screen that contains all provincial residents, thus is not as up to date or accurate. Thus, a fundamental part of the creation of a Health Information Network is an evaluation of the elements that make up the Network.

11.   Sample size: *[if measuring statistical differences/equivalencies]* **Not Applicable [X]**

Give the basis – power, alpha, difference to be detected, etc., for the choice of sample size.

12.   Participants:

- Describe the participants to be contacted or whose record information will be used.

    (a) Adults [X]   (b) Children under 19 [ ]
    (c) Persons incompetent to give consent [ ]   (d) Protected or vulnerable populations [ ]

    If including children, incompetent adults or persons in protected or vulnerable populations, please justify their inclusion in the research study.

- Number of participants at this site: ~ **16 (~14 Health Records Directors and 2 Registry Integrity Unit personnel; two focus groups, one with Directors from Active regions and one with Directors from Passive regions)**

- Will pregnant women be excluded?   Yes [ ]   No [X]
- Is this a part of a national/international study?   Yes [ ]   No [X]

- If yes, what is the total number of participants at all sites.
- If yes, where is the main study site?

- Will contact be made with potential participants? Yes [X]   No [ ] records only
  Via mail

- If yes, who will contact?

    (a) Attending physician [ ]   (b) Community agency [ ]   (c) School [ ]
    (d) Investigator [X] *[See guidelines]*   (e) Other: *[Please specify]*

13.   Consent process:

- Will there be a consent process   Yes [X]   No [ ] records only

- If yes, who will obtain the consent? **Investigator**

- Is the consent: Written [X]   Verbal [ ]   Implied [ ] by return of distributed questionnaire

- Explain the procedure you will use to obtain consent.
A letter of consent will be given to participants when Questionnaire is sent out and again when focus groups and interviews are conducted.

   [If including children, incompetent adults, or persons in protected or vulnerable populations, describe in detail how parental or proxy consent will be obtained [see application guidelines]

14.   Risks, discomforts and inconveniences:

What risks, discomforts or inconveniences are involved? *[See guidelines]*

There will be no anticipated risk involved, nor discomfort. Participants will have to give of their time however, for both the focus group and the questionnaire. There is always the chance that the participants may feel it would be risky to divulge true opinions and feelings given that the sample size is so small and in such a small group.

15.   Benefits:

Are there any immediate benefits for participants, including controls?

There are no anticipated immediate benefits.

16.   Privacy and confidentiality:

- What steps will be taken to protect privacy and confidentiality of information?
   (a) Oath of confidentiality [X]   (b) Coded study number [X]
   (c) Locked storage [X]   (d) Locked room [X]
   (e) Limited access [X] *[Access to data and materials will be restricted to the investigator]*
   (f) Password-protected computer files [X]   (g) Anonymous responses to investigator [X]
   (h) Denominalized files provided by data holder to investigator [ ]

- List below the names of **all** personnel who can access the identities of study participants:
Michelle Rees

17.   Debriefing:

Explain the process, if any, for feedback to participants, agencies, communities. [*See guidelines*]

Letter or report summary to participants via mail. Also, a presentation will be given to NLCHI and Potentially to Canada Health Infoway. The government of Newfoundland and Labrador will be made aware of the findings through meetings.

18.   Payments: Not Applicable [ ]

- Do you intend to reimburse participants for expenses incurred?   Yes [X]   No [ ]
  Amount [$] **(In the event that the focus groups require that the Health Records Directors have to stay an extra night (their time will be utilized during a monthly meeting of Health Records Directors) in St. John's they will be reimbursed for expenses incurred).**
- Do you intend to pay participants an honorarium/lost wages for participation in the study?
  Yes [ ]   No [X]   Amount [$?]
- Will there be any payment to a third party for referral of patients? Yes [ ]   No [X]
  Amount [$]

19.   Budget: Not Applicable [ ]

- Please attach a copy of the budget to each application including the sources of funding.
- Is this an industry-sponsored study?   Yes [ ]   No [X]
- Will the budget be administered through the University Finance Office?   Yes [ ]   No [X]
  If no, please specify the person or agency responsible: **Newfoundland and Labrador Centre for Health Information (NLCHI)**

20.   Potential conflict of interest:

- Is any investigator an employee of a sponsoring company?   Yes [X] No [ ]
- Is any investigator a shareholder in any company/agency
  funding this study?   Yes [ ]   No [X]
- Will any investigator receive direct financial or other benefit?   Yes [ ]   No [X]
    If yes, please describe:
- Will any investigator receive indirect financial or other benefit? Yes [X] No [ ]
  [Michelle Rees, the principal investigator, will be using the results of this project to produce a masters thesis]

21.   Ownership, storage and destruction of data:

- **The investigator must be free to publish within 6 months after submitting the manuscript to the sponsor for review. Publication of the full study must be assumed no longer than 1 year after the completion of the study. In agreement with the Office of Research, HIC will assume these terms will be negotiated in any research contract.**

- Do you intend to destroy the data collected <u>at the end of the study</u>?   Yes [ ]   No [X]
    If no:

(a) Please give the anticipated date of destruction: **December 2006 (Post-implementation of beginning phases of HIN)**

(b) In what form will the data be retained, e.g., frozen samples, computer tapes, paper? **Secure Computer files and paper copies of questionnaires and transcripts**

(c) Where will the data be stored? **The Newfoundland and Labrador Centre for Health Information (NLCHI) – locked/secure storage**

(d) Who will be the data guardian?
Name: **Michelle Rees**
Contact information: **Research and Development Division, NLCHI ((709)757-2400)**

- Will any form of identifier – name, postal code, study code, be retained? Yes [X]   No [ ]

- If yes, please describe the identifiers to be retained and give the rationale for their retention. **A code will be retained to make it possible to determine the role or title of each of the participants and their respective regions if there are enough to do so.**

22.   Concurrent submissions or approvals:

Has this proposal been submitted for review or been approved by another Newfoundland ethics review committee? **NO**

If yes, please list committee names and locations.

