Enhancing Cancer Systemic Therapy Surveillance in Nova Scotia: Development of Quality Indicators and Exploration Of a Potential Data Source

by

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Performed at
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In partial fulfillment of the requirements of the Master of Health Informatics Program
Dalhousie University

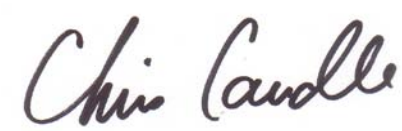
Report of internship for the period January 9 – April 14, 2006

Date submitted: April 17, 2006

Acknowledgements and Endorsement

I would like to thank Cancer Care Nova Scotia for the opportunity to complete this internship. I am grateful for the learning experience and the relationships I have formed with the staff in the Surveillance and Epidemiology Unit at Cancer Care Nova Scotia.

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



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Executive Summary

The internship project described in this report was to research indicators and health care quality frameworks as related to cancer systemic therapy. Part of the project was also to explore the potential linkage of data from the Oncology Patient Information System (OPIS) cancer registry with data from the newly implemented MEDITECH Pharmacy Module. The Pharmacy Module is a new system that has been implemented as part of the Nova Scotia Hospital Information System (NShIS). The linkage will allow disease and stage information to be linked with treatment information to produce indicators that will help improve the quality of cancer care.

The work was done in the Surveillance and Epidemiology Unit (SEU) of Cancer Care Nova Scotia (CCNS). CCNS is a provincial program of the Nova Scotia Department of Health (NSDOH) and works to coordinate, support, and evaluate cancer services throughout Nova Scotia. The Cape Breton Cancer Centre (CBCC) was also involved as they are a central cancer centre that has already been using the MEDITECH Pharmacy Module for over 18 months. If the linkage works here, it would then be extended to cover the rest of the province.

Indicators and health care quality frameworks were researched through a thorough literature review. The review utilized online databases, Internet search engines, websites, and personal communications. In total, about 160 cancer systemic therapy indicators and 13 quality frameworks were found. This will provide an excellent reference and starting point for the selection of systemic therapy indicators to be used in Nova Scotia. The experience also enabled the author to advance his knowledge of approaches to literature reviews.

A Canadian environmental scan was completed to gather relevant information from systemic therapy monitoring projects in cancer agencies in other provinces. Valuable information was acquired regarding indicators reported, data sources, and methods of data capture from provinces that have systemic therapy surveillance systems in place. One of the most valuable pieces of information was from a facility that captures systemic therapy data using the same system intended for use in the current project. They had customized the MEDITECH Pharmacy Module to capture regimen drug level information rather than only individual drug information. This will be necessary to report on systemic therapy in meaningful ways. Further investigation of this customization is warranted. This finding illustrated first hand for the author the importance of undertaking an environmental scan.

The administrative and technical requirements to perform a linkage of the two datasets were investigated. Because of the respective ownerships of the datasets and privacy issues, permissions will be required from CCNS, DHAs, NSDOH, NShIS, as well as approval from the respective DHA ethics review boards. Technical requirements include

extraction of data files from each system and linkage of the two files based on common patient attributes. This would have to be performed by a MEDTECH systems analyst and staff in the CCNS SEU. Specialized software will be used to complete the linkage. The author had the opportunity to view a sample linkage exercise undertaken in the SEU. It could be seen that it is a very useful tool for data integration, which is a common step in the data preprocessing required for many types of data analyses.

In anticipation of data extraction and linkage, a set of data variables that would be required from each system was compiled. This was easy to do for the OPIS system as a detailed data dictionary is maintained by CCNS. Such a data dictionary does not exist for the MEDTECH Pharmacy Module, thus a system demo and screenshots were used. Further discussions with a systems analyst and Pharmacy Application Team members will be required to acquire the details necessary to choose which fields are most appropriate for the creation of indicators and to perform the data linkage. This illustrates the concept of tacit knowledge and the difficulty in acquiring knowledge that exists only in the minds of experts. It is recommended that a data dictionary be created as it is certain there will be more requests for such information for other research projects in the future.

The health informatics problem tackled for this report is one that is related to the next step in the development of systemic therapy quality indicators. Because a framework specific to cancer systemic therapy was not found in the literature the author chose to create one based on the indicators and frameworks that were found. Both common and relevant framework dimensions were used and these were then populated with relevant indicators from the literature search. The dimensions used for the framework are:

- Accessibility
- Effectiveness
- Appropriateness
- Efficiency
- Safety
- Patient Satisfaction

Some indicators were created “from scratch” to fill in some missing gaps in the framework. This framework may be useful to informing discussions regarding indicator selection for the current project.

With the completion of the first phase of the systemic therapy surveillance project, it can now be seen what needs to occur next. The following recommendations are made at this time:

- **Assemble a working group** to review the results of the literature review and select indicators that are relevant for local stakeholders. A list of indicator criteria and considerations was compiled and will be useful in these discussions. As well, consideration should be given to the creation of novel indicators where necessary.

- Examine more closely the feasibility of altering the MEDITECH Pharmacy Module to **capture regimen level drug information**. If it is found to be feasible, then steps should be taken to implement the change.
- Acquire the necessary details regarding the **Pharmacy Module data variables** that would be used in the data linkage and in the calculation of indicators. This would be done with systems analysts and Pharmacy Application Team members.
- **Perform a trial data linkage** with a test sample of data from OPIS and MEDITECH. This will uncover any hidden obstacles and begin to show the merit of the linkage project.

At this point, the project remains feasible. There are a few obstacles to be overcome, but with perseverance and a continuation of the current momentum, the final goals of enhancing the surveillance and reporting of systemic therapy in Nova Scotia will become a reality.

Introduction

The primary focus of this internship was on a study to assess the feasibility of linking cancer systemic therapy (chemotherapy and other drugs) data from hospital pharmacy information systems with data from the provincial cancer registry to allow for the reporting of useful and actionable indicators related to systemic therapy.

The pharmacy information system of interest for this project is the MEDITECH Pharmacy Module. It is one of the modules chosen for implementation as part of the Nova Scotia Hospital Information System (NShIS). This system is designed to link 34 hospitals across the province to allow electronic sharing of patient information among health care professionals. The Pharmacy Module records all medications ordered for all patients receiving treatment within a hospital. As such, it is an excellent record of drugs ordered for patients undergoing systemic therapy for the treatment of cancer. It should be noted that facilities in Capital Health will not be using the Pharmacy Module because they already have their own systems in place; although, the NShIS will be linking to these systems in the future. For this initial phase, the Pharmacy Module in use in the CBDHA was examined. It has been in use there for 18 months and covers systemic therapy administered at the CBCC. As such, it is an ideal location to test the feasibility of a data linkage.

The provincial cancer patient registry is the OPIS system and it falls under the responsibility of CCNS. OPIS is a database of all cancer patients in Nova Scotia. It has demographic, disease, and some limited treatment and visit information on everyone in the province who has been diagnosed with cancer. Systemic therapy is not recorded in OPIS. The linkage with data from the MEDITECH Pharmacy Module is being sought as a way to fill this gap. It should be noted at this point that the type of linkage proposed is not a "live" linkage in which one database could automatically connect to and extract data from the other through a network. The planned link would be the sort whereby data from each database is extracted to individual files then combined into a single file based on patient attributes common to both datasets. Work to generate indicators would then be done on this single file.

Since the main purpose of the linkage is for the reporting of indicators related to systemic therapy, part of the work of this initial phase was to find systemic therapy indicators that have been reported in the literature or are in use by other cancer agencies in other provinces. We were also interested in finding indicator frameworks that would help us organize a complete yet streamlined set of indicators. A great deal of the author's time at CCNS was spent on this part of the project.

