

# Development of reports containing health indicators generated with data extracted from cancer data management software

by

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# Acknowledgement and Endorsement

This report has been written by me and has not received any previous academic credit at this or any other institution.

I would like to thank Theresa Foley, Prof. Mohamed Abdoell and Ryan Duggan for their guidance and encouragement during this internship and for their helpful review and feedback on this manuscript.

James Wills

# Executive Summary

This report describes the Master of Health Informatics internship undertaken by James Wills at the Nova Scotia Breast Screening Program (NSBSP) in 2011. NSBSP is mandated to provide early detection of breast cancer through breast screening mammography and it oversees the entire patient journey including diagnostic testing, pathology, and surgery. As part of an update to the NSBSP health information system, the primary objective of the internship was to update the Program's Annual Report to use the new system as its source of data. The Annual Report provides information about the operations of the Breast Screening Program as well as nationally defined health indicators for breast cancer and breast screening and is submitted to clinicians and administrators at the provincial and national levels.

The internship was successfully completed with positive feedback from colleagues and managers. In addition to achieving the primary objective of updating the Annual Report, contributions were made to restructure the report, add GIS mapping, provide customization for future reports, and create a new plug-in to calculate breast cancer risk. The work was closely related to the field of Health Informatics specifically focusing on coursework topics such as health indicators, clinical workflow and information use, screening benefits and harms, statistics, research methods, and project management.

Opportunities to improve patient family history records became evident during the internship. Accuracy of self-reporting can be limited for second-degree relatives and routine biennial breast screening may not be frequent enough if a woman's risk of breast cancer has risen due to a family member's diagnosis. A Health Informatics solution is proposed that would allow breast cancer patients to share their diagnosis with family members and the relationship to be explicitly recorded in the NSBSP information system. Family members would be notified that their breast cancer risk has increased and have their screening plan modified if necessary. The proposal details software requirements for this solution and outlines the technical solution that would be required. Concerns around privacy, additional paperwork, and non-biological family members are discussed.

The successful completion of the internship, including the primary objective and additional contributions, has resulted in several recommendations. The efforts made during the internship have allowed NSBSP to continue generating the Annual Report and develop new reports using the newly created components. The proposed solution for proactive family history recording should be considered for the additional benefits it provides to patient care.

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# 1 Introduction

The Master of Health Informatics program at Dalhousie University allows students to pursue an internship to supplement the coursework of the program. Internships consist of a requisite number of hours employed in a setting relevant to Health Informatics.

This report describes the internship undertaken by James Wills from May to August of 2011 at the Nova Scotia Breast Screening Program (NSBSP). The report details the objectives of the internship, the Program and its business objectives, the student's duties and achievements during the internship, and the relationship between the work performed and its impact on the field of Health Informatics. The report analyzes the need for more timely and accurate tracking of patient family history and proposes a Health Informatics solution to this problem.

## 1.1 Background

Breast Cancer is a disease in which abnormal cells form in the tissues of the breast, usually in the ducts and lobules (*Breast Cancer*, 2011a). In the province of Nova Scotia the incidence rate of breast cancer is estimated to be 0.101% and the mortality rate due to breast cancer is estimated to be 0.022% (*Canadian Cancer Statistics 2011*, 2011). There are numerous risk factors for breast cancer including age, genetics, life events, and lifestyle (*Breast Cancer*, 2011b). The World Health Organization recommends prevention through the reduction of risk factors as well as early detection through mammography screening as an effective means to improve breast cancer outcome and survival (*Breast cancer: prevention and control*, 2011).

In Canada, each province and territory is responsible for its own breast cancer early detection strategy and in Nova Scotia all mammography screening and follow-up is managed by the Nova Scotia Breast Screening Program. NSBSP provides the ability for women to book screening appointments at local screening sites either through self- or physician-referral. Women with normal results are reminded by the Program to return for screening on a regular basis whereas abnormal results lead to more comprehensive diagnostic testing with the potential for a biopsy or surgery to remove the tumour at an early stage.

NSBSP has collected and stored the information necessary to manage breast screening and follow-up procedures since its inception in 1991. This comprehensive set of information is stored and accessed in a central database which serves as the source of information for reports. In 2011 NSBSP plans to migrate this data to a modern relational database and user interface based on customized open-source software.