23.   Reminders:

We would like to remind you that it is your responsibility to ensure that permission is obtained from the clinicians, departments, agencies, institutions or communities whose patients/residents are being approached to be in the study. **Please indicate any preliminary contacts made.**

[Note: The use of personnel and/or resources of the Health Care Corporation of St. John's requires the approval of the Research Proposal Approval Committee subsequent to HIC approval. Such approvals may also be required by institutions outside the HCCSJ and/or by regional health boards]

Signature of principal investigator:

Signature of supervisor in the case of a student applicant:

Date:

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Appendix B
<u>RPAC Approval Letter</u>

HealthCare

Corporation of St. John's

September 17, 2003

Ms. Michelle Rees
Grad Student
Community Medicine
General

Dear Ms. Rees:

Your research proposal *"HIC # 03.132 – Evaluation framework of the Newfoundland and Labrador unique personal identifiers and client registry"* was reviewed by the Research Proposals Approvals Committee (RPAC) of the Health Care Corporation of St. John's at its meeting on September 16, 2003 and we are pleased to inform you that the proposal has been approved.

This approval is based on the understanding that it has the necessary funding and that it is being conducted as outlined in the approved research proposal. Additionally, the Committee requires a progress report to be submitted annually.

If you have any questions or comments, please contact Lynn Purchase, Manager of the Patient Research Centre at 777-7283.

Sincerely,

Mr. Wayne Miller
Director, Planning and Research
Chair, RPAC

cc: Ms. Pamela Elliott, Vice President Quality and Planning
        Ms. Lynn Purchase, Manager, Patient Research Centre

St. Clare's Mercy Hospital

154 LeMarchant Road, St. John's, NL, Canada A1C 5B8 Tel. (709) 777-5000 Fax (709) 777-5210
Website: www.hccsj.nf.ca

SITES: Health Sciences Centre (General Hospital/Janeway Children's Health and Rehabilitation Centre/Women's Health Centre)
Dr. Leonard A. Miller Centre • St. Clare's Mercy Hospital • Dr. Walter Templeman Health Centre • Waterford Hospital

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Appendix C
<u>Human Investigative Committee (HIC) Approval Letter 1</u>

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

August 5, 2003

TO: **Ms. Michelle Rees**

FROM: Dr. F. Moody-Corbett, Assistant Dean
                   Research & Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee - #03.132

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"Evaluation framework of the Newfoundland and Labrador Unique Personal Identifier and client registry"**.

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

F. Moody-Corbett, PhD
Assistant Dean

FMC/jjm

cc: Dr. C. Loomis, Vice-President (Research), MUN
        Mr. W. Miller, Director of Planning & Research, HCCSJ

Appendix D
Human Investigative Committee (HIC) Approval Letter 2

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

August 8, 2003

Reference #03.132

Ms. Michelle Rees
404 Elizabeth Avenue
St. John's, NL A1B 1V2

Dear Ms. Rees:

This will acknowledge your correspondence dated August 5, 2003, wherein you provide a copy of an amendment, questionnaire and revised consent form for your research study entitled **"Evaluation framework of the Newfoundland and Labrador Unique Personal Identifier and client registry"**.

The Chairs of the Human Investigation Committee have reviewed your correspondence and granted approval of the amendment, questionnaire and revised consent form, as submitted. This will be formally reported to the full Human Investigation Committee at the meeting scheduled for **September 4, 2003.**

Please be advised that the Human Investigation Committee currently operates according to the Good Clinical Practice Guidelines, the Tri-Council Policy Statement and applicable laws and regulations.

Sincerely,

Sharon K. Buehler, PhD
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

SKB;RSN\jd

C   Dr. C. Loomis, Vice-President (Research), MUN
        Dr. R. Williams, Vice-President, Medical Affairs, HCC

Appendix E
Human Investigative Committee (HIC) Approval Letter 3

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

October 20, 2003

Reference #03.132

Ms. Michelle Rees
404 Elizabeth Avenue
St. John's, NL A1B 1V2

Dear Ms. Rees:

This will acknowledge your correspondence dated September 24, 2003, wherein you provide study procedure changes for your research study entitled "**Evaluation framework of the Newfoundland and Labrador Unique Personal Identifier and client registry**".

The Chairs of the Human Investigation Committee have reviewed your correspondence and granted approval of the procedure changes, as submitted. This will be formally reported to the full Human Investigation Committee at the meeting scheduled for **October 30, 2003.**

Please be advised that the Human Investigation Committee currently operates according to the Good Clinical Practice Guidelines, the Tri-Council Policy Statement and applicable laws and regulations.