It is relevant to state at this point the definition of systemic therapy that was chosen for use in the project. A specific definition was chosen to ensure all team members were clear on the scope. The definition used is as follows:

> *The use of drugs for the treatment or support of cancer patients. Systemic therapy includes cancer chemotherapy, hormone therapy, immunotherapy and supportive care drugs, and includes drugs administered by any route.*

This definition was adapted from, *Systemic Therapy Manual for Cancer Treatment*, edited by Larry Broadfield [2]. Larry is Manager of the Systemic Therapy Program at Cancer Care Nova Scotia and was also part of the core team assigned to work on this project.

The project team had representation from all relevant fields. There was representation from the SEU at CCNS, including staff familiar with the OPIS cancer registry and the use of record linkage software. Cancer systemic therapy expertise was provided by pharmacists at CCNS and CBDHA as well as a medical oncologist. There was also administrative representation from the CBCC. A complete list of all team members can be found in Appendix A.

The project work was made possible by funding provided by the Public Health Agency of Canada (PHAC). As part of the contract, CCNS was responsible for several specific deliverables related to the project work:

- Results of the literature review on systemic therapy indicators and indicator frameworks
- Results of a Canadian environmental scan to investigate systemic therapy surveillance and reporting ongoing in other provinces
- A list of the administrative and technical requirements to link the two datasets
- A list of potential data variables from both the MEDITECH Pharmacy Module and OPIS that would be used to link the two datasets and to calculate indicators
- An estimation of how much of the total provincial systemic therapy utilization the proposed linkage would actually cover

The author had primary responsibility for the literature review and provided support for all other deliverables.

The first section of this report provides a description of CCNS and the range of work performed by the program. Following that is a section that describes the main work the author completed or was involved in related to the systemic therapy project. This section is subdivided based on the deliverables mentioned above. A section addressing the estimation of the coverage of provincial systemic therapy that would be obtained by using MEDITECH is not included. At the time of writing of this report, the project team had not fully addressed this issue.

Next is the “Health Informatics Problem and Solution: A Systemic Therapy Framework” section. This outlines the authors approach to a problem relating to the current project. Since an indicator framework that was specific to cancer systemic therapy was not found in the literature search, the author took this opportunity to develop one based on the indicators and frameworks that were found.

Finally, the “Conclusions and Recommendations” section summarizes some of the main findings of this early phase of the surveillance project and outlines what the author, as well as the project team, recommends should be completed next.

The appendices at the end of this report contain samples of the output created for each of the deliverables. Appendix B is a guide to the acronyms and abbreviations used throughout this report.

Cancer Care Nova Scotia

CCNS is a provincial program of the NSDOH under the Division of Acute and Tertiary Care. Established in 1998, their directive is to coordinate, support, and evaluate cancer services in Nova Scotia. Their work is guided by the following four broad goals [1]:

1. To ensure all Nova Scotians have access to high quality cancer care
2. To reduce the number of people getting cancer and the number of cancer deaths
3. To provide reliable and helpful cancer information to Nova Scotians
4. To facilitate stronger cancer research programs in Nova Scotia.

To achieve these goals, CCNS has numerous programs which are described below [1]:

- **Cancer Patient Family Network** – provides information to, support, and representation for cancer patients through work with cancer patients, cancer survivors, and families.

- **Cancer Patient Outreach Clinics** – provides cancer patients in Yarmouth, Antigonish, and neighboring communities with more of the care they need without having to travel to the more centralized cancer centres in Halifax and Sydney.

- **Cancer Patient Navigation** – improves access to and coordination of cancer services for patients.

- **Cancer Site Teams** – review cancer care plans and develop clinical practice guidelines specific to each kind or anatomical site of cancer.

- **Cervical Cancer Prevention Program** – works to decrease the incidence of cervical cancer through monitoring of all pap smears in Nova Scotia and to increase awareness of the importance of regular Pap testing.

- **District Cancer Programs** – network of cancer services across the province whose development was facilitated by CCNS. They work to deliver consistent and quality cancer care.

- **Education for Health Professionals and Patients** – undertakes development, testing, and implementation of a series of continuing education modules for health care professionals who work in cancer-related areas.

- **Palliative and Supportive Care** – works to ensure that the most appropriate palliative care programs and services are provided to cancer patients and their families.

- **Patient Navigation Community Liaison** – works to meet the unique cancer-related needs of African Nova Scotians, First Nations, and immigrants.

- **Prevention Coordinator** – supports community efforts to encourage healthy lifestyle choices to reduce cancer risk.

- **Dalhousie Cancer Research Program** – This joint initiative of CCNS and Dalhousie Faculty of Medicine, Dalhousie Medical Research Foundation, the Canadian Cancer Society, the Queen Elizabeth II Health Sciences Centre, and The IWK Health Centre provides a coordinated approach to cancer research in Nova Scotia.

- **Surgical Oncology Network** – through education, quality assurance studies, and the development of clinical practice guidelines this network ensures consistent delivery of high quality surgical cancer treatment across the province.

- **Systemic Therapy Program** – standardizes how cancer drug therapies are administered.

- **SEU** – collects and analyzes cancer data to provide valuable information regarding cancer incidence, risk factors, the success of various treatments, and other information that may be required for developing and planning cancer services across the province.

The work for the internship was completed in the SEU under the supervision of **Maureen MacIntyre**, who is the Director of that department.

Work Performed at CCNS

As mentioned in the introduction, the work completed as part of the author's internship was primarily related to the early phase of a project to monitor and report on cancer systemic therapy in Nova Scotia. The work completed for each of the major deliverables required for this first phase of the project as well as reflections on how it relates to health informatics and the author's own knowledge and experience is described in this section.

Literature Review of Systemic Therapy Indicators and Indicator Frameworks

The literature review was a major undertaking and focused on two key areas. The first was to discover specific indicators already in use as part of other cancer systemic therapy surveillance projects (or as recommended by authoritative bodies), and the second was to find general frameworks that could be used as a guide in developing a comprehensive yet focused set of systemic therapy indicators.

The author created a literature review protocol based on information, guidelines, and recommendations found in a number of authoritative sources:

- Personal communications with Janet Joyce, Director, Library and Information Services, at the Canadian Coordinating Office for Health Technology Assessment [3]
- *Undertaking Systematic Reviews of Research on Effectiveness* by the Centre for Reviews and Dissemination; Stage II, Phase 3 – Identification of Research [4]
- *Cochrane Handbook for Systematic Reviews of Interventions*, Section 5: Locating and Selecting Studies for Reviews [5]
- Published Journal Articles:
    - Systematic Literature Reviews, by Adrian White and Katja Schmidt [6]
    - Beyond Medline for Literature Searches, by Vicki S. Conn et al. [7]
- Appendix 1 from a Canadian Coordinating Office for Health Technology Assessment technology report as an example of a documented literature review protocol [8]

A draft version of the author's planned protocol was circulated to the core team members for review. Additional revisions were made to the protocol to incorporate new sources, relevant keywords, and subject headings as they were discovered during the initial stages of the search. The protocol made use of online electronic databases, Internet search engines, websites, and personal communications. As a sample, the search strategies used to search for systemic therapy indicators in the online electronic databases can be found in Appendix C.

The literature review was quite successful. Even though the final total number of articles used to compile indicators and frameworks was small (23), it still provided adequate information for use in the project. Some sources described indicators and elements of framework that would not have otherwise been considered by the team. In total, there were approximately 160 indicators and 13 frameworks found. The indicators were summarized in detail in an indicator inventory table and the frameworks were compiled into a separate master list. As a sample, a portion of the indicator inventory is shown in Appendix D and a sample framework is shown in Appendix E.