Provincial screening programs measure health indicators relevant to breast cancer and breast screening and submit results to Health Canada's Centre for Chronic Disease Prevention and Control where the information is compiled in the Canadian Breast Cancer Screening Database (*Report from the Evaluation Indicators Working Group: Guidelines for Monitoring Breast Screening Program Performance*, 2007). Many screening programs, including NSBSP, also publish yearly reports that include these required indicators in addition to other useful information about the programs' operations. The NSBSP Annual Report is published by the Program and contains performance indicators as well as details about the organization of the screening program, core business functions, former and current initiatives, budget information, and research activities. The report has been customized and generated using a suite of open source tools that extract data from the NSBSP database, generate statistical analysis and summaries, typeset, and generate the final report. The report is then posted on the NSBSP website and distributed to physicians, radiologists, and administrators throughout the province and the country.

## 1.2 Objectives

The primary objective of this internship was to update the NSBSP Annual Report to use the new system as the source of data. The outcome of this objective was that NSBSP could run the 2011 Annual Report using migrated data in the new system and have a more flexible and manageable report that uses fewer resources to generate. The standardization of the definition of health indicators and the ability of health information systems to generate and share those indicators is a fundamental component of the field of Health Informatics. The resulting indicators allow stakeholders to evaluate interventions and make the necessary modifications to improve the services provided to patients.

## 1.3 Contributions

The primary objective of updating the Annual Report was met and the report is now generated using the new database as the source of information. Additional contributions were made during the internship including automation and report restructuring, GIS mapping of health information, adding the ability to quickly add and customize future reports, and the creation of a new plug-in to provide real-time patient-specific calculation of breast cancer risk. The student enjoyed several opportunities to learn about the operations of a screening program, clinical workflow, measurement and evaluation techniques, and cancer research objectives.

## 2 Nova Scotia Breast Screening Program

The goal of the Nova Scotia Breast Screening Program “is to reduce the mortality from breast cancer in Nova Scotia women aged 50-69 years of age by 30% within ten years following development of a province wide screening program” (*Annual Report 2010 (2009 Data)*, 2010). To succeed, NSBSP has been mandated to provide breast screening, maintain standards and policies for screening, and monitor and evaluate screening outcomes. The organization supplements this work with coordination of the entire breast screening patient journey: mammography, diagnostic testing, biopsy, surgery, follow-up reminders, and the collation of procedure results.

NSBSP informs its work with the results of numerous ongoing research projects that make use of the rich and complete set of data collected during the screening process. The existing Mammography Information System (MIS) presented challenges in accessing this dataset for operations and research purposes in a timely and flexible manner. To remedy these challenges and provide a more modern and friendly interface for its users, NSBSP embarked on a project to replace the MIS. To conserve resources, an open-source web-based software package called CAISIS was chosen as a replacement system. The CAISIS software has the advantages of being targeted specifically at cancer data management, being evaluated and improved by a large community of developers and users, and a core team that is open to feedback and collaboration (*Integrated Clinic and Research Management System*, 2011). The project was structured around a small team of individuals defining requirements used by an external software developer to customize the open-source interface and define the mapping between the old and new databases. Health Informatics interns were a vital part of reproducing and extending the functionality of the system.

The system supports a broad spectrum of users and uses. NSBSP Booking Clerks receive calls from patients and referrals from physicians and use the system to find and schedule an appointment slot in the patient’s area. When patients arrive for their screening appointment, Mammography Technologists review the patient files and add new information to the system before recording digital images in the Picture Archiving and Communications System (PACS). The availability of both the images and patient data allow Radiologists to review high volumes of cases from various geographic locations. Normal readings are recorded in the system and the patient is flagged to receive a reminder to make their next screening appointment. Abnormal results trigger notifications in the system which are sent to the patient and her physician. Abnormal results also cause the scheduling of additional diagnostic testing in the system. Abnormal diagnostic testing may lead to surgical procedures including biopsy and mastectomy. Although the Pathologists and Surgical Consultants that are involved in these procedures do not access the system directly, their results are communicated to NSBSP and entered in the system to ensure that the patient’s file is complete and subsequent testing can be scheduled according to clinical guidelines and procedures.

# 3 Internship Duties

## 3.1 Job Description

The job description for the internship position was defined as follows:

The Nova Scotia Breast Screening Program is replacing its Mammography Information System with a more flexible open source web-based system. The ability to automatically generate statistical reports formed a key component of the previous system. The internship will involve an analysis of the current system and current reports in order to provide the equivalent functionality in the new system. The intern will also have the opportunity to be involved in all aspects of the software development lifecycle for the new system including participation in analysis, design, implementation, and user acceptance testing. The intern will also participate in the development of a Privacy Impact Assessment (PIA) report for the new system, to be submitted to the Department of Health.

