

Building a Quality Improvement Coalition: A Cancer Information Management Strategy for Ontario

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Cancer care in Ontario is becoming increasingly important. The proportion of disease and deaths from cancer is dramatically increasing, and there is a growing awareness of the broad continuum of cancer care. Currently, Ontario spends about \$1.5 billion annually on cancer care with increasing pressures to invest more.

As with other services within the broader health system, resources for cancer services are scarce, demand for services is increasing, complexity of patient care is rising, and navigating the system is becoming more challenging. While it is positive news that patients are living longer with cancer due to new and complex therapies, this trend places an increasing burden on services for cancer patients.

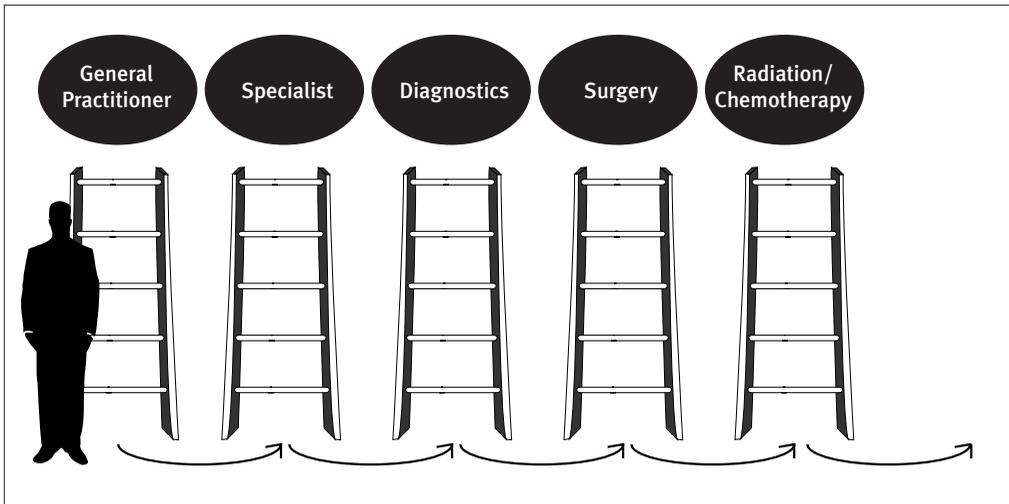
In July 2001, the Cancer Services Implementation Committee was appointed by the Ontario Minister of Health in response to public concerns about waiting lists for radiation therapy and the ability of the current system

to meet the growing need for cancer services of all kinds. The Committee found that the cancer system was fragmented and needed better coordination at the local and regional levels. While patients receive high-quality care through each portion of their care, there are few links between each portion, often leaving the patient with the responsibility of creating his or her own plan of care. Recommendations included integrating cancer services of the province's regional cancer centres and their host hospitals, developing a cancer information system that would become the backbone for the integrated cancer system, and establishing a quality council to monitor, assess and improve cancer services.

Figure 1 depicts the fragmented nature of the system. After climbing up the waiting list for each type of service, the patient joins another waiting list for the next required service.

Figure 2 outlines the distribution of service delivery between different provider organizations.

FIGURE 1



A “NEW” CANCER CARE ONTARIO

The committee’s recommendations have been the driving force for Cancer Care Ontario’s (CCO) new strategic directions, with the principal goals being the improvement of the quality of care for cancer patients and the creation of a seamless journey for them as they access services. To move toward an integrated, high-quality and responsive cancer system for Ontarians, Cancer Care Ontario (CCO) is working with its partners to build a cancer system that ensures patients and their families are cared for by a seamless, coordinated network of services and professionals that is comprehensive and patient-centred. To achieve this, four priorities have been identified.

- **Integration.** The first and most important step toward a seamless system of cancer care is the creation of the Integrated Cancer Program (ICP). To form each ICP, CCO’s regional cancer centres will integrate service delivery with the adjoining host hospital, to put a full range of cancer services and an integrated team of cancer specialists under single management at the local level.