This literature review was an excellent learning experience. It was an excellent opportunity to do some in depth self-directed learning about potential electronic databases, the ways in which search terms can be combined, as well as typical ways to document the results and to organize the relevant findings. The literature review references listed above were very informative and gave the author the confidence to know that the work being done would be of an acceptable caliber. Being of such great value, the references that were used were compiled as a sort of literature search learning package and stored on a CR-ROM for future use by the author and by CCNS.

This experience also came at an appropriate point in the author's knowledge and skills development. Enough was already known about literature reviews that the new information could be readily assimilated and rapidly applied. Yet, the additional knowledge still brought the author's skills, knowledge, and comfort level up to a much higher level. There was also a great sense of autonomy and satisfaction afforded by the self-directed nature of the learning. It is also recognized that this is a skill that can be applied to any topic in health informatics and beyond and in a wide variety of research-related jobs. It is also realized, however, that, as with any topic, there is still much to be learned.

Many of the details of the search including the protocols for searching each of the electronic databases, the numbers of articles retrieved at each step, the personal communications made, and the dates and addresses of websites that were searched were accurately documented. Being so meticulous was time consuming but proved very useful in presenting the final results for this deliverable. This was important to show PHAC and any other readers the level of rigor of the search and will help prevent redundancies for anyone interested in extending the search at a later date.

The subject of the search was also highly relevant to health informatics. Indicators and indicator frameworks are currently one of the most popular areas in measuring quality in health care. Excellent introductions to this topic were provided in two of the author's classes: HINF 6100 Health Information: Flow and Use and HESA 6305 Health Services Outcomes (elective). This part of the project was an excellent extension of those introductions (specific materials studied in HESA 6305 were actually used in the compilation of frameworks). In depth knowledge of the dimensions, their definitions, and applications will be a great asset for any future work related to indicator development.

Even though it was not part of the deliverables required by PHAC, there were a number of articles found in the literature search that described criteria or considerations for the selection of the best possible indicators. It was decided that this should also be summarized for use in the project at a later date. The compilation is included in Appendix F. This information is perhaps the most valuable piece for indicator development. Without some knowledge of what makes a truly useful indicator, there is the risk that reported indicators simply become a bunch of numbers on a page in a report that do little to improve health care delivery.

Canadian Environmental Scan

To review cancer systemic therapy surveillance practices at other Canadian cancer agencies an environmental scan was completed. The systemic therapy indicators in use and the information systems used to collect the required data for the indicators were of primary interest.

To ensure that the environmental scan was carried out with as much consistency as possible among all respondents, a list of standard questions to be asked was prepared and reviewed by all team members. The questions are provided in Appendix G. Interviews were conducted over the telephone and each typically took between 20 minutes and 1 hour depending on the scope of surveillance occurring in a particular province. These interviews were conducted by the author and his supervisor. Respondents typically consisted of experts in the areas of cancer systemic therapy or clinical analysts who were familiar with efforts ongoing in their province. A written summary was completed for each interview to highlight the key points and to document the scan for the deliverable required by PHAC. A sample summary is provided in Appendix H.

Many provinces were noted to be at a similar stage in terms of systemic therapy monitoring and reporting. They had discovered a need, but had not yet implemented any formal surveillance mechanisms nor had they decided upon what indicators would be of the most value. As such, several provinces expressed interest in receiving a copy of the final report so they could benefit from the results of the literature review and environmental scan. Other provinces were much further ahead and were important sources of information.

The environmental scan was a valuable experience. It is a necessary requirement whenever embarking on a major new project. It is a very good way to ensure that mistakes made in other jurisdictions are not repeated and that what did work well is incorporated. In a paper written by the author for the HINF 6110 course in the fall of 2004 on the topic of information technology strategic planning in health care, the application of the environmental scan was discussed. To participate in a scan for a real project was an excellent way to realize the true importance of this step.

There is an element of the project that illustrates the usefulness of the environmental scan quite clearly. Early on in the project work, the team made the realization that some of the

systemic therapy reporting would have to be done at the *regimen* level rather than at the individual drug level[1]. Initially, it appeared that information regarding what regimen a patient received would have to be acquired by using custom-made algorithms to search through the lists of individual drugs and the dates on which they were administered to match them to regimen descriptions. Through the environmental scan it was found that cancer agencies that report indicators at the regimen level have regimen names entered into their systems at the point of physician order entry (see Appendix H for an example). With this discovery it was realized that it might be better to try to adapt this method of data collection rather than use potentially cumbersome algorithms. One site reported that they collect regimen information by using a custom built input screen in the MEDITECH Pharmacy Module—the very same module under consideration for the drug data source for the current project. This was a major discovery that was very reassuring to the project team in that it meant it might be easier than initially thought to capture regimen level information here in Nova Scotia. It is also a piece of information that should have been discovered in conversations with local NShIS representatives, but wasn't—again illustrating the importance of an environmental scan.

Requirements to Link the Datasets

The requirements for access to, and linkage of, the datasets from the MEDITECH Pharmacy Module and the provincial cancer registry fall into two categories. There is a set of administrative requirements that would have to be fulfilled to comply with access and privacy policies that apply based on the ownership of the datasets. The second set is the technical requirements required to extract and link the data from the two sources.

To determine the administrative requirements to access data from MEDITECH at the CBCC, the team had interviews with a variety of people involved in the implementation and maintenance of various modules of the MEDITECH system. This included the NShIS Project Owner, a Pharmacy Module systems analyst, and members of the NShIS Integration Team.

Even though the intent of the NShIS is to allow sharing of patient information among health care providers across the province, each district health authority (DHA) has ownership and responsibility for the data collected in each of its facilities. Because of this, the following DHA and NShIS permissions will be required to access data residing in the MEDITECH Pharmacy Modules in the CBDHA:

- Administrative authorization from CBDHA
- Ethics approval from CBDHA
- Permission from the NShIS Privacy Group through the Nova Scotia Department of Health.

[1] Regimens are specific combinations of chemotherapy drugs that are administered together to maximize the toxicity for a cancer while keeping the toxicity to the patient at a manageable level.

Permission from CCNS, ethics approval from the CDHA Ethics Review Committee, and permission from the Nova Scotia Department of Health Privacy Office will be required to access the data from OPIS for this linkage. Staff at the SEU were already familiar with these requirements.

The technical requirements were what could be expected for any sort of data linkage from two different datasets. First, a review of the details of potential MEDITECH data fields (field name, definition, data type, possible values, etc.) would have to be completed to ensure that all relevant fields were chosen and known to be compatible with those in OPIS. This could be done alongside someone with detailed knowledge of the implementation and day to day use of the Pharmacy Module. Through discussions with members of the NShIS Integration Team, it was discovered that each module implemented as part of NShIS has an application team. Each team is comprised of specialists from the applicable health care domains who were heavily involved in the process of implementing the respective modules. This would include defining the data fields for standard use across the province. Discussions with the Pharmacy Application Team had not taken place at the time of writing of this report, but will be a necessary next step.

Next would be an actual extraction of the required data from the MEDITECH system in a form that is suitable for linkage with data extracted from OPIS. This will require the technical expertise of someone familiar with the structure of the MEDITECH data tables, such as a system analyst. The same tasks would have to be performed for OPIS, but the knowledge and expertise is already possessed by staff at the SEU. Lastly, the data from the two datasets would have to be linked together. This will be done using LinkageWiz record linkage software, which is a tool already available and in use at the SEU. The software links datasets based on patient identifiers that are common to both.