## 3.2 Role and Responsibilities

The main task for the internship was to update the eighty-six-page Annual Report to obtain data from the CAISIS database rather than the MIS. Data had been extracted from the MIS using a customized portion of the interface, from which specific numbers were extracted and processed by statistical software. In updating the report, it was necessary to trace each data element back to the source in the MIS system, determine how it was mapped to the CAISIS database, and create Structured Query Language (SQL) queries to extract the corresponding data from the CAISIS database.

Participation in the development of the PIA report was no longer required as it was to be performed by the Department of Health and Wellness.

As the internship progressed additional responsibilities were encountered. The intern provided technical leadership to other students in working with the new system and served as a key technical contact with the external developer to ensure that the data mapping met the needs of NSBSP. The intern took responsibility for ensuring that the reporting infrastructure was flexible, easy to maintain, easy to use, and extensible for future work. The intern was also given the tasks of designing additional reports to aid the clinical workflow of the Program and incorporate a widely known risk calculator into the new system.

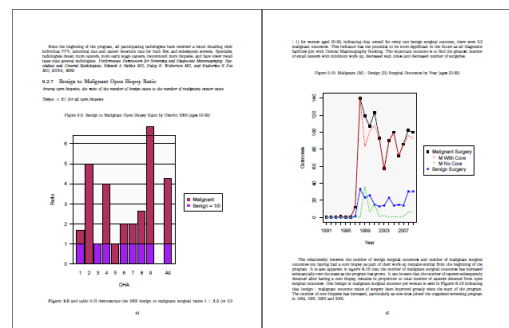


Figure 1: Annual Report



## 3.3 Achievements

### 3.3.1 Extracting Data from CAISIS

To update the NSBSP Annual Report (figure 1), it was first necessary to obtain and install the required software. This included Windows Server, SQL Server, Internet Information Services (IIS), CAISIS, R, and LaTeX. The full setup procedure was documented and shared with other interns so that the environment could be replicated quickly and consistently.

To extract the data necessary for the Annual Report, more than 150 SQL queries were written. The queries were separated from the file structure of the main report and placed in a shared location so that they may be used in the development of other reports. The report was reproduced in full reusing the existing LaTeX typesetting. Continued use of an open-source suite of software that includes CAISIS, R, and LaTeX, allows NSBSP to develop and generate reports at a low cost and with a low dependency on vendors.

A simple command-line interface was created to allow for the generation of a report for any year with no additional setup. The reports are now organized within the following file structure:

- annualreport
  - base
    - \* annualreport.Snw
    - \* setup.Snw
    - \* PerformanceIndicators.Snw
    - \* ...
  - 2010
    - \* annualreport.Snw
    - \* setup.Snw
    - \* PerformanceIndicators.Snw
    - \* ...
  - 2011
    - \* annualreport.Snw
    - \* setup.Snw
    - \* PerformanceIndicators.Snw
    - \* ...
  - images
- report2
- shared
  - queries.Snw

The following command can be used to generate the 2011 Annual Report using the files in the *2011* folder and the *shared* folder:

```
> generate annualreport 2011
```

The same command can be used to generate the 2012 Annual Report using the files in the *base* folder (because there is no folder called *2012*) and the *shared* folder:

```
> generate annualreport 2012
```



Figure 2: Reporting Interface

### 3.3.2 Extracting Data from Nova Scotia Community Counts

Nova Scotia Community Counts is a provincial website containing population data used in the NSBSP Annual Report. As census information for the nine Nova Scotia district health authorities (DHA) was being manually transcribed from this website to text files, it was a valuable exercise to automate this process to extract census data from the Community Counts site and import it into a separate database on the same database server. The data is organized by year, DHA, gender, and five-year age groups so that it may be combined with CAISIS data in any existing or future queries. The data extraction can be run yearly or when the Community Counts data changes.

### 3.3.3 Automating Report Generation

To make it easier for NSBSP to generate reports, including the Annual Report, the new report was added to the CAISIS reporting interface (figure 2). This work involved customization of the CAISIS code so that the Annual Report is available in the list of reports and so that the year of the report can be selected.