There will be an ICP at every hospital that has a regional cancer centre. The head of the ICP will report through both the CEO of the hospital and the CEO of Cancer Care Ontario. This joint lead-

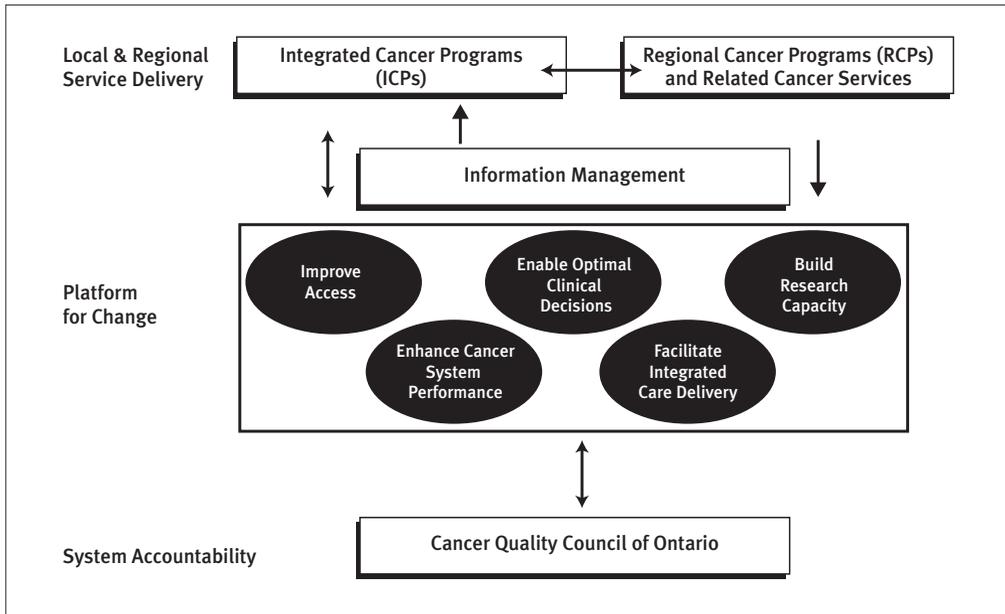
FIGURE 2

Treatment	Regional Cancer Centres	Host Hospitals	PMH (UHN)	Other Hospitals
Radiation	75%	—	25%	—
Surgery	—	22%	6%	72%
Systemic	~ 50%		~ 50%	

ership model will help strengthen cancer services both locally and provincially. The establishment of the ICPs will mean that CCO will transfer responsibility for the direct management and delivery of patient services to the host hospitals. However, as a provincial government agency and the Ministry of Health’s chief advisor on cancer issues, CCO will continue to distribute funds for cancer care to the ICPs under this new model.

Each ICP will become the hub of a Regional Cancer Program (see Figure 3). The Regional Cancer Program (RCP) is the next step in achieving a seamless cancer services system and will bring together services at a regional level. Each RCP will ultimately link regional cancer service providers such as community cancer clinics, family physicians, Community Care Access Centres and volunteer organizations. In fact, many regional cancer centres already have established strong relationships with many cancer care providers in their regions.

FIGURE 3



- **Cancer Quality Council of Ontario.** In September 2002, the Minister of Health and Long-Term Care announced the establishment of the Cancer Quality Council of Ontario (CQCO). Working at arm’s length from the provincial government, Cancer Care Ontario and other cancer providers in the province, the CQCO will focus its efforts on the promotion of quality and efficiency of cancer services. To achieve this, the group will, among other things, monitor and assess indicators such as cancer incidence and prevalence, treatment outcomes, access to care, waiting times, length of stay and patient satisfaction. Cancer Care Ontario will use the findings of CQCO in its advisory role to the provincial government.
- **Surgical Oncology.** CCO will develop a surgical oncology program that will link practitioners in a network that allows them to share information and shape local programs according to regional needs for improved quality and continuity of care.
- **Provincial Information Management System.** Building a seamless system of care for cancer patients means linking and coordinating various information management systems. This

will require the participation, facilitated by CCO, of a wide number of stakeholders.