The LinkageWiz software is a very useful tool. The author had the opportunity to observe the software in action as staff in the SEU used it to link data from MSI with the cervical cancer screening database. Essentially, fields that are common to both datasets, such as date of birth, first name, last name, and health card number, are used to match records from a master data source with those in another. The different fields have different weights or scores associated with them based on the likelihood that a match signifies a true match. Partial scares are awarded for partial matches. Matches with very high total scores are assumed to be accurate, matches that are very low are assumed to not be matches. Those falling somewhere in between are checked and decided manually. The result is a list of patients with attributes from both datasets. In this case, females from the MSI database were matched with screening histories to determine those who were unscreened or underscreened.

There are many situations in which this type of interlinking of datasets would be of great value. Many types of research involve combining two different datasets to merge attributes for individual patients. This is one of the major steps discussed in HINF 6210 Data Mining for Health Informatics. Data integration was the term used in the class, but it describes the same type of data manipulation or preprocessing that is often required

before any actual analysis can be performed. The knowledge of this linkage tool will be important to the author when encountering future data integration challenges. Although budgetary considerations will be relevant, as the LinkageWiz software is expensive.

Potential Data Variables from OPIS and MEDITECH Datasets

Both the OPIS cancer registry and the MEDITECH Pharmacy Module were examined to determine relevant data variables that could be used. Data variables are required for two main purposes. The first is to enable an electronic linkage between the two databases. This would be done using demographic data fields that would be common to both datasets (described above). The second purpose is for the calculation of the desired indicators and measures. It is the disease, visit, date, drug, dose, and cost types of variables that would be used for this purpose

It was easy to determine what OPIS data fields would be necessary. This was because team members from the SEU are very familiar with the data screens and data tables that comprise the database. It was also because of the readily available OPIS data dictionary maintained at CCNS. The data dictionary lists all fields in the entire database and has a very detailed description of each one. This made it easy for the author to attain knowledge of each field as well.

Attaining the same information for the MEDITECH Pharmacy Module was not as easy. After some exploration with MEDITECH users, NShIS project members, and MEDITECH technical staff, it was discovered that a data dictionary does not exist. It would seem that definitions for the many data elements were created during the initial phases of implementation but these were never compiled into a single, organized document. The only options were to view the data screens from the module during a site visit, to read field names from hard copies of screen shots, and to have detailed discussions with MEDITECH technical staff. The discussions with technical staff had not taken place at the time of the writing of this report and so the descriptions obtained are only assumed definitions based on what could be seen on the data screens.

Appendix I contains a selection of data variables from each of the data sets, a brief description of each, and the purpose of each—either for data linkage or for the calculation of indicators.

This component of the project clearly illustrates the importance of a data dictionary. Without one it is very difficult for potential users to determine the exact specifications of the data fields and they are left to make assumptions that may be incorrect. This can lead to difficulties in data integration and analysis. Or it may prevent the use of data altogether.

At a higher level, this data dictionary problem illustrates one of the key principles discussed in HINF 6230 Knowledge Management for Health Informatics. That is the problem of tacit knowledge. Tacit knowledge is the term used to describe knowledge

that only exists in the minds of subject experts and can only be accessed through personal communications with these experts. One of the challenges of Health Informatics is to capture such knowledge and make it readily available for those that could benefit from it. Unique solutions are required to solve such problems. Although the data dictionary could be created by funding someone to interview the application teams and document the results, alternate approaches may be possible if the information already exists in electronic forms such as e-mails or meeting minutes. There is a good chance that it does and would be a very challenging research project.

Health Informatics Problem and Solution: A Systemic Therapy Framework

It was hoped that through the literature review, an indicator framework that was specific to cancer systemic therapy would be found that could be used to guide the development of indicators for the current project. Several indicator frameworks were found, but none were as specific as that. Therefore, for this section, the author has chosen to develop an indicator framework that is specific to the monitoring of cancer systemic therapy which may be used in subsequent stages of this surveillance project.

The process used to build the framework involved two main steps. The first was to ascertain the indicator dimensions that would be most relevant. The second step was to find (or create "from scratch") specific systemic therapy indicators that would apply to each dimension. The main purpose of the intended framework is to monitor for quality in the delivery of systemic therapy. Elements that are not directly related to the assessment of quality will not be included.

To ascertain the most important dimensions all frameworks found in the literature review were compared side by side to see which dimensions were the most common. A framework comparison grid was used for this and is shown in Table 1. Dimensions are listed down the left side of the table and the adjacent column shows a count of the number of times that dimension appears in the grid. The dimensions are ordered from most common to least common. It can be assumed that dimensions that appear frequently have been deemed important to a variety of authors and so should be given consideration in any new framework as well. Definitions of the dimensions listed in Table 1 can be found in Appendix J.

The top five most commonly used dimensions from the framework comparison grid were adopted for the new framework. They are **accessibility, effectiveness, appropriateness, efficiency,** and **safety**. Continuity also appeared several times, but did not seem to apply to systemic therapy because it refers to the coordination of care among different services that may be required by the same patient. Continuity would certainly apply to cancer in general but since systemic therapy is essentially a single service it does not seem relevant here.

Table 1: Framework Comparison Grid

DIMENSIONS	TOTAL	FRAMEWORKS												
		ISO [9]	CCHSA [10]	revised CCHSA [11]	Donabedian [12]	HCC [13]	NHS [14]	HSURC [15]†	CSQI [16]*	Greenberg et al. [17]*	Manitoba [18]**	Melnychuck et al. [19]**	AMCP [20]**	MacKinnon & McCaffrey [21]** †
Accessibility	11	✓	✓	✓		✓	✓	✓	✓	✓	✓		✓	✓
Effectiveness	11	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓
Appropriateness	9	✓	✓				✓	✓	✓	✓		✓	✓	✓
Efficiency	8	✓	✓	✓	✓	✓	✓		✓					✓
Safety	8	✓	✓	✓		✓	✓			✓			✓	✓
Continuity	7	✓	✓	✓			✓			✓			✓	✓
Client-Centered Care	5		✓	✓		✓	✓						✓	
Competence	5	✓	✓				✓						✓	✓
Acceptability	5	✓			✓			✓		✓				✓
Population Health	4	✓				✓	✓			✓				
Use Intensity	4									✓	✓	✓	✓	
Human and Material Resources	4	✓				✓				✓			✓	
Timeliness	4		✓			✓	✓			✓				
Equity	4		✓		✓		✓	✓						
Focus on the Community	3		✓	✓				✓						
Communication	3		✓				✓						✓	
Expenditure	3									✓	✓		✓	
Work Life	2		✓	✓										
Measurement	2								✓	✓				
Legitimacy	2		✓		✓									
System Alignment	1		✓											
Innovation	1													✓
Competitiveness	1													✓

* Framework is specific to cancer
** Framework is specific to drug therapy
† Adapted from other frameworks

Next, the grid was examined for any further dimensions that may apply based on relevance to systemic therapy despite not being common to several different frameworks. Expenditure seems relevant and may be of great interest in terms of financial planning, but how much is spent alone does not provide a picture of the quality of care. What is of greater interest should be what outcomes were achieved with what was spent. This falls under the efficiency dimension and so is already accounted for.

There are two dimensions that relate to the patient's perspective—client-centered care and communication. Because these two dimensions both relate to the patient's experience and because this element is often overlooked when assessing the quality of

health care, it was decided that these should be included, but combined into one dimension called "**patient satisfaction**."

"Use intensity" and "human and material resources" also seem like viable candidates for inclusion, but alone they do little to indicate the quality of care that is provided to patients. They may be of great interest to those concerned with financial planning, but they will not be included in this framework. Elements of these dimensions, however, will be seen under measures of efficiency.