### 3.3.4 Creating New Publications

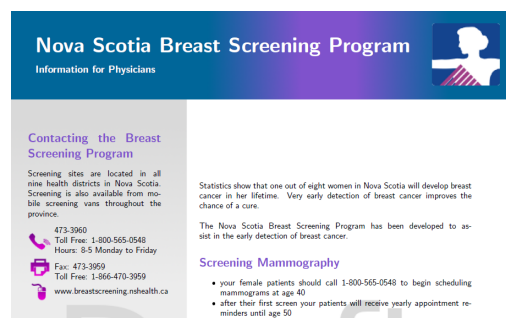


Figure 3: Physician Info Publication

The structure of the Annual Report was updated by separating chapters and sections of text into files. This modular approach offers several advantages over keeping all of the text and code in one file. Future Annual Reports can be customized simply by adding or removing the name of the section of text required. Annual reports can be created for other jurisdictions in a similar manner by choosing the desired text from the existing “library” of components. NSBSP may eventually wish to provide an interface to do this within CAISIS.

These structural changes also facilitate the creation of new publications. During the internship, a publication called *Information for Physicians* was created that included two pages of information that physicians can share with their patients. The publication used customized text and images as well as statistics calculated from data extracted from the CAISIS system.

It was created in a short amount of time because the queries used in the publication were reused from the Annual Report.

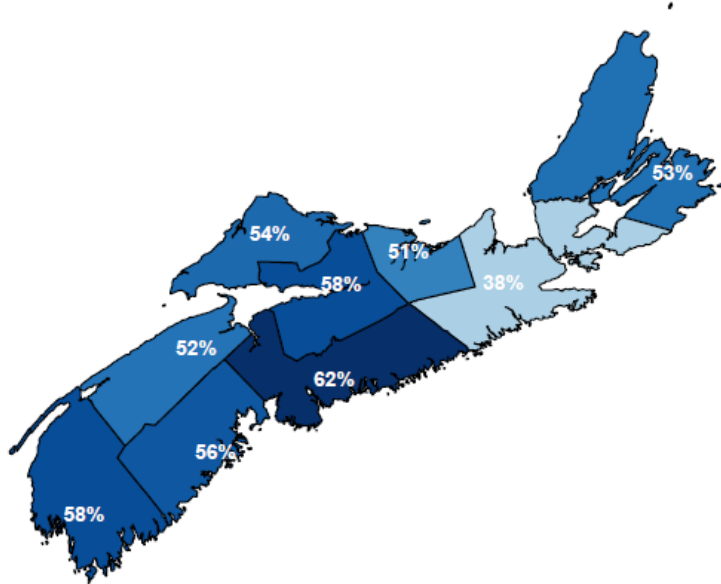


Figure 4: Automated Map of DHA Participation Rates

Additional publications may be created in a similar fashion. Potential publications could include a Patient Information Sheet, Radiologist Report Card, Annual Statistical Report, and an Annual Summary Report.

### 3.3.5 Mapping Participation Rates

As part of the updates made to the Annual Report, NSBSP indicated a requirement to map DHA performance indicators on a map of Nova Scotia. This was accomplished by obtaining a Geographic Information System (GIS) shape file with DHA coordinates, using the R software to automatically import the coordinates and calculate the corresponding participation rates, and generating a provincial map with DHA coloured by relative participation rates. The generated map (figure 4) was added to the library of components available for use in the next Annual Report.

### 3.3.6 Gail Model Plug-in

The Gail Model is a statistical model that uses “a woman’s own personal medical history to estimate her risk of developing invasive breast cancer over specific periods of time” (*Breast Cancer Risk Assessment Tool*, 2011a). To add additional value to the data stored within CAISIS a plug-in was created that calculates each woman’s risk of developing breast cancer using the information available and displays it amongst her summary information. Displaying the risk to clinicians is important so that women at higher risk levels are prompted to return for screening at more frequent intervals. Although the Gail Model incorporates only risk factors that are not under the patients’ control, such as a family history of breast cancer, clinicians can use it to discuss risk factors with patients and encourage regular screening (Gail et al., 1989). Other statistical models that use controllable risk factors, such as body mass index, could be incorporated into the system in a similar fashion to provide opportunities to discuss lifestyle changes with patients.

The source code for the Breast Cancer Risk Assessment Tool was provided by the National Cancer Institute (*Breast Cancer Risk Assessment Tool*, 2011b).

## 3.4 Evaluations

An informal presentation of student work was given on August 11, 2011. The achievements above were demonstrated for the NSBSP team involved in the project and were received with positive feedback.

The following feedback was provided via email by Prof. Mohamed Abdoell on August 29, 2011.

Hi James,

I want to thank you for your outstanding work during your summer internship this year.