Sincerely,

Sharon K. Buehler, PhD
Co-Chair
Human Investigation Committee
Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation

SKB;RSN\jjm

C   Dr. C. Loomis, Vice-President (Research), MUN
        Mr. W. Miller, Director, Planning & Research, HCCSJ

Appendix F
Human Investigative Committee (HIC) Approval Letter 4

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

June 28, 2004

Reference #03.132

Ms. Michelle Rees
404 Elizabeth Avenue
St. John's, NL A1B 1V2

Dear Ms. Rees:

This will acknowledge your correspondence dated August 5, 2003, wherein you provide a completed amendment form dated June 11, 2004, for your research study entitled "**Evaluation framework of the Newfoundland and Labrador Unique Personal Identifier and client registry**".

The Chairs of the Human Investigation Committee have reviewed your correspondence and granted approval of the amendment, dated June 11, 2004, as submitted. This will be formally reported to the full Human Investigation Committee at the meeting scheduled for **July 8, 2004.**

This Research Ethics Board (the HIC) has reviewed and approved the documentation as noted above for the trial which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Good Clinical Practice Guidelines, the Tri-Council Policy Statement and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations.

Sincerely,

John D. Harnett, MD, FRCPC   Richard S. Neuman, PhD
Co-chair   Co-chair
Human Investigation Committee   Human Investigation Committee

C   Dr. C. Loomis, Vice President, Research, MUN
       Mr. W. Miller, Director of Planning & Research, HCCSJ

Appendix G
Questionnaire

Introduction to study, and signing of Consent Forms.

1. How long have you worked as a Health Records Director?_____

2. Prior to being a Health Records Director, what, if any, health record related work were you involved in?

   _____

   _____

   _____

3. Do you work as a Health Records Director in a region where an active interface using the Unique Personal Identifier to utilize the common Client Registry has been implemented?

   Yes_____ No_____

You will now be asked a series of questions regarding Client registries.

4. I am aware of the Common Client Registry.
   [Circle one]

   Strongly Disagree 1 2 3 4 5 6 7 8 9 Strongly Agree

5. I feel that I am capable of providing feedback to those involved in evaluating the Client Registry regarding the Client Registry in the region that I work.
   [Circle one]

   Strongly Disagree 1 2 3 4 5 6 7 8 9 Strongly Agree

6. The current Client Registry is beneficial. [Circle one]

   Strongly Disagree 1 2 3 4 5 6 7 8 9 Strongly Agree

   Why?_____

   _____

   _____

7. The current Client Registry provides me with useful information. [Circle one]

   Strongly Disagree 1 2 3 4 5 6 7 8 9 Strongly Agree

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Why?_____

_____   ____

_____   _____

8. In my opinion, the Unique Personal Identifier is an effective building block for an Electronic Health Record. [Circle one]

   Strongly Disagree   1 2 3 4 5 6 7 8 9   Strongly Agree

9. In my experience, a Client Registry that uses the Unique Personal Identifier Interface would be an effective building block for an Electronic Health Record. [Circle one]

   Strongly Disagree   1 2 3 4 5 6 7 8 9   Strongly Agree

10. The feedback that I have received from Registry Clerks and Registry Technicians in my region regarding the current Client Registry in my region has been positive. [Circle one]

   Strongly Disagree   1 2 3 4 5 6 7 8 9   Strongly Agree

The following questions may not be relevant for all regions

11. The feedback that I have received from Registration Clerks in my region regarding the implementation of an active Unique Personal Identifier system has been positive. [Circle one]

   Strongly Disagree   1 2 3 4 5 6 7 8 9   Strongly Agree

12. How useful to you find each of the following reports to be on a scale of 1-5, 1 being not at all useful, 5 being extremely useful?

   a) Potential Duplicates [circle one]   1   2   3   4   5

   b) Birth Report [circle one]   1   2   3   4   5

   c) Death Listing [circle one]   1   2   3   4   5

   d) Alias Report [circle one]   1   2   3   4   5

13. On average how much time *per week* does your RIU contact person spend on the phone with the RIU? [circle one]

   0-15 minutes
   16-30 minutes

31-45 minutes
46-60 minutes
> 60 minutes

14. Are there any additional reports that you would like to have generated? [circle one]

Yes
No

If yes, please list in order of preference...

1)_____ 3)_____

2)_____ 4)_____

15. Have you initiated any changes in business processes as a result of the data/reports received from the Registry Integrity Unit? [circle one]

Yes
No

If yes, what changes have you made?

_____
_____
_____
_____

16. Please use the space provided if you have any further comments to make regarding the Client Registry or use of the unique personal identifier as a building block for a health information network.

_____
_____
_____

Please bring this questionnaire and your signed consent form to your September meeting of Health Records Directors and place it in the appropriate envelope provided for you. Thank you very much for taking the time to fill out this questionnaire, your feedback is important to this study.

Appendix H
Study Introductory Letter

Introduction to UPI/Client Registry Evaluation Study

Title: Evaluation of the Unique Personal Identifier/Client Registry in Newfoundland and Labrador

Investigator: Michelle L. Rees

Sponsor: Newfoundland and Labrador Centre for Health Information

Date: August 14th, 2003

Background:

An evaluation framework of the Unique Personal Identifier (UPI) and common Client Registry in Newfoundland and Labrador is a fundamental component of identifying their success as building blocks to a complete Health Information Network. Identifying the benefits and challenges associated with the current registries and systems in each region is an important part in the process of creating the best possible solution to the creation of an Electronic Health Record (EHR). One goal of the HIN team and Canada Health Infoway is to create a "Best of Breed" solution to Canada's need for an electronic exchange of health information. Thus, benchmarking the state of the registries in Newfoundland and Labrador now, will not only allow for comparison in the future, it will also shed light on the strengths and weaknesses that currently exist.