The second step was to select indicators to fill the framework. This was done by choosing from the indicator inventory. Again, it is important to note that there are many indicators that seem relevant but were not included because they did little to indicate the quality of care. It is important to make the distinction between quality indicators and those that may be used for financial planning or those that just seem to be desired out of simple availability or curiosity.

Table 2 shows the final recommended framework with the associated indicators. It should be noted that the indicators are not in their final useable form, but rather left at a higher level so that they can be specified in more detail as appropriate for their specific intended application. Ideally, they would be specified nationally to allow for comparisons and standard benchmarking across the country. A brief comment is included beside each indicator to provide direction on its measurement and/or use.

Table 2: Final Suggested Indicator Framework with Indicators

Accessibility	
Chemotherapy wait time [22]	This can be expressed in a number of ways: time from referral to consult, time from consult to first treatment, time from diagnosis to first treatment, or as a proportion of people who have waited longer than a given or recommended time. It would also be useful to stratify this by geographical location to check for inequalities
Percentage of systemic therapy drugs covered by provincial drug plan [21]	This would be targeted more at inter-provincial comparisons rather than for a single facility. It would be valuable if drugs that were prescribed more often were somehow given more weight in this measure.
Provider satisfaction with access to new drugs for their patients' condition [21]	This would have to be assessed through a survey of health care providers (physicians and pharmacists primarily) and would be intended for comparison among provinces. A nationally-developed standard survey would be appropriate here.
Accessibility of systemic therapy services	This is meant to be an indication of how difficult it is for patients to get themselves to the facilities that provide their treatments. It could be a measure of the average distance or a subjective assessment by the patients themselves through a survey.
Other measures of equity of service across a jurisdiction	Could be applied anywhere there is suspicion that there is inequality of service provision.
Appropriateness	
Proportion of patients treated according to guidelines [21, 22]	This could be done for a variety of cancer sites and stages.

Institution or continuation of treatments very near death [22]	An indication of inappropriate use.
Effectiveness	
Patient satisfaction with the management of pain, nausea, or other symptoms [16]	As assessed through a patient satisfaction survey.
Quality of Life [21]	This could be assessed at various points along the cancer spectrum, i.e., during diagnosis, treatment, palliative care, or in cancer survivors. A number of patient quality of life assessment instruments already exist. This should be considered one of the ultimate measures of the effectiveness of cancer management
Survival rates	This could be expressed as the proportion of people receiving chemotherapy who survive a certain length of time or as an average or median years of life lived post diagnosis. It could also be narrowed down more specifically to a measure of disability-free life expectancy [21] although this would be more difficult to measure.
Efficiency	
Cost per life year saved [21]	Two of the most relevant measures combined to produce a measure of how much health care value for money is being obtained. This would be a good measure to compare among provinces and with other countries.
Pharmacoeconomic evaluations [21]	To assess the cost effectiveness of drugs. For example, to ensure that the lowest costing drug among equally effective alternatives is used [21].
Other measures	The efficiency of any element of systemic therapy can be assessed by dividing the resources used by the output achieved. This should be considered over and above simply tracking total costs of resources. Without an efficiency measure that accounts for outputs gained, the appropriateness of the use of resources cannot be seen.
Measures of resource use intensity per unit of wait time	This measure provides a good indication of how intensely or effectively resources are being used to produce the wait times that are seen. Caution should be exercised here as many factors beyond that of resources determine wait time.
Safety	
Medication error rates [21, 22]	Errors that are attributable to providers. This should be used as part of a continuous quality improvement tool.
Systemic Therapy incident rates [21, 22]	This would include incidents that happen in the absence of provider error, e.g., unforeseen allergic reactions.
Opioid abuse rates among cancer patients [22 (adapted)]	This would be relevant only where it was thought to be a concern.
Patient Satisfaction	
Patient satisfaction with provision of care [21]	As assessed through a patient satisfaction survey
Patient satisfaction with knowledge of treatment plan and drugs [21]	As assessed through a patient satisfaction survey
Assessment of affordability of drugs and willingness to pay [21]	As assessed through a patient satisfaction survey

Ideally, a framework of this nature should be compiled by a group of stakeholders along with experts in indicator development. This is an intended step in the current project but has not yet been scheduled. Perhaps the framework shown above will be used as a starting point that can be then refined to meet the needs of all involved. It is the author's hope that indicators are selected on the basis of need, rather than availability and curiosity.

Conclusions and Recommendations

This initial stage of the systemic therapy surveillance project was very valuable and provided a good foundation on which to build subsequent work.

The literature review provided a solid starting point for the development of indicators for surveillance of cancer systemic therapy in Nova Scotia. Over 160 indicators and 13 quality frameworks were found. Due to the exhaustive nature of the literature review, it would appear that no further work in this area is required at this time. The next step in terms of indicators will now be to select those that will be useful and applicable to the actual monitoring of cancer systemic therapy in Nova Scotia.

There are a number of recommendations for selecting relevant indicators. The process should be completed by a working group of stakeholders and experts in the field of systemic therapy. The list of considerations for indicator selection (Appendix F) will be useful in informing the group's discussions. Perhaps the novel framework created for this report (see "Health Informatics Problem and Solution: A Systemic Therapy Framework") will also be of value to these discussions. Such a group should also not hesitate to exercise some creativity to produce novel indicators that were not found in the environmental scan or literature review. It is good to base work on that of others, but no real progress is ever made without original ideas. The indicator selection process should also be aligned, or perhaps even combined, with the work of related groups, such as the Nova Scotia Provincial Cancer Control Indicators Working Group. They are currently working to produce a set of indicators that will encompass all aspects of cancer care. Part of the indicator selection process should also be to consider if other data sources need to be investigated to provide a complete indicator reporting picture. The *right* indicators are not necessarily those that can be calculated with the currently available data.

The environmental scan proved quite successful to the systemic therapy project. It was through the scan that the key discovery was made regarding the potential ability to capture regimens in the MEDITECH Pharmacy Module. At this point, it may be worthwhile to examine this capability more closely, perhaps even scheduling a visit or teleconference with the IT staff that already have customized the system in this way. Certainly, this also merits discussions with the MEDITECH Pharmacy Application Team in Nova Scotia to determine its feasibility. If it is found that the system can be customized to capture regimen information, then the proper steps should be taken to implement this change as soon as possible, as it is likely to take a long time.

The requirements for access to and linkage of the datasets from the MEDITECH Pharmacy Module and the provincial cancer registry were discovered. Permissions will be required from the NShIS, DHAs, NSDOH, CCNS, and the relevant ethics review boards.

Both the OPIS cancer registry and the MEDITECH Pharmacy Module were examined to determine relevant data variables that would be useful for the creation of potential indicators. The relevant fields from OPIS were easily determined from the available data

dictionary, but more investigation is required to verify the *assumed* data field definitions from the Pharmacy Module, as they were based solely on screen shots and basic discussions with users. This should be done with a Pharmacy Module systems analyst as well as members of the Pharmacy Application Team. Recommendations should be made for the documentation of this type of information in the form of data dictionaries for all of the NShIS modules. It is certain that this type of information will be sought by others who will require this same type of information for their data linkage projects in the future.

The next major step in the project should be to perform a *trial* linkage with a small test data sample from each dataset. This will serve as a trial run of the technical and administrative requirements. This should be completed soon to maintain the momentum of the project and to find any hidden barriers that have not yet been discovered. As was learned in management skills development, this would serve as the "do" in the plan, do, check, act cycle of implementation and would help push the project into a second cycle and bring the actual surveillance closer to fruition. This should be done despite the fact that regimen level data is not yet available in the source dataset. The investigations and alterations required to pursue the capture of regimens can be done in parallel to help move the project along at a faster rate. As well, some of the indicators not related to regimens can be calculated, tested, and presented to stakeholders in order to check, and perhaps prove, the overall value of the project.