The task of fully automating the generation of the Annual Report on the new Breast Imaging EMR that has been developed on the CAISIS platform is not trivial. Yet you were able to not only complete this substantial task, but were also able to improve on and add to the original implementation plan. For instance the ease and speed with which you were able to learn about and implement the GIS mapping was remarkable and will become a marquee feature of the new EMR. Your insights and contributions to the final product have given it a polish that it would not have had otherwise. And your suggestions for further outputs from the core reporting system will certainly be considered for implementation in the future. The fully automated reporting aspect of the new Breast Imaging EMR is something that other provinces and the PHAC are keenly interested in and will adopt and have already emulated to a certain extent.

In addition to outstanding work on your own internship, I want to thank you for your leadership in helping to synchronize the initial setup of the CAISIS system amongst the other summer interns, as well as acting as the point person for communications with the core development team of software engineers developing the Breast Imaging EMR on technical matters.

Thank you again for your outstanding work and your contributions to a very important (inter)national initiative.

## 4 Relation to Health Informatics

A number of concepts from the first year of the Master of Health Informatics program were encountered during the internship at NSBSP. In addition, an intimate knowledge of the inner workings of NSBSP was obtained previously during December 2010 whilst completing the final project for *HINF 6101: Information Flow and Use*. The project introduced the mission and vision of NSBSP and provided a detailed overview of how the MIS supported the clinical journey of the patient from booking, screening, and diagnostics, to the receipt of biopsy and surgery results, sending results to physicians, and reminding women of their next screen (Wills, 2010).

### 4.1 Health Indicators

Several concepts garnered from *HINF 6101* were applicable during the internship. Mortality is a health indicator used to measure the effectiveness of breast screening on a national level (*Canadian Cancer Statistics 2011*, 2011). As discussed in class, mortality has strengths and weaknesses as a health indicator: it is relatively easy to measure across regions yet it is often over-counted and does not necessarily give a good indication of living a healthy life (Hurley, 2010). The course material provided the intern with the ability to examine each health indicator used by NSBSP with a critical eye. Knowledge of the flow of these measurements up to the national level and their effect on future breast screening efforts nationally and worldwide provided inspiration towards developing a set of queries that provide reproducible results and can be used by any organization that uses the CAISIS software.

### 4.2 Benefits and Harms of Screening

In the course *HINF 6120: Fundamentals of Clinical Care for Non-Clinicians* students learn the difference between beneficial and harmful screening and how to use available information to determine when screening should be used. Screening tests having low specificity are more likely to falsely yield positive results. As with many types of screening tests, each level of breast cancer screening tests have a higher specificity but become more invasive. For instance, mammography carries a slight risk of exposure to radiation (*Understanding Mammograms and Your Risk of Breast Cancer*, 2011) but a false-positive result may lead to an unnecessary biopsy with the risk of infection, bleeding, or bruising (*Breast biopsy*, 2011). These considerations have contributed to a U.S. Preventative Services Task Force grade B recommendation of biennial screening mammography for women aged 50 to 74 years, a grade C recommendation to begin screening before age 50, and a recommendation against teaching breast self-examination (*Guide to Clinical Preventive Services, 2010-2011*, 2011).

The understanding of the benefits and harms of screening acquired through the Health Informatics program provided an extra level of comprehension of the need for accurate and timely reporting. Continuously monitoring the success of the screening program for various demographics of patients allows policy-makers to refine screening guidelines as necessary. This knowledge also provided the background needed to design a useful software plug-in that calculates breast cancer risk using the Gail Model so that clinicians may discuss risks with patients and schedule the appropriate screening.

## 4.3 Statistics and Research

The *HINF 6030: Statistics for Health Informatics* and *HINF 6020: Research Methods* courses in the Health Informatics program provided the basis to understand the value of the data contained in the NSBSP system. The vast array of demographic information collected and stored allows for the stratification of patients for various research purposes and tracking the various health outcomes allows for a broad spectrum of research to be performed.

This component of the Program also provided understanding of how Canadian screening programs calculate health indicators. For example, Retention Rate, which is “The estimated percentage of women who are re-screened within 30 months of their previous screen” (*Report from the Evaluation Indicators Working Group: Guidelines for Monitoring Breast Screening Program Performance*, 2007) must be calculated using the actuarial method for survival data. Having a basic understanding of survival analysis made the Retention Rate definition easier to understand and calculate.

## 4.4 Project Management

Although familiar with Project Management prior to the Health Informatics program, the concepts from *HINF 6300: Project Management for Health Information Projects* were applied throughout the internship. The Annual Report updates were divided into work packages and organized so that they coincided with the completion of dependencies by the external developer. Creation of a plan for the internship also allowed NSBSP to coordinate their tasks and activities accordingly.