Objectives:

There are several distinct objective associated with the current study:
- To identify the perceived benefits of the common Client Registry
- To identify the perceived challenges faced with the current Client Registries
- To benchmark opinions and experiences of those who work closely with the Registry
- To compare passive and active systems
- To benchmark the minimum staff and resources needed for a Registry Integrity Unit
- To get a detailed look at first-hand involvement in the development of a Unique Personal Identifier-based system
- To evaluate the Unique Personal Identifier as a building block for a complete Health Information Network

Description of the study procedures:

In early September 2003 a questionnaire will be sent to all Health Records Directors (HRD) in Newfoundland and Labrador to provide us with short answers to specific UPI/Client Registry related questions. In addition, each HRD will be asked to participate in a focus group during their scheduled HRD meeting in September 2003.

Also, Registry Integrity Unit (RIU) staff members will be asked to participate in face-to face interviews in early September 2003.

Confidentiality:

Documentation of your participation in this study will be maintained at the Newfoundland and Labrador Centre for Health Information until such time that it is no longer required for further evaluations of the Health Information Network. Only the Primary Investigator will have access to any confidential document pertaining to your participation in this study that may identify you by name. Furthermore, your name will not appear in any report or article published as a result of this study. By signing this consent form, you will be giving your permission for this inspection of information given by yourself during your participation.

Questions:

If you have any questions about taking part in this research, you can meet with or contact the investigator who is in charge of the study at the Newfoundland and Labrador Centre for Health Information. That person is:

<u>Michelle Rees, (709) 757-2420</u>

Thank you very much for taking the time to inform yourself about this study.

Appendix I
Consent Form – Questionnaire

Consent to Take Part in Research –
Health Records Directors Questionnaire

**Title: Evaluation of the Unique Personal Identifier/Client Registry in
Newfoundland and Labrador**
Investigator: Michelle L. Rees
Sponsor: Newfoundland and Labrador Centre for Health Information

**You have been asked to take part in a research study. It is up to you to
decide whether to be in the study or not. Before you decide, you need to
understand what the study is for, what risks you might take and what
benefits you might receive. This consent form explains the study.**

The researchers will:
- **Discuss the study with you**
- **Answer your questions**
- **Keep confidential any information which could identify you
  personally**
- **Be available during the study to deal with problems and answer
  questions**

You may decide not to take part in or to leave the study at any time.

1. Introduction/Background:

Newfoundland and Labrador is moving toward a complete Health Information
Network. As a result, an evaluation of where the Province is at in developing a common
Client Registry using a Unique Personal Identifier (UPI) is important. Feedback from
those individuals who see the benefits and challenges on a daily basis is an integral part
of this evaluation. This research is important in that e-health records are the way of the
future. An evaluation of the UPI will identify challenges and benefits associated with the
current systems and with the development of the UPI Client Registry. The ultimate goal
of the Health Information Network is to have a complete electronic health record,
including electronic physician records, prescription records and hospital records. The
availability of all of this information to a health professional will benefit the care patients
receive, thus it is important to evaluate the different stages of implementation of an
electronic health record.

Initials:_____

2. Purpose of study:

To determine the benefits and challenges of developing a common Client Registry and of using a Unique Personal Identifier.

3. Description of the study procedures:

A questionnaire will be given to you and all other Health Records Directors in Newfoundland and Labrador. We ask that you please complete this questionnaire as soon as possible, as the information you provide to us is considered time sensitive. Please bring the questionnaire with you to your Health Records Directors meeting in September and place it in the proper envelope (either passive system or active system) that will be provided to ensure that responses are anonymous.

4. Length of time:

Health Records Directors will be asked to give approximately 20 minutes of your time at your own convenience in the coming two weeks to complete a 2 page questionnaire.

5. Possible risks and discomforts:

There are no anticipated risks or discomforts associated with this evaluation. However, participants will be asked to give freely of their time and will be asked to provide honest feedback.

6. Benefits:

It is not known whether this study will benefit you personally.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

Initials: _____

8. Confidentiality:

Your name will not appear in any report or article published as a result of this study. By signing this consent form, you will be giving your permission for this inspection of information given by yourself during your participation.

9. Questions:

If you have any questions about taking part in this research, you can meet with the investigator who is in charge of the study at the Newfoundland and Labrador Centre for Health Information. That person is:

Michelle Rees, (709) 757-2420

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigative Committee (HIC) at (709) 777-6974
Email: hic@mun.ca

Conflict of Interest Statement:

The investigator in this study is an employee of the Newfoundland and Labrador Centre for Health Information and therefore may have a particular interest in the success of this study.