The work completed for this first phase of the systemic therapy surveillance project is a small part of the overall picture. Thus far, however, the project remains feasible. If care is taken to select appropriate systemic therapy indicators, if the OPIS and MEDITECH datasets can be linked to provide a suitable portion of those indicators, and if the ability to capture regimen level data can be incorporated, then the project will likely be a success. It may seem as if there is a lot to be accomplished between now and the realization of the final goal, but if the current momentum is sustained it will occur in due time. And one must always remember, as the Chinese proverb states, "Be not afraid of going slowly; be afraid only of standing still."

APPENDICES

Appendix A: Project Team Members

Core Team Members:

- **Maureen MacIntyre**, Director, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia
- **Larry Broadfield**, Manager, Systemic Therapy Program, Cancer Care Nova Scotia
- **Ron Dewar**, Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia
- **Mona Baryluk**, Director, Cape Breton Cancer Centre
- **Karen Gallivan**, Director of Pharmacy, Cape Breton District Health Authority
- **Dr. Rajbir Pahil**, Medical Oncologist, Cape Breton District Health Authority
- **Rosalee Walker**, Research Assistant, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia
- **Chris Caudle**, Health Informatics Resident, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia

Corresponding Members:

- **Rose Ali**, Director, Administration and Special Projects, Cancer Care Nova Scotia
- **Nathalie St. Jacques**, Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia

Appendix B: Guide to Acronyms and Abbreviations

AMCP	Academy of Managed Care Pharmacy
CBCC	Cape Breton Cancer Centre
CBDHA	Cape Breton District Health Authority
CCHSA	Canadian Council on Health Services Accreditation
CCNS	Cancer Care Nova Scotia
CCO	Cancer Care Ontario
CSQI	Cancer System Quality Index
DARE	Database of Abstracts of Reviews of Effects
DHA	District Health Authority (Nova Scotia)
EMBASE	Excerpta Medica Database
HCC	Health Council of Canada
HITS NS	Health Information Technology Systems Nova Scotia
HSURC	Health Services Utilization and Research Commission (Saskatchewan)
ISO	International Organization for Standardization
NHS	National Health Service (United Kingdom)
NHS EED	National Health Service Economic Evaluation Database
NShIS	Nova Scotia Hospital Information System
OPIS	Oncology Patient Information System
PHAC	Public Health Agency of Canada
SEU	Surveillance and Epidemiology Unit

Appendix C: Electronic Database Search Protocols

Table C1: Electronic Database Search Protocols for Systemic Therapy Indicators

Database and Host System	Date of Search	Search Terms
MEDLINE on PubMed	February 3, 2006	"Neoplasms"[MeSH] AND "Health Services Research"[MeSH] OR "Drug Utilization Review"[MeSH] OR "Quality Indicators, Health Care"[MeSH] AND "Drug Therapy"[MeSH] Limits: English
EMBASE.com	February 10, 2006	#2. 'health care quality'/exp AND [2002-2006]/py #3. 'pharmacoeconomics'/exp AND [2002-2006]/py #4. 'health care utilization'/exp AND [2002-2006]/py #5. 'health services research'/exp AND [2002-2006]/py #6. 'pharmacoepidemiology'/exp AND [2002-2006]/py #7. 'outcomes research'/exp AND [2002-2006]/py #8. #2 OR #3 OR #4 OR #5 OR #6 OR #7 #9. 'drug therapy'/exp AND [2002-2006]/py #10. 'neoplasm'/exp AND [2002-2006]/py #11. #8 AND #9 AND #10 #12. 'drug use'/exp AND [2002-2006]/py #13. #11 AND #12 #14. #11 AND #12 AND [pharmacology and pharmacy]/lim AND [english]/lim AND [humans]/lim #15. #11 AND #12 AND [pharmacology and pharmacy]/lim AND [english]/lim AND [humans]/lim AND [2004-2006]/py
The Cochrane Library on Wiley Interscience Simultaneous searches of : Database of Abstracts of Reviews of Effects (DARE) NHS EED Cochrane Reviews	February 10, 2006	#1 MeSH descriptor Quality Assurance, Health Care explode all trees in MeSH products #2 MeSH descriptor Quality Indicators, Health Care explode all trees in MeSH products #3 MeSH descriptor Economics, Pharmaceutical explode all trees in MeSH products #4 MeSH descriptor Health Services Research explode all trees in MeSH products #5 MeSH descriptor Drug Utilization Review explode all trees in MeSH products #6 MeSH descriptor Pharmacoepidemiology explode all trees in MeSH products #7 MeSH descriptor Outcome Assessment (Health Care) explode all trees in MeSH products #8 (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7) #9 MeSH descriptor Neoplasms explode all trees in MeSH products #10 MeSH descriptor Drug Therapy explode all trees in MeSH products #11 (#8 AND #9 AND #10) [no language or date restrictions]

Database and Host System	Date of Search	Search Terms
Gateway at the National Library of Medicine	February 15, 2006	((Quality Assurance, Health Care[MESH] OR Quality Indicators, Health Care[MESH] OR Economics, Pharmaceutical[MESH] OR utilization[SH] OR Health Services Research[MESH] OR Drug Utilization Review[MESH] OR Pharmacoepidemiology[MESH] OR Outcome Assessment Health Care [MESH]) AND (Drug Therapy[MESH_NOMAP]) AND (Neoplasms[MESH])) AND NOT (Clinical Trials[MESH_NOMAP])
Google Scholar	February 7, 2006	allintitle: indicators chemotherapy –prognostic Date range: 1990-2006 Search only in Medicine, Pharmacology, and Veterinary Science.
Dogpile Internet Search Engine (Simultaneous searches of Google, Yahoo! Search, MSN Search, and Ask Jeeves)	February 15, 2006	indicator cancer 'systemic therapy' andnot "clinical trial" English only Dates: Jan 1, 1990 – date of search Moderate filtering applied

Appendix D: Sample of Systemic Therapy Indicators Found

Dimension	Indicator	Notes/ Examples	Reference
Accessibility	Chemotherapy wait time	Proportion of patients waiting beyond recommended time	CCHSA [22]
		Average time from diagnosis to treatment	CCHSA [22]
		Time from referral to medical oncology consultation	Systemic Therapy Task Force [24]; Env. Scan: ACB
		Time from consultation to treatment	Systemic Therapy Task Force [24]; Env. Scan: ACB
		time from referral to the start of systemic therapy treatment	CCO and CQCO's CQCI [16]
	Timeliness guidelines for treatment of specified cancers, as developed		CCHSA [22]
	Percentage of patients receiving chemotherapy according to site (home, MD office, other outpatient, or inpatient)		CCHSA [22]
	Overall % of drugs reimbursed in each province out of those approved for use in Canada; % reimbursed with restrictions; % not reimbursed		MacKinnon and McCaffrey [21]
	Average annual personal cost for average and high needs consumer of pharmaceutical therapy who rely on public plan		MacKinnon and McCaffrey [21]
	% of population having access to funding support through provincial drug plan		MacKinnon and McCaffrey [21]
	% of requests for special authorization that are approved	Including repeat requests following denial	MacKinnon and McCaffrey [21]
	Benchmarking of benefits provided by each province, territory, federal government, and in other countries		MacKinnon and McCaffrey [21]
	Comparisons of approvals of new drug therapies (including the content) in Canada and elsewhere	need to account for differences in criteria used in processing approvals	MacKinnon and McCaffrey [21]
	Patient satisfaction with access to new therapies and cost-sharing requirements		MacKinnon and McCaffrey [21]