# 5 Proactive Family History Tracking

## 5.1 Family History as a Risk Factor

Family history of breast cancer has long been recognized as a risk factor for the disease. In the United States, up to 9.1% of breast cancer cases can be attributed to a family history of breast cancer in first-degree relatives (Madigan, Ziegler, Benichou, Byrne, & Hoover, 1995). First-degree relatives include a patient's mother, sister, or daughter. The same article reports that the relative risk of being diagnosed with breast cancer with a first-degree family history is higher for women aged 30-49 compared to women in older age groups. A higher risk of breast cancer has also been identified in women having a second-degree relative with breast cancer, such as an aunt or grandmother (Sattin et al., 1985). The degree of increased risk was also found to vary according to some of the characteristics of the relatives' cancer such as whether the woman was pre- or post-menopausal, whether the cancer was found on one or both sides of the body, and the number of relatives with breast cancer.

NSBSP Clinical Practice Guidelines (*NSBSP Clinical Practice Guidelines*, 2011) recommend annual mammography screening for women above age 40 with a family history that includes at least one first-degree relative with breast cancer. This contrasts with women without a family history of breast cancer who are recommended for annual screening after age 40 and biennial screening after age 50.

## 5.2 Self-Reporting of Family History

In Nova Scotia women are interviewed about their family history at their first screening appointment. This information is reviewed with the patient at each subsequent appointment. Family history is stored in the Program's information system and used to generate the recommended date of the next screening appointment.

Reliance on self-reported family history information in this context is problematic for several reasons. Although it has been found that there is a high probability (95.4%) of accurate self-reporting of breast cancer amongst first-degree relatives (Ziogas & Anton-Culver, 2003) this result is generalizable only to patients that have themselves been diagnosed with breast cancer. There is little information on the accuracy of self-reporting of breast cancer family history by women that have not been diagnosed with breast cancer but it can be speculated that a diagnosis of breast cancer may increase patient awareness and lead to further investigation of their family history. Research has shown a lower accuracy of self-reporting of breast cancer amongst second-degree relatives (Ziogas & Anton-Culver, 2003). Omission of second-degree relatives from the Gail Model has also been shown to result in an underestimation of risk (Crispo et al., 2008).

The current method of collecting family history suffers from a time delay in responding to changes in history. For most women between 50 and 69 years of age there is at least a two year interval between screening appointments. When a relative is diagnosed with breast cancer a women will likely not return for screening within a year, as the guideline prescribes, even though her risk has increased. In the best case an attentive family physician may be aware of breast screening guidelines and ensure that a newly-diagnosed patient's relatives receive more frequent screening; otherwise NSBSP must rely on the relatives to self-report the change in family history at the next screening appointment.

Family history of breast cancer tends to change significantly for women between the ages of 30 and 50 (Ziogas et al., 2011). NSBSP accepts self-referral for screening of women aged 40-49 but women under 40 with a family history of breast cancer depend solely on their physician's discretion to be referred for screening.

An accurate and up-to-date family history would assist in the earlier detection of breast cancer amongst those most at risk. A Health Informatics solution can assist in addressing these issues in recording family history and result in improved outcomes for patients.

## 5.3 Proposal for Proactive Family History Recording

NSBSP has the opportunity to implement proactive family history recording because of its involvement in the full patient journey for the early detection of breast cancer for all Nova Scotian women. NSBSP is notified of all breast cancer diagnoses which are then recorded in its information system. The following changes are proposed to facilitate links between breast cancer patients and their relatives to address the problems identified in this report.

### 5.3.1 Clinical Workflow

Once notified of a patient's diagnosis of breast cancer, NSBSP must contact the woman to establish relationships to other biological family members. It is proposed that this contact be established through the patient's family physician using the same means as existing secure communication (fax or letter). The patient must give explicit permission to share her diagnosis of breast cancer with only those family members she wishes and has already informed about the diagnosis. She must also provide enough information to uniquely identify and contact the members of her family, for instance: name, age, and postal code allow for unique identification of 99.9991% of patients in the NSBSP system while name and postal code alone allow for unique identification of 99.94% of patients according to the NSBSP sample dataset. A full address would be required for relatives that are not in the system so that they could be contacted by mail. The patient must record the type of relationship with each family member such as 'daughter' or 'niece'. For relatives that have not yet reached a legal age, contact information should be gathered for their parents or guardians.