Initials:___

Signature Page

Study title:

Name of principal investigator:

To be filled out and signed by the participant:

Please Check as appropriate

I have read the consent [and information sheet]	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study	Yes { }	No { }
I have received satisfactory answers to all of my questions	Yes { }	No { }
I have received enough information about the study	Yes { }	No { }
I have spoken with a qualified member of the study team	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- At any time
- Without having to give a reason

I understand that it is my choice to be in the study and that I may not benefit Yes{ }No{ }
In agree to take part in this study   Yes { }   No { }

_____   _____
Signature of participant   Date

_____   _____
Signature of witness   Date

<u>To be signed by the investigator:</u>

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____   _____
Signature of investigator   Date

Telephone number: _____

Initials:_____

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Appendix J
Focus Group Content Areas

Introduction to study, and signing of Consent Forms.

1. What benefit do you see in getting back accurate data sets (e.g., death listings)?
2. What are your thoughts on currently having an active system in your area? (only for   those two regions that have active system implemented)
3. What are your thoughts on having an active system implemented in your region?
4. What benefits, if any, have you seen with the current active/passive system in place in your region?
5. What challenges, if any, have you been faced with in relation to the current passive/active system operating in your region?

Expanded verbal explanation to follow. *Will include: for the following two questions please remember that an active system feeds directly into and receives feedback from the common Client Registry, and a passive system feeds into the common Client Registry but does not receive feedback.*

6. 6. Do you feel that an active system will help provide more accurate Client identification than a 1-way passive system? Why?
7. 7. Do you feel that an active system is the gold standard for an effective Health Information Network? Why? Why not?
8.
9. 8. Do you currently receive reports from the RIU, if so, what reports do you find most useful, if not, do you think you would find it useful?
10. 9. Are there any reports that you do not receive that you would like to have generated?
11. 10. Do you feel that the Unique Personal Identifer is an effective building block for an electronic health record?
12. 11. What do you feel will be the benefits, if any, of the common Client Registry in the future?
13. 12. What do you feel will be the challenges, if any, of the common Client Registry in the future?
14. 13. Have businesses processes changed with the prospect of having an active system implemented in your region?
15. 14. Is there any other area with regard to the Unique Personal Identifier or Client Registry, or passive or active systems that you would like to provide feedback on?

Thank-you very much for giving of your time today, your feedback is very important to this study.

Appendix K
Consent Form – Focus Group

Title: Evaluation of the Unique Personal Identifier/Client Registry in Newfoundland and Labrador
Investigator: Michelle L. Rees
Sponsor: Newfoundland and Labrador Centre for Health Information

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:
- **Discuss the study with you**
- **Answer your questions**
- **Keep confidential any information which could identify you personally**
- **Be available during the study to deal with problems and answer questions**

You may decide not to take part in or to leave the study at any time.

1. Introduction/Background:

Newfoundland and Labrador is moving toward a complete Health Information Network. As a result, an evaluation of where the Province is at in developing a common Client Registry using a Unique Personal Identifier (UPI) is important. Feedback from those individuals who see the benefits and challenges on a daily basis is an integral part of this evaluation. This research is important in that e-health records are the way of the future. An evaluation of the UPI will identify challenges and benefits associated with the current systems and with the development of the UPI Client Registry. The ultimate goal of the Health Information Network is to have a complete electronic health record, including electronic physician records, prescription records and hospital records. The availability of all of this information to a health professional will benefit the care patients receive, thus it is important to evaluate the different stages of implementation of an electronic health record.

Initials:_____

2. Purpose of study:

To determine the benefits and challenges of developing a common Client Registry and of using a Unique Personal Identifier.

3. Description of the study procedures:

One focus group will be conducted with you and all other Health Records Directors in Newfoundland and Labrador. We will divide the Health Records Directors into two groups and execute two separate focus groups for this study. A series of questions will be presented to you at the focus group that encourage you to discuss the UPI/Client Registry.

4. Length of time:

With approval of the Chair of the Health Records Directors meetings, you will be asked to give approximately 2 hours of your time during a regular meeting of Health Records Directors to take part in this focus group.

5. Possible risks and discomforts:

There are no anticipated risks or discomforts associated with this evaluation. However, participants will be asked to give freely of their time and will be asked to provide honest feedback.

6. Benefits:

It is not known whether this study will benefit you personally.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

Initials:_____

8. Confidentiality:

Your name will not appear in any report or article published as a result of this study. By signing this consent form, you will be giving your permission for this inspection of information given by yourself during your participation.

9. Questions:

If you have any questions about taking part in this research, you can meet with the investigator who is in charge of the study at the Newfoundland and Labrador Centre for Health Information. That person is:

Michelle Rees, (709) 757-2420
Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigative Committee (HIC) at (709) 777-6974
Email: hic@mun.ca

Conflict of Interest Statement:

The investigator in this study is an employee of the Newfoundland and Labrador Centre for Health Information and therefore may have a particular interest in the success of this study.

Initials:_____

Signature Page

Study title:

Name of principal investigator:

To be filled out and signed by the participant:

Please Check as appropriate

I have read the consent [and information sheet]	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study	Yes { }	No { }
I have received satisfactory answers to all of my questions	Yes { }	No { }
I have received enough information about the study	Yes { }	No { }
I have spoken with a qualified member of the study team	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- At any time
- Without having to give a reason

I understand that it is my choice to be in the study and that I may not benefit Yes{ }No{ }

In agree to take part in this study   Yes { }   No { }

_____   _____
Signature of participant   Date

_____   _____
Signature of witness   Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____   _____
Signature of investigator   Date

Telephone number: _____

Initials:_____

Appendix L.
Focus Group Thematic Analysis

Method	Focus Group Content Categories	Color
	Benefit	
	Challenge of CR Active	
	Benefit of Going Active in a Couple of Regions	
	Worry	
	Challenge	
	Challenge of Passive	
	Benefit Activie	
	Useful	
	Privacy	
	Suggestions	
	Education and Awareness	
	Changes and Realization	

Appendix M
RIU Interview Script

Introduction to study, and signing of Consent Forms.