DEVELOPING THE INFORMATION MANAGEMENT STRATEGIC PLAN FOR THE PROVINCIAL CANCER SYSTEM

To begin the development of this provincial Information Management (IM) program, Cancer Care Ontario brought together stakeholders and facilitated the development of an Information Management Strategy for cancer services. It is designed to ensure that all providers in the cancer system participate in the creation, sharing and use of information and knowledge to improve cancer care. This requires that:

- Integrated health records are accessible to physicians and other healthcare workers to support them in providing appropriate care to patients, while maintaining an appropriate level of privacy and confidentiality of patient information;
- Relevant, consistent information and appropriate analytical tools are available to assist management decision-making at provincial, regional and local levels;

- Evidence-based guidelines are appropriately available and followed in all care settings to facilitate high-quality care;
- Cancer system performance is monitored at the provincial, regional and local levels to evaluate performance and ensure achievement of expected outcomes and adherence to an accountability framework;
- Comprehensive datasets, with common data standards, are established to support practice reviews, peer comparisons, research and outcome evaluation; and
- Information technology infrastructure is implemented to support IM strategy initiatives.

The Information Management Strategy was approved by Cancer Care Ontario's Board of Directors in November, and has since been endorsed by the boards of many partner organizations in the broader cancer system. The plan outlines a range of initiatives that, over the next few years, will be implemented across the province, changing the way cancer care is delivered in Ontario. These initiatives are grouped into five strategic directions, which are summarized below:

- **Improving Access to Cancer Care.** Lengthy waiting times for diagnosis and treatment can lead to suboptimal clinical outcomes. Waits can occur in several areas, including access to surgical procedures, radiation treatment, systemic therapy and diagnostic tests. The ability of healthcare agencies to manage and monitor wait times for these services varies. Initiatives will be undertaken to improve access to cancer care in Ontario, including the implementation of a comprehensive referral and wait list management system. A comprehensive approach will track each patient as he or she moves between surgery, radiation and systemic therapy, rather than manage these as independent events.
- **Enhancing Cancer System Performance.** To ensure that the resources available to the cancer system lead to the best possible outcomes for Ontarians, and can continue to do so in the future, decision-makers need access to timely, accurate and relevant system-level

information. At present, a significant amount of detailed inter-institution information is not available. Using funding from the Ministry of Health, CCO and its partners will implement initiatives to identify pending constraints in the system, support development of mitigation strategies, identify best practices and increase efficiency in cancer service delivery.

- **Enabling Optimal Clinical Decisions.** All care programs should be designed to help caregivers make the most appropriate clinical decisions and prevent clinical errors. For example, there is strong evidence to suggest that Computerized Physician Order Entry (CPOE) of drug orders can significantly reduce error rates; this is especially true if the drug order entry system offers Clinical Decision Support (CDS) tools to provide physicians with clinical alerts at the time of order entry. Currently in Ontario, approximately 50% of chemotherapy orders are entered through CPOE. The information management strategy sets out the goal of increasing this to 100% by 2007. A second example is CCO's Program in Evidence-Based Care, which uses research results to influence practice by developing evidence-based clinical practice guidelines. Having guidelines readily available at the point of diagnosis and treatment enhances a physician's ability to make effective clinical decisions. Greater resources will be dedicated to developing guidelines, enhancing the quality and safety of systemic and radiation therapy, and managing the health record as part of a larger hospital/regional electronic health record. By providing tools to enable optimal clinical decisions, quality and consistency of cancer care will improve in Ontario.
- **Building Research Capacity.** In late 2000, the Ontario government established the Ontario Cancer Research Network with a four-year budget of \$100 million for cancer research infrastructure. An increasing area of focus in cancer research is the study of specific genetic profiles that control the aggressiveness of certain tumours, their likely clinical course, or their susceptibility to treatment. Ultimately, it is hoped that a genetic profile can be obtained for each patient's tumour cells so that thera-

py can be individualized. A major determinant of success in genomic research is the volume of patients available for investigation. Linkage of a patient's genetic "bio-file" with his or her clinical course is required to determine the clinical significance of each genotype. Given the large number of genes in the human genome and the multifactorial nature of genetic expression, it takes large numbers of patients in a single database to correlate genotype with clinical behaviour. To address this requirement, the plan envisions the development of fully linked database(s) for cancer research that include clinical records, the genetic bio-file and linkage to tissue samples in a tumour bank.