When the information has been collected and entered into the system there are three possible situations for each relative: a unique match with an existing record in the system, no matches with existing records, or multiple matches with existing records. In the former situation, it may be assumed that we have found the relative in the system and use the contact information on record. For the two latter situations, the system may use only the provided information to contact the relative.

The NSBSP Clinical Practice Guidelines may then be used to determine the changes to the recommended screening for each relative. For instance, consider the following storyboard:

At age 57, Marie has recently been diagnosed with breast cancer. The Nova Scotia Breast Screening Program has sent a form to her physician to gather more information about female family members that may be affected. Marie lists the following family members:

1. daughter Cynthia, age 30
2. sister Francine, age 62
3. niece Kelly, age 45
4. after some thought she adds her granddaughter Anna, age 7

Once NSBSP receives the information, the following action is taken:

1. Cynthia has not had any encounters with NSBSP in the past. She is sent a letter that notifies her that because her mother has been diagnosed with breast cancer she should begin annual screening at age 40. Cynthia calls NSBSP to give her permission to be added to the system and receive a screening reminder when she turns 40.
2. Francine has received mammograms in the past but has not been screened in three years. She is sent a letter that notifies her that because her sister has been diagnosed with breast



cancer her risk is higher and she should be screened annually. Francine calls NSBSP to give her permission to be recorded as Marie's sister and schedules an appointment for a mammogram.

3. Kelly has not had any encounters with NSBSP in the past. She is sent a letter that notifies her that because her aunt has been diagnosed with breast cancer she should begin annual screening. Kelly does not respond to the letter and after six months NSBSP discards her information.
4. As part of the same letter, Cynthia is notified that her daughter Anna should be screened annually starting at age 40. When Cynthia called NSBSP she also gave permission for Anna to be linked in the system as Marie's granddaughter and Cynthia's daughter and receive future reminders.

Patients that have familial relationships established within the system should continue to have their family history reviewed at scheduled appointments. If they have had children since the most recent breast cancer diagnosis they should consider establishing links to these children in the system.

### 5.3.2 Software Requirements

Requirements for this functionality are summarized as follows:

1. The system must allow the entry of contact information for a patient's biological family members: first name, last name, address, postal code, relationship, with the possibility of entering approximate age. This information must be stored in a temporary location until each family member has consented to the relationship in the system.
2. The system must uniquely match each family member's information with existing patients where possible.
3. The system must use all available information along with the NSBSP Clinical Practice Guidelines to adjust each family member's recommended screening plan.
4. The system must generate customized letters for each family member that indicates the relationship to the diagnosed patient and the recommended changes to the family member's screening and reminder schedule.
5. The system must record legal guardian information for minors and combine notification letters where possible.
6. The system must allow booking clerks to record verification of a relationship by a family member and consent for that relationship to be recorded in the system.
7. The system must remove unverified family member information six months after they have been entered.
8. The system must display family members and allow navigation to the profiles of those family members that have records in the system.

### 5.3.3 Technical Solution

Figure 5 shows a simplified UML class diagram with the entities that would be required to facilitate this solution as a CAISIS module. Patient information is already stored in the CAISIS system. A new relationship would be required to link patients to other patients. In addition, a new class would be required for family members that have not been verified as patients in the system or have not yet provided their consent to be related in the system.

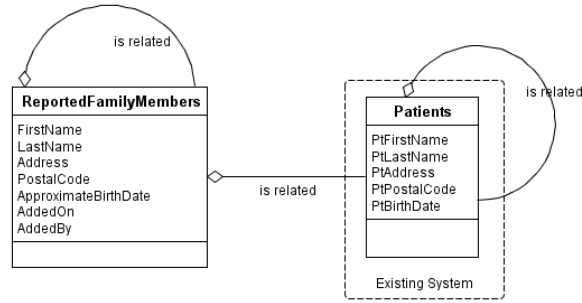


Figure 5: UML Class Diagram

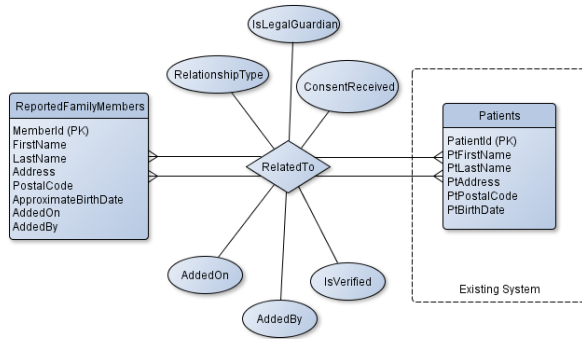


Figure 6: Entity Relationship Diagram

Figure 6 shows the resulting Entity Relationship Diagram. A RelatedTo table would be necessary to link ReportedFamilyMembers with Patients, ReportedFamilyMembers with other ReportedFamilyMembers, and Patients with Patients. The RelatedTo table would need attributes to indicate the type of relationship, whether consent and verification has been received, and whether the relationship indicates a legal guardianship.