1. What is your role in the development of the common Client Registry?

2. What is your role in the process of implementing the Unique Personal Identifier as a building block for an electronic health record?

3. What are your responsibilities as a member of the Registry Integrity Unit?

4. About what proportion of your time is spent cleaning data?

5. About what proportion of your time is spent completing reports?

6. About what proportion of your time is spent merging Client files?

7. What do you feel are the benefits, if any, of the Unique Personal Identifier/Client Registry as it currently exists?

8. What do you feel are the potential future benefits, if any, of the Unique Personal Identifier/Client Registry?

9. What do you feel are the challenges, if any, of the Unique Personal Identifier/Client Registry as it currently exists?

10. What do you feel are the potential future challenges, if any, of the Unique Personal Identifier/Client Registry?

11. Is there anything else in relation to your role as a member of the Registry Integrity Unit that you would like to give us feedback on?

Thank you very much for providing valuable feedback on the current roles and responsibilities of the Registry Integrity Unit.

Appendix N
Standards Director Interview Script

I will ask you a series of questions directly related to your involvement in the development of the UPI/Client Registry in Newfoundland and Labrador (signing of consent form).

1) Could you sum up the chain of events leading up to the development of the UPI/Client Registry?

2) How did you become involved in the process of developing the UPI/Client Registry?

3) What has your role been in the development and maintenance of the UPI/Client Registry?

4) What was the process of communicating with the necessary individuals and groups to develop the Registry?

5) What issues and or elements of registration needed to be addressed?

6) Was there a change in registration processes as a result of the development of the UPI/Client Registry?

7) At what stage of development is the UPI/Client Registry at this point in time?

8) What is your continuing role in the maintenance of the UPI/Client Registry?

9) What benefits and or challenges do you anticipate in the Client Registry once it is complete?

10) Is there any other feedback that you would like to provide on either the development or maintenance of the UPI/Client Registry here in NL?

Appendix O
Key Informant Interview Script

Evaluating the Fundamentals of Developing and Maintaining a Client Registry

1) Why create a Client Registry?

2) Why was this project supported?

3) What has been your involvement or role in the development of the Client Registry?

4) What benefits/challenges have been associated with the creation of the Client Registry?

5) Where and how do privacy and ethics come into play with the Client Registry?

6) What do you think the implications of the Client Registry will be?

Additional Interview Questions:
January 27th, 2004

1.

1) Why create a Client Registry?

2) How will a computer system benefit health care?

3) What are the expectations associated with the development of the Client Registry?

4) How is the Client Registry going to impact health care?

5) What is the usefulness/value of the Client Registry?

6) What is the cost-effectiveness of the Client Registry?

3.

7) What has been your involvement or role in the development of the Client Registry?

8) What are your thoughts/opinions on the Client Registry?

9) Do you have any concerns regarding the Registry?

10) What are your thoughts on using the UPI as a basis for the Client Registry?

4.

11) What benefits are expected? What benefits have already been seen?

12) Where are the benefits of the UPI/Client Registry visible?

13) What benefits can be attributed solely to the creation of the Registry?

14) How will the Client Registry benefit research?

15) What challenges are expected? What challenges have been experienced?

16) What is the importance of duplicate control?

5.

17) What privacy/ethical issues need to be or have been addressed?

18) Do you have concerns surrounding the impact the Client Registry will have on privacy?

6.

19) Will the Client Registry aid in accountability reporting? If so, how?

20) Was the business case accurate?

Appendix P
<u>Consent Form – RIU Interviews</u>

Consent to Take Part in Research –
Registry Integrity Unit Staff Interviews

Title: Evaluation of the Unique Personal Identifier/Client Registry in Newfoundland and Labrador
Investigator: Michelle L. Rees
Sponsor: Newfoundland and Labrador Centre for Health Information

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:
- **Discuss the study with you**
- **Answer your questions**
- **Keep confidential any information which could identify you personally**
- **Be available during the study to deal with problems and answer questions**

You may decide not to take part in or to leave the study at any time.

1. Introduction/Background:

Newfoundland and Labrador is moving toward a complete Health Information Network. As a result, an evaluation of where the Province is at in developing a common Client Registry using a Unique Personal Identifier (UPI) is important. Feedback from those individuals who see the benefits and challenges on a daily basis is an integral part of this evaluation. This research is important in that e-health records are the way of the future. An evaluation of the UPI will identify challenges and benefits associated with the current systems and with the development of the UPI Client Registry. The ultimate goal of the Health Information Network is to have a complete electronic health record, including electronic physician records, prescription records and hospital records. The availability of all of this information to a health professional will benefit the care patients receive, thus it is important to evaluate the different stages of implementation of an electronic health record.

Initials: _____

2. Purpose of study:

To determine the benefits and challenges of developing a common Client Registry and of using a Unique Personal Identifier.

3. Description of the study procedures:

An interview will be conducted with you and other members of the Registry Integrity Unit (RIU) in Newfoundland and Labrador. We ask that you please take part in this study by answering a series of questions related to your RIU duties that the investigator will ask you. With the approval of your superiors, the interview will take place in Carbonear at your place of work.