Dimension	Indicator	Notes/ Examples	Reference
	Prescriber and pharmacist satisfaction with access to new therapies for their patients' medical conditions		MacKinnon and McCaffrey [21]
Acceptability	Assessment of affordability and willingness to pay	through patient survey tools	MacKinnon and McCaffrey [21]
	Assessment of patient satisfaction with formulary	through patient survey tools	MacKinnon and McCaffrey [21]
	patient satisfaction with pharmaceutical use	from patient satisfaction surveys	MacKinnon and McCaffrey [21]
	patient satisfaction with provision of care by pharmacists and physicians	from patient satisfaction surveys	MacKinnon and McCaffrey [21]
	patient satisfaction with knowledge of pharmaceuticals	from patient satisfaction surveys	MacKinnon and McCaffrey [21]

Appendix E: Sample Indicator Framework

Table E1: International Organization for Standardization Health Indicators Conceptual Framework [9]

Health Status	
Well-being	physical, mental and social well-being
Health Conditions	Alterations or attributes of the health status of an individual which may lead to distress, interference with daily activities, or contact with health services
Human Function	Levels of human function associated with the consequences of disease, disorder, injury and other health conditions.
Deaths	Age-specific and condition-specific mortality rates, and derived indicators.
Non-Medical Determinants of Health	
Health Behaviours	Aspects of personal behaviour and risk factors that are known to influence health status.
Socioeconomic Factors	Indicators related to the socioeconomic characteristics of the population that epidemiological studies have shown to be related to health.
Social and Community Factors	Measures the prevalence of social and community factors, such as social support, life stress, or social capital that epidemiological studies have shown to be related to health.
Environmental Factors	Environmental factors with the potential to influence human health.
Genetic Factors	Factors outside those normally influenced by individual behaviours or by the social, economic, or physical environment.
Health System Performance	
Acceptability	All care/services provided meet the expectations of the client, community, providers, and paying organizations.
Accessibility	The ability of clients/patients to obtain care/service at the right place and the right time, based on respective needs.
Appropriateness	Care/service provided is relevant to the clients'/patients' needs and based on established standards.
Competence	An individual's knowledge and skills are appropriate to the care/service being provided.
Continuity	The ability to provide uninterrupted coordinated care/service across programs, practitioners, organizations, and levels of care/service, over time.
Effectiveness	The care/service, intervention, or action achieves the desired results.
Efficiency	Achieving the desired results with the most cost-effective use of resources.
Safety	Potential risks of an intervention or the environment are avoided or minimized.
Community and Health System Characteristics	
Resources	(definition not available)
Population	(definition not available)
Health System	(definition not available)

Appendix F: Considerations for Indicator Selection

One of the references discovered was the National Quality Measures Clearinghouse (NQMC) sponsored by the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. The following list of desirable measure attributes and associated descriptions comes directly from the resources section of the NQMC website [25].

- **Relevance to stakeholders** - the topic area of the measure is of significant interest, and financially and strategically important to stakeholders.

- **Health importance** - the aspect of health the measure addresses is clinically important as defined by high prevalence or incidence, and a significant effect on the burden of illness.

- **Applicable to measuring the equitable distribution of health care** - the measure can be stratified, or analyzed by subgroup to examine whether disparities in care exist among populations of patients.

- **Potential for improvement** - there is evidence indicating that there is overall poor quality or variations in quality among organizations indicating a need for the measure.

- **Susceptibility to being influenced by the health care system** - the results of the measure can be operationalized into actions or interventions that are somewhat or substantially under the control of the targets of measurement, leading to improvements that are known to be feasible.

- **Explicitness of evidence** - the evidence supporting the measure is explicitly stated.

- **Strength of evidence** - the topic area of the measure is strongly supported by the evidence (i.e., indicated to be of great importance for improving quality of care).

- **Reliability** - the results of the measure should be reproducible and reflect results of action when implemented over time; reliability testing should be documented.

- **Validity** - the measure is associated with what it purports to measure. The strength of the evidence supporting the validity should be documented. This should include references to published peer-reviewed studies, systematic reviews, clinical practice guidelines, or formal consensus procedures involving experts in relevant fields.

- **Allowance for patient/consumer factors as required** - the measure allows for stratification or case-mix adjustment.

- **Comprehensible** - the results of the measure should be understandable for the users who will be acting on the data.

- **Explicit specification of numerator and denominator** - a measure should have explicit and detailed specifications for the numerator and denominator; statements of the requirements for data collection should be understandable and implementable.

- **Are all individuals in the denominator equally eligible for inclusion in the numerator?** A valid measure of quality of care should exclude individuals that should not receive the indicated care or are not at risk for the outcome.

- **Data availability** - the data source that is needed to implement the measure should be available, accessible, and timely. The burden of measurement should also be considered, where the costs of abstracting and collecting data are justified by the potential for improvement in care.

- **Applicability** – the measure should apply to the desired setting of care and to the providers of the care that is being assessed.

- **Selection from the appropriate domain of measurement** - measures should be selected from the appropriate domain of measurement (structure, access, process, patient experience, or outcome) to ensure that the data produced will be suitable for its intended use. For example, an organization wishing to focus on the perceptions of patients should use patient experience measures since the information is collected directly from the patient. Likewise, an organization wishing to collect data that identifies processes that may affect patient care, and are in need of improvement, should select measures that assess processes of care.

- **Comparisons** - When selecting a quality measure, it is important to determine an appropriate comparison in order to make reliable assessments of quality. Comparisons can be made to prescriptive standards, national benchmarks, or comparisons can be made by stratifying results to examine potential disparities in care among different subgroups.

Another reference found to contain information useful for the process of indicator selection was that by Mainz [26]. The only consideration that was not already covered by the NQMC desirable measure attributes above is presented below.

- **Specificity and Sensitivity** – indicators should be calculated in a way that reduces as much as possible the numbers of false positives and false negatives that are captured.

The article in which the HSURC describe their performance measurement framework also lists some elements thought to be important when choosing indicators [15]. Considerations not already covered in the above two references are listed below.

- **Goal oriented** – indicators should be focused on specific health system goals. They should be specific enough so that the indicator users can tell where modifications are required to facilitate any necessary improvements. For example, post-surgical mortality rates would be of greater use to cardiovascular surgeons than would mortality rates for cardiovascular disease in general.

- **System focused** – indicators should measure the overall performance of the health care *system* and not just *clinical* effectiveness. Individual components of the health care system may be working well, but if they are not coordinated and working synergistically the system may not achieve its goals effectively. System-focused indicators will allow for a better evaluation of this outcome.

- **Outcome focused** – examining outcome allows us to see the true effects of the processes applied in health care. Increased use of drugs, x-rays, and more hospital admissions may actually be harmful to our health. Process measures are suitable for short-term feedback if there is a proven link between the process and intended outcome. An outcome focus also forces us to shift from considering how services are delivered to thinking if there are more appropriate services that could be provided.

Appendix G: Questions Used for the Environmental Scan

1. Do you currently have a system for monitoring and reporting on cancer systemic therapy in your province? Yes No
(If the answer is no, proceed to question 16)

2. What are the main goals of the monitoring and reporting system?

3. Is there a document that describes the system or project?

4. What indicators do you report? Is there a list of indicators that we can have? Do you have an indicator inventory that describes each indicator in detail (e.g., description, purpose, rationale, users, calculation, and health system dimension addressed)?

5. How did you select the indicators to be reported? Working group? Framework? Other? Is the process documented anywhere?