The information infrastructure will also be a key tool to increase the level of enrollment in clinical trials, by developing electronic approaches so clinicians can be aware of clinical trials with enrollment criteria that match their patients' clinical status. Currently, enrollment in clinical trials is a largely manual process, made even more complex due to the number of trials conducted across the province, the variety of sponsors and the relative independence of each trial.

- **Facilitating Integrated Delivery of Cancer Care.** As described earlier, integration at the care, management, information and technology levels will form the basis for a coordinated approach for cancer care across a multitude of providers and will be a key enabler to achieving improved quality and access. In addition, a Cancer Coalition Intranet/Extranet will link all cancer system participants and serve as the conduit for disseminating cancer-related information and facilitating the creation of new knowledge and standards for use by all providers.

Within each of these strategic directions are a number of initiatives that are summarized in Figure 4.

The estimated incremental cost of implementing this strategy is \$98 million over 4.5 years. As described below, other partners within the health system will undertake many of the projects; therefore, not all these funds should or will flow through CCO. As of March 2003, approximately half the funding is already in

FIGURE 4

- Referral Management & Wait List Tracking System
- Pathology Information Management System (PIMS)
- Capturing Clinical Stage Information
- Surgical Activity Tracking
- Systemic Therapy (Chemotherapy) Management System
- Radiation Therapy Management System
- Clinical Trials Enrollment and Management
- Clinical Databases to Support Tumour Banking
- Provincial Human Resources Planning System
- Screening Tracking System
- Guideline Use Tracking System
- Enhancement of the Ontario Cancer Registry
- Integrating with Regional Electronic Health Record Initiatives

place. Cancer Care Ontario is working with coalition and funding partners to secure additional project funding.

KEY UNDERLYING CONCEPTS WITHIN THE STRATEGIC PLAN

The plan is built on five key concepts:

- **Quality Improvement Focus.** The strategies and initiatives contained in the plan are all designed to improve the quality of care for Ontario cancer patients, in both the short and long term. For example, they will address issues such as patient safety (for example, the emphasis upon CPOE for chemotherapy orders), and appropriateness and access (such as enabling reporting of wait-time data, and data to allow the provider community to understand the relationship between the volume of care and the resulting patient outcomes). They will also support the development of cancer system performance indicators that can be publicly reported through the Cancer Quality Council of Ontario.
- **Coalition Concept.** A central theme of the plan is that it can be accomplished only through the combined effort of the many organizations and individuals involved in various aspects

of cancer care in Ontario. The coalition concept is the foundation for a coordinated approach for cancer care to improve quality and access. This strategy will be driven by new integration approaches, improved application of information management and a fundamental change in the roles and responsibilities of participants involved in cancer care. For example, the coalition will enable Cancer Care Ontario to move into a facilitative role and away from its current service delivery role, allowing other participants to deliver services in a more integrated and comprehensive manner. To ensure services are provided at a high level of quality, new incentive mechanisms (such as contractual agreements that are tied to funding) will be established to support achievement of the cancer vision for Ontario. To launch the coalition, Cancer Care Ontario has played the role of catalyst, bringing together the stakeholders and completing the strategic plan. Initiatives will be carried out on a project-by-project basis and the management of individual projects may come from hospitals, other agencies or CCO. CCO will work with all stakeholders to secure project funding to undertake the strategic initiatives and will play a coordinating role through a Project Management Office that has been established to promote successful completion of projects by ensuring coordination and rigour in project implementation.