4. Length of time:

You, as a member of the RIU will be asked to give approximately one hour of your time to answer a series of questions.

5. Possible risks and discomforts:

There are no anticipated risks or discomforts associated with this evaluation. However, participants will be asked to give freely of their time and will be asked to provide honest feedback.

6. Benefits:

It is not known whether this study will benefit you personally.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. Confidentiality:

Your name will not appear in any report or article published as a result of this study. By signing this consent form, you will be giving your permission for this inspection of information given by yourself during your participation.

Initials: _____

9. Questions:

If you have any questions about taking part in this research, you can meet with the investigator who is in charge of the study at the Newfoundland and Labrador Centre for Health Information. That person is:

Michelle Rees, (709) 757-2420
Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigative Committee (HIC) at (709) 777-6974
Email: hic@mun.ca

Conflict of Interest Statement:

The investigator in this study is an employee of the Newfoundland and Labrador Centre for Health Information and therefore may have a particular interest in the success of this study.

Initials:_____

Signature Page

Study title:

Name of principal investigator:

To be filled out and signed by the participant:

                                                              Please Check as appropriate

I have read the consent [and information sheet]	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study	Yes { }	No { }
I have received satisfactory answers to all of my questions	Yes { }	No { }
I have received enough information about the study	Yes { }	No { }
I have spoken with a qualified member of the study team	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- At any time
- Without having to give a reason

I understand that it is my choice to be in the study and that I may not benefit Yes{ }No{ }

In agree to take part in this study   Yes { }   No { }

_____   _____
Signature of participant   Date

_____   _____
Signature of witness   Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____   _____
Signature of investigator   Date

Telephone number: _____

                                                              Initials:_____

Appendix Q
Consent Form – Standards Director Interview

<p style="text-align:center">Consent to Take Part in Research –
Standards Director Interview</p>

**Title: Evaluation of the Unique Personal Identifier/Client Registry in
     Newfoundland and Labrador**

Investigator: Michelle L. Rees

Sponsor: Newfoundland and Labrador Centre for Health Information

**You have been asked to take part in a research study. It is up to you to
decide whether to be in the study or not. Before you decide, you need to
understand what the study is for, what risks you might take and what
benefits you might receive. This consent form explains the study.**

The researchers will:
- **Discuss the study with you**
- **Answer your questions**
- **Keep confidential any information which could identify you
  personally**
- **Be available during the study to deal with problems and answer
  questions**

You may decide not to take part in or to leave the study at any time.

1. Introduction/Background:

Newfoundland and Labrador is moving toward a complete Health Information
Network. As a result, an evaluation of where the Province is at in developing a common
Client Registry using a Unique Personal Identifier (UPI) is important. Feedback from
those individuals who see the benefits and challenges on a daily basis is an integral part
of this evaluation. This research is important in that e-health records are the way of the
future. An evaluation of the UPI will identify challenges and benefits associated with the
current systems and with the development of the UPI Client Registry. The ultimate goal
of the Health Information Network is to have a complete electronic health record,
including electronic physician records, prescription records and hospital records. The
availability of all of this information to a health professional will benefit the care patients
receive, thus it is important to evaluate the different stages of implementation of an
electronic health record.

Initials:

2. Purpose of study:

To determine what was required in the development and maintenance of the Client Registry in Newfoundland and Labrador.

3. Description of the study procedures:

An interview will be conducted with you in private. We ask that you please take part in this study by answering a series of questions related to your Client Registry responsibilities (past and present) that the investigator will ask you. The interview will be conducted at your place of work (NLCHI).

4. Length of time:

You will be asked to give approximately one hour of your time to answer a series of questions.

5. Possible risks and discomforts:

There are no anticipated risks or discomforts associated with this evaluation. However, participants will be asked to give freely of their time and will be asked to provide honest feedback.

6. Benefits:

It is not known whether this study will benefit you personally.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. Confidentiality:

Your name will not appear in any report or article published as a result of this study. By signing this consent form, you will be giving your permission for this inspection of information given by yourself during your participation.

Initials:_____

9. Questions:

If you have any questions about taking part in this research, you can meet with the investigator who is in charge of the study at the Newfoundland and Labrador Centre for Health Information. That person is:

Michelle Rees, (709) 757-2420
Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigative Committee (HIC) at (709) 777-6974
Email: hic@mun.ca

Conflict of Interest Statement:

The investigator in this study is an employee of the Newfoundland and Labrador Centre for Health Information and therefore may have a particular interest in the success of this study.

Initials: _____

Signature Page

Study title: Evaluation of the Newfoundland and Labrador UPI/Client Registry

Name of principal investigator: Michelle L. Rees

To be filled out and signed by the participant:

Please Check as appropriate

I have read the consent [and information sheet]	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study	Yes { }	No { }
I have received satisfactory answers to all of my questions	Yes { }	No { }
I have received enough information about the study	Yes { }	No { }
I have spoken with a qualified member of the study team	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- At any time
- Without having to give a reason

I understand that it is my choice to be in the study and that I may not benefit Yes{ }No{ }

In agree to take part in this study   Yes { }   No { }

_____   _____
Signature of participant   Date

_____   _____
Signature of witness   Date

<u>To be signed by the investigator:</u>

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____   _____
Signature of investigator   Date

Telephone number: _____

Initials:_____

Appendix R
Consent Form – Key Informant Interviews

Consent to Take Part in Research –
Interview

Title: Evaluation of the Unique Personal Identifier/Client Registry in Newfoundland and Labrador
Investigator: Michelle L. Rees
Sponsor: Newfoundland and Labrador Centre for Health Information

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:
- **Discuss the study with you**
- **Answer your questions**
- **Keep confidential any information which could identify you personally**
- **Be available during the study to deal with problems and answer questions**

You may decide not to take part in or to leave the study at any time.