6. What is the source of the data? Database, registry, chart review, other? What are the sampling procedures?

7. Is the data linked at the individual patient level to enable reporting related to incidence, diagnosis, treatment, and outcomes?

8. How often are reports produced? Is one available to us?

9. To whom is the information distributed?

10. What types of actions are taken based on the information?

11. How has the reliability and validity been determined?

12. How have the indicators been tested for accuracy?

13. Are your indicators comparable with those in any other jurisdictions, national standards or initiatives?

14. Are any data reported to CIHI?

15. Do you have any lessons learned that you would like to share with us?

If the answer to question 1 was "No":

16. Do you have formal plans to monitor systemic therapy in the future? If yes: Does this plan include specific indicators yet? Are these plans described in a document?

Appendix H: Sample Summary from Environmental Scan

Newfoundland Cancer Treatment and Research Foundation (NCTRF)

Reporting related to systemic therapy is primarily for budgeting and financial forecasting. Reporting is not done on a regular basis, but rather only as a need arises. When required, they can list for any disease site and stage, the number of patients treated with systemic therapy, the regimens that were used, the physicians who ordered them, and the total costs of each regimen. They also frequently report on the total cost of systemic therapy for each disease site per year. They will also occasionally perform a breakdown by geographic region.

This information comes from data in the OPIS 2000 electronic order entry system which is used to order all systemic therapy drugs administered at the NCTRF. Physicians select the regimen to be ordered, enter the patient's height and weight, and the individual drug orders are automatically generated. The intent of the treatment (e.g., adjuvant) is also entered into the system at this point. This allows for reporting based on intent.

Drug cost information is not available from the OPIS 2000 system. The cost element of their measures is calculated manually based on the unit cost of each drug and the total units administered.

The data is felt to be very accurate. The OPIS 2000 system records when drugs have been administered so there is no concern about drugs that were ordered but not administered. All discontinued orders are noted in the system.

Occasionally, the indicators are compared to similar measures for Nova Scotia, especially those related to the cost of new treatments.

Future considerations include the monitoring of systemic therapy wait times.

Appendix I: Selection of Data Variables from OPIS and MEDITECH

The following sample data variables are some of those that would be required from each dataset to perform a linkage and derive useful indicators. Table H1 lists those from MEDITECH and Table H2 lists those from OPIS. The lists presented in this appendix are not complete and are merely for demonstration purposes.

Table I1: Sample MEDITECH Data Variables

Data Variable Name	Variable Description	Intended Purpose
Hospital Card Number	Unique patient identifier used in each facility	Linkage
Health Card Number	Provincial Health Card Number	Linkage
Surname	The surname/family name/last name currently used by the patient	Linkage
1st Name	First name (or initial) used by the patient	Linkage
2nd Name	Second Given Name, Middle Name	Linkage
Sex	Gender of the patient	Linkage and Indicators
Birth date	The patient's date of birth represented by the year, month and day	Linkage and Indicators
Address	Residence description	Linkage
City	City of residence	Linkage
Province	Province of residence	Linkage
Postal Code	Postal code of patient's current address	Linkage and Indicators (geographical)
Reg Dr.	Physician to whom the patient has been admitted	Indicators
Prescription number	Unique number assigned to each prescription	Indicators
Medication	Name of medication prescribed	Indicators
DIN	Drug information number of the medication prescribed	Linkage
Site	Route of administration (e.g., IV)	Indicators
Dose	Dose of medication ordered	Indicators

Table I2: Sample OPIS Data Variables

Data Variable Name	Data Field Description	Intended Purpose
Demographic Variables		
Chart Number	Unique number assigned by the Nova Scotia Cancer Centre or the Nova Scotia Cancer Registry to each new patient at the time of initial registration	
Health Card Number	Provincial Health Card Number	Linkage
Surname	Surname/family name/last name currently used by the patient	Linkage
Previous Surnames	Surnames previously used by the patient	Linkage
Birth/Maiden	Legal surname under which the patient was registered at birth	Linkage
1st Name	First name (or initial) used by the patient	Linkage

Data Variable Name	Data Field Description	Intended Purpose
2nd Name	Second Given Name, Middle Name	Linkage
Sex	Gender of the patient	Linkage
Birth Date	Patient's date of birth represented by the year, month, and day	Linkage
Address	Line one of the patient's mailing address. This line of the address entry captures street number, street name, street type and unit number if applicable, or the postal box, rural route or suburban service address	Linkage
City	City/town/municipality where the patient's mail is delivered	Linkage
Province	Province of residence	Linkage
Postal Code	Postal code or American ZIP code associated with the patient's current address	Linkage and Indicators (geographical)
Disease Variables		
Disease Number	Sequence of registered diseases	Indicators
Initial Diagnosis Date	Date of cytological diagnosis, date of histological diagnosis (including autopsy), date of non microscopically confirmed diagnosis, or date of death if not reported at any other time.	Indicators
Definitive Diagnosis Date	The date this tumor was confirmed by the most definitive method	Indicators
Definitive Diagnosis Method	Method of the most accurate diagnostic confirmation	Indicators
Site	A code from the International Classification of Disease to denote the anatomical site of the primary malignancy or benign condition	Indicators

Appendix J: Dimension Definitions Used for the Framework Comparison Grid

Dimension	Definition	Source
Accessibility	The ability of clients/patients to obtain care/service at the right place and the right time, based on respective needs.	ISO [9]
Effectiveness	The care/service, intervention, or action achieves the desired results.	ISO [9]
Efficiency	Achieving the desired results with the most cost-effective use of resources.	ISO [9]
Appropriateness	Care/service provided is relevant to the clients'/patients' needs and based on established standards.	ISO [9]
Safety	Potential risks and/or unintended results are avoided or minimized.	CCHSA [10]
Continuity	The ability to provide uninterrupted coordinated care/service across programs, practitioners, organizations, and levels of care/service, over time.	ISO [9]
Client-Centered Care	Focusing on the client's experience/putting clients first	Revised CCHSA [11]
Competence	An individual's knowledge, skills, and attitudes are appropriate to the service provided.	ISO [9], CCHSA [10]
Population Health	The health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services	PHAC [27] (not a framework)
Use Intensity	Measures of the size of the demand placed upon the health care system	Local Interpretation
Human and Material Resources	Measures of the amount of human and material resources available and the relative workload placed upon them	Local Interpretation
Timeliness	Services are provided and/or activities are conducted to meet client and/or community needs at the most beneficial or appropriate time.	CCHSA [10]
Equity	Decisions are made and services are delivered in a fair and just way.	CCHSA [10]
Communication	All relevant information is exchanged with the client, family, and/or community in a manner that is ongoing, consistent, understandable, and useful.	CCHSA [10]
Expenditure	Measures of the actual costs of providing health care	Local Interpretation
Acceptability	All care/services provided meet the expectations of the client, community, providers, and paying organizations.	ISO [9]
Work Life	Having a safe, healthy, and supportive work environment	Adapted from CCHSA [10]
Measurement	Have there been improvements in measuring and reporting on health quality?	CCO & CQCC [16]
Legitimacy	Services and/or activities conform to ethical principles, values, conventions, laws, and regulations.	CCHSA [10]
Focus on the Community	Working with the community to meet its needs	Revised CCHSA [11]

Dimension	Definition	Source
System Alignment	The mission, vision, goals, and objectives [of the organization] are clear, well-integrated, coordinated and understood both internally and externally. These are reflected in organization plans, delegations of authority, and decision-making processes.	CCHSA [10]
Innovation	Measures of scientific advancement.	MacKinnon & McCaffrey [21]
Competitiveness	Assessment of the level of competitiveness (in the pharmaceutical industry) relative to other countries	MacKinnon & McCaffrey [21]

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