Figure 7 is a screen shot showing how family history is currently displayed in the new NSBSP system. Figure 8 provides an example of how the system interface could be modified to facilitate the solution. This mock-up shows how the record for Cynthia from the example above would look once she is added to the system. Cynthia’s mother Marie is clearly shown as having a breast cancer diagnosis. Cynthia’s other known relationships are listed including her daughter and aunt. Those family members with a patient record in the system have a hyperlink for their name that can be clicked to navigate to their record.

These modifications could be implemented as a CAISIS module with database changes made using SQL queries and the user interface changes written in C#.

### 5.3.4 Limitations

#### 5.3.4.1 Privacy

Privacy is a key concern for this solution because personal information is being collected and stored and personal health information is being shared with other people. To comply with privacy legislation, a patient must give the authority to collect personal information. When a patient is providing the names of their biological relatives it is important that they are informed about how the information will be used and give explicit consent for the collection of the information. The patient should also provide explicit consent for

**Family Members for LQJ ZIL**

# of

Side of Family

Relation

Death Age

[-] **Family Diagnosis**

Diagnosis	Diagnosis Age	Notes	Reset
Breast Cancer			

Figure 7: Family History Screen Shot

**Family Members for Cynthia**

[-] **Family Diagnoses**

Name	Relationship	Diagnosis	Diagnosis Date
<a href="#">Marie</a>	Mother	Breast Cancer	Aug-11-2011

[-] **Other Family Members**

Name	Relationship	Date of Birth	Screening Status
Anna	Daughter*	April 8, 2004	Not Eligible For Screening
<a href="#">Francine</a>	Aunt	January 2, 1949	Screened 4-Sep-2008

\* Indicates patient is legal guardian of this family member.

expand

Figure 8: Example Interface

the nature of their diagnosis to be disclosed to the individuals they list on the form. Because there are two parties involved in each familial relationship it is necessary to also obtain consent from the family member before retaining and using the information in the system. To satisfy regulations, it is also vital that no more information is collected than necessary and the information is not used for any other purposes than to provide care to patients and their family members.

#### **5.3.4.2 Paperwork**

Information about a patient's family members is recommended to be collected and communicated to NSBSP on paper. This is not an ideal means of communication because it requires the management of paper forms and transcription of the information into the electronic system. However, the NSBSP system does not currently extend its interface either to the general public or to family physicians. Future work could include an electronic interface for directly entering family member data at a patient's family physician office.

#### **5.3.4.3 Adoptions**

As research around the risks of a family history of breast cancer has been limited to biological relationships, it is necessary to capture only biologically related family members. The solution should clarify this in the instructions communicated to the patient.

## 6 Conclusions

- The objectives of the Master of Health Informatics internship at the Nova Scotia Breast Screening Program have been achieved.
- The primary goal of updating the NSBSP Annual Report to use the new system as the source of data was met.
- Additional contributions were made to restructure the report, add GIS mapping, provide customization for future reports, and create a new plug-in to calculate breast cancer risk.
- Contributions to the project were well-received with positive feedback from supervisors and colleagues.
- Internship contributions were closely related to the field of Health Informatics, specifically focusing on coursework topics such as health indicators, clinical workflow and information use, screening harms and benefits, statistics, research methods, and project management.
- Problems associated with self-reported family history in the context of breast screening were analyzed and a Health Informatics solution was proposed.

## 7 Recommendations

- NSBSP should continue to build on the library of report queries and report components to facilitate the timely and consistent development of future reports.
- The Program should consider using the existing libraries of reusable components to develop additional reports such as a Patient Information Sheet, Radiologist Report Card, Annual Statistical Report, and an Annual Summary Report.
- The automatic extraction of Nova Scotia Community Counts data should be run on a yearly basis and the website monitored for changes that could affect the script.
- NSBSP should extend the existing system to manage relationships between patients that have been diagnosed with breast cancer and other family members at risk.
- The system should collect contact information for each family member, generate notifications for these family members, allow family members to verify and consent to the relationship, suggest modifications to screening recommendations, and allow for navigation between the profiles of family members in the system.

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