1. Introduction/Background:

Newfoundland and Labrador is moving toward a complete Health Information Network. As a result, an evaluation of where the Province is at in developing a common Client Registry using a Unique Personal Identifier (UPI) is important. Feedback from those individuals who see the benefits and challenges on a daily basis is an integral part of this evaluation. This research is important in that e-health records are the way of the future. An evaluation of the UPI will identify challenges and benefits associated with the current systems and with the development of the UPI Client Registry. The ultimate goal of the Health Information Network is to have a complete electronic health record, including electronic physician records, prescription records and hospital records. The availability of all of this information to a health professional will benefit the care patients receive, thus it is important to evaluate the different stages of implementation of an electronic health record.

Initials:_____

2. Purpose of study:

To determine what was required in the development and maintenance of the Client Registry in Newfoundland and Labrador.

3. Description of the study procedures:

An interview will be conducted with you in private. We ask that you please take part in this study by answering a series of questions related to your Client Registry involvement.

4. Length of time:

You will be asked to give approximately one hour of your time to answer a series of questions.

5. Possible risks and discomforts:

There are no anticipated risks or discomforts associated with this evaluation. However, participants will be asked to give freely of their time and will be asked to provide honest feedback.

6. Benefits:

It is not known whether this study will benefit you personally.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. Confidentiality:

Your name will not appear in any report or article published as a result of this study. By signing this consent form, you will be giving your permission for this inspection of information given by yourself during your participation.

Initials: _____

9. Questions:

If you have any questions about taking part in this research, you can meet with the investigator who is in charge of the study at the Newfoundland and Labrador Centre for Health Information. That person is:

Michelle Rees, (709) 757-2420

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigative Committee (HIC) at (709) 777-6974
Email: hic@mun.ca

Conflict of Interest Statement:

The investigator in this study is an employee of the Newfoundland and Labrador Centre for Health Information and therefore may have a particular interest in the success of this study.

Initials:_____

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Signature Page

Study title: Evaluation of the Newfoundland and Labrador UPI/Client Registry

Name of principal investigator: Michelle L. Rees

To be filled out and signed by the participant:

Please Check as appropriate

I have read the consent [and information sheet]	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study	Yes { }	No { }
I have received satisfactory answers to all of my questions	Yes { }	No { }
I have received enough information about the study	Yes { }	No { }
I have spoken with a qualified member of the study team	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- At any time
- Without having to give a reason

I understand that it is my choice to be in the study and that I may not benefit Yes{ }No{ }

In agree to take part in this study   Yes { }   No { }

_____   _____
Signature of participant   Date

_____   ____   _____
Signature of witness   Date

<u>To be signed by the investigator:</u>

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____   _____   _____
Signature of investigator   Date

Telephone number: _____   _____

Initials:_____

Appendix S
RIU Interview Thematic Analysis

Method	RIU Interview Con Cat.	Color
	RIU Role	
	Process of Cleaning Data	
	UPI Functioning	
	MCP & UPI	
	MCP	
	UPI/CR Process Maintain	
	Reports	
	Benefit	
	Future Benefits	
	Pharmacy Benefits	
	Challenge	
	Problems at Registration	
	Duplicates	
	Future Challenge	
	Advice /Suggestion	

Appendix T
Key Informant Interview Thematic Analysis

Method	Interview Content Categories	Color
	Registration Protocol	
	Passive	
	Benefit	
	Challenge	
	Maintenance	
	Why Supported Government	
	Computer Benefit	
	Research Benefit	
	Expectations	
	Privacy	
	Concerns	
	UPI Functioning	
	Consent	
	Duplicate Control	
	UPI Process	
	Implications	
	Accountability	
	Business Case	
	Importance of Standards	
	Pharmacy Network	
	MCP	
	MCP Duplicates	
	Suggestions	
	Interviewee Role	
	Project Steering Committee	
	Opinions	
	Board	
	Why Client Registry	

Appendix U
<u>Letter from CEO of NLCHI to Interview Participants</u>

NLCHI
Crosbie Place
St. John's,NL

January 20th, 2004

(Name),

An evaluation of the Newfoundland and Labrador Unique Personal Identifier
Client Registry is being conducted by the Newfoundland and Labrador Centre for Health
Information. Masters of Science Candidate Michelle Rees is doing a research study on
the development and maintenance of the Client Registry in the Province and will be
interviewing several key individuals that were involved in the creation of the Registry.
The Newfoundland and Labrador Centre for Health Information supports this Registry
evaluation study as it will provide invaluable knowledge with regard to development and
maintenance of a Client Registry. We encourage you to accommodate Michelle's request
to have you participate in this study. If you have any questions please do not hesitate to
contact me (757-2409).

Sincerely,

Steve O'Reilly
Chief Executive Officer