- **Blend of “Carrot & Stick” Incentives.** The plan outlines explicit and implicit incentives to guide future behaviour. For example, a current program at CCO that funds hospitals for certain chemotherapy agents could be modified so that, at a defined future date, drug funding is only available when these agents are ordered through CPOE.
- **Data Integration Infrastructure.** One of the differences between this information management plan and those proposed in other provinces is the focus on data integration between a series of regional Electronic Health Records (EHRs) rather than the development of an integrated provincial EHR. In the Ontario context, several factors support the need for regional EHRs rather than a provin-

cial or disease-specific EHR. First, while hospitals across the province are at different points on the timeline of implementing EHRs, many have made significant investments, and the presence of different vendors across the province increases the difficulty of implementing a provincial EHR. Second, most of the care provided to an individual patient occurs within the same region. Third, while it is conceptually possible to construct a “cancer EHR,” we felt that the EHR should be patient-centric and not based on a single disease. At the same time, the approach selected within the plan increases the importance of clearly articulated and adopted data standards and integration strategies across CCO and the hospitals.

Given the provincial nature of the plan, it is focused primarily on inter-hospital integration of systems – the integration of data across hospitals and CCO – rather than the integration of disparate systems within a given hospital. While hospitals and/or regions will maintain their own clinical information systems, the strategy proposes a provincial data infrastructure that will enable the collection and aggregation of data to support surveillance, planning, care and research.

Cancer Care Ontario has played the role of catalyst, bringing together the stakeholders and completing the strategic plan

To support these requirements, this infrastructure must be able to provide linkage of records on a near real-time basis, using linkage methodologies that differ from current approaches. Currently, records within the CCO’s cancer registry are linked using probabilistic algorithms, which provide sufficient levels of assurance that the records are related to the same patient for surveillance purposes. However, several of the initiatives in the information management strategy require

a higher degree of certainty regarding the match of records (known as a deterministic linkage). For example, tumour banks rely on exact longitudinal tracking of patients in order to understand the clinical relevance of differences identified within the tissue sample. A second requirement is the ability to easily generate subsets of data to support research initiatives, in which any patient identifiers are masked (“de-identified” data). In this way, clinical information can be linked with tumour information, without compromising patient privacy.

An example of how this infrastructure will be of value is the Pathology Information Management System (PIMS). This project will use the infrastructure to collect pathology information from hospitals and laboratories across Ontario, in order to improve timeliness, completeness and quality of reporting. The collected information will be used for a range of purposes, including cancer surveillance/cancer system planning and to rapidly identify patients who might be interested in participating in a clinical trial. While a pilot project was able to collect 20% of the reports electronically using project-specific data infrastructure, CCO was recently funded by the MOHLTC to use the common infrastructure with the expectation that 70% of pathology reports will be received electronically by CCO by March 2004.

- **Close Linkage Between Research and Clinical Care.** Traditionally, information plans for clinical services have been developed in isolation of research informatics plans. With the role of CCO changing to become more focused on the development and application of robust clinical evidence, quality of care is linked more closely to a successful research agenda. This involves increasing patient enrollment in clinical trials and developing linkages between tumour banks and longitudinal patient record data. It is important that information management plans for research and clinical care initiatives be closely aligned.

The initiatives in the plan will be carried out on a project-by-project basis. The management

of individual projects may come from hospitals, other agencies or CCO. CCO will play a coordinating role through a Project Management Office, which has been established to promote successful completion of projects by ensuring coordination and rigour in project implementation. By providing a mechanism to track and report the status of the plan implementation to the broader cancer system, the PMO will also reinforce the notion of the coalition and help to maintain momentum.

SUMMARY

Information management plans should support the organization’s overall business objectives rather than being crafted in isolation from overall organizational strategies. The cancer system is undergoing significant transformation, including integration of service delivery at the regional level and a revamped role for Cancer Care Ontario. The Cancer Information Management plan for Ontario outlines an approach to linking and coordinating various information management systems and projects to support the new directions. Through a coalition of partners working together and by building on the success of earlier initiatives – including the widespread adoption of CPOE within a large part of the cancer system – the plan will improve the quality of care for Ontario cancer patients.

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