

## Cancer Care in Smaller Communities

### A SAMPLE OF COMMUNITY CLINICS ACROSS CANADA

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#### Introduction

Six million Canadians, about 20 per cent of the country's total population, live in small towns<sup>1</sup>. While the major urban centres have large cancer centres and comprehensive care in their midst, people living two hours away in a smaller community have a very different reality.

Management of cancer requires, in virtually every case, multidisciplinary treatment delivered by a large number of health care personnel based in different locations.<sup>2</sup>

Until recently, delivery of cancer treatment and care has been coordinated under the jurisdiction of provincial or regional cancer care programs in most provinces. In British Columbia, Alberta, Saskatchewan, Manitoba, PEI, Newfoundland/Labrador and Nova Scotia coordination of the activities in many community oncology cancer clinics falls in the provincial category. In Ontario and New Brunswick they are part of a regional cancer care program. Under these circumstances, use of an Electronic Health Record would seem to be uniquely appropriate for optimizing treatment and care. It might even be viewed as a critical component of any provincial or regional program when toxic chemotherapy prescribed by specialists at the tertiary centre must be delivered in distant communities by non-specialists.

With these considerations in mind, CACC conducted a cross-Canada survey to sample the use of EHRs and the resources available to community cancer clinics, specifically where patient treatment with cytotoxic drugs occurs in communities at a distance from, but still within the jurisdiction of, large tertiary centres.

#### Methods

For the survey, we selected communities from across Canada that were more than a two hour drive from the regional tertiary centre, and were of a population size usually unable to justify a permanent medical oncologist. The communities were selected by perusal of regional maps, with no prior knowledge of their service patterns or access to an EHR. PEI and Quebec were not included in the survey, the former because of its size

and the latter because of its heterogeneous jurisdictional configuration.

Respondents were administrative personnel at each tertiary centre who were responsible for some measure of administrative support for the selected community sites. In most cases, answers were verified with separate follow up communications with the survey respondent; and in two cases additional interviews were conducted with health professionals at the community sites.

TABLE 1 **Description of the Distant Communities**

Distant Community	Pop.	Distance to Regional Cancer Centre (Km)
1	<10,000	300
2	<10,000	350
3	<10,000	280
4	10–25,000	475
5	10–25,000	220
6	10–25,000	760
7	10–25,000	250
8	10–25,000	690
9	10–25,000	230
10	25–50,000	370
11	50–75,000	790
<b>Average 19,927</b>		<b>429</b>
<b>Median 13,200</b>		<b>350</b>

As shown in Table 1, a total of 11 communities populated by approximately 220,000 Canadians were included in the survey. The communities were an average distance of 430 km from the coordinating provincial or regional (tertiary) cancer centre.

## PART 1:

# The Use of an Electronic Health Record in the Provision of Cancer Services

An Electronic Health Record is a digital version of an individual's health record. It may contain a person's full health and medical record, or it can include only certain records, such as those related to management of a particular condition, e.g., cancer, or to laboratory results that can be used in conjunction with more traditional paper-based patient charts.

An EHR is particularly effective when it is accessible online through an interoperable network. By facilitating the retrieval of information about patients when and where it is most needed by practitioners concerned with the patient's care and by gathering the scattered notes in doctors' offices, clinics, test centres, laboratories and hospitals, the EHR can provide full details about each case, easing referrals among different facilities. Such coordination can lead to optimal and timely treatment, reducing errors resulting from mislaid or missing information, unnecessary delays, duplication of effort, and unnecessary costs.

Canada Health Infoway, a federal organization, in collaboration with Canadian provinces and territories, strategically coordinates and funds projects to build standardized EHRs for patients. Infoway also supports extensions of these systems. The objective is to link records containing critical health information across sources of care delivery within a jurisdiction, as the basis for delivering healthcare in Canada. Its ambitious goal is to have EHRs accessible for 50 per cent of Canadians by 2010. The specific EHR data elements required for cancer treatment and care go beyond those for standard clinical applications.<sup>3</sup>

Canadian Medical Association (CMA) President, Dr. Robert Ouellet, noted recently in his inaugural address that among major industrial nations, "Canada has the dubious honour of ranking last in the use of electronic patient files". Despite concerns regarding patient privacy, the Canadian Medical Association (CMA) has been a strong advocate in favour of a fully interoperable, pan-Canadian EHR to improve patient outcomes and health system efficiency and accountability. According to the CMA, the benefits of an investment of \$570 million over five years could include an estimated savings of \$6.1 billion in transcription costs as well as less duplica-

tion of medical test requisitions and fewer adverse drug reactions.<sup>4</sup>

In a recent national survey of Canadian hospitals<sup>5</sup>, slightly more than half (54.2 per cent) reported having some sort of EHR in place; however, 97.6 per cent indicated that the EHR was not the sole method for recording patient information. Very few institutions had predominantly an electronic record; most commonly hospitals had records that were 11 to 50 per cent electronic. The survey results suggested the adoption of EHRs by Canadian healthcare institutions is in its infancy.

## Methods

We considered that the EHR should be:

- headquartered at the regional or provincial tertiary centre
- internet-based
- secure
- integrated
- accessible to the community clinic personnel
- configured to allow community personnel to enter as well as extract data

We considered the minimum elements required of the EHR at the community level include:

1. quick and easy access to a patient's general medical information (attending physicians' and consultants' notes)
2. lab and imaging results
3. complete pathology reports
4. protocol descriptions of treatments
5. allowing physicians to enter drug orders directly, or at least allow the use of standardized pre-printed orders
6. checkpoints to prevent inappropriate drug treatments from being ordered
7. protocols for managing treatment complications
8. nursing processes
9. a list of all prescribed medications and treatments administered

We also asked for an estimate of the population in these distant communities who would be covered by the EHR system currently in place.

**TABLE 2 EHR Link Between Tertiary and Community Centres**

Distant Community	Is the EHR in the Regional Cancer Centre Integrated with the Community	Population Covered by an Integrated EHR in the Region (%)
1	Yes	76-100%
2		
3	Yes	76-100%
4	Yes	51-75%
5	Yes	51-75%
6	Yes	76-100%
7		
8		N/A
9		
10	Yes	76-100%
11	Yes	76-100%
<b>Average</b>	<b>80.4%</b>	(of the 7 with an EHR)

Blank indicates a response of “No”  
N/A indicates no answer received

Seven of the 11 communities surveyed were linked to their tertiary centres by an EHR. In five of the eight provinces surveyed, the sampled communities were linked to the appropriate tertiary centre. In provinces with EHR systems in place, an average of 80 per cent of the region’s population was linked to the tertiary centre.

Table 3 indicates the extent to which the EHR contained the nine essential elements. None had all nine elements, the actual number varying from three to seven. The most comprehensive systems were those from Manitoba, Alberta, and New Brunswick with six to seven elements each. The remaining EHR systems contained three and four elements.

Many of the essential elements were particularly lacking in all EHRs.

- drug protocols were present in only four of seven
- three of seven had capability for order entry
- two of seven had safety checkpoints on chemotherapy orders
- one of seven had protocols to guide treatment of complications
- one of seven had allowance for nurses’ notes
- two of seven had a list of all medications for all conditions

Table 4 indicates the degree of access to, and the mode of interaction with the EHR system available to health care professionals at the community level. While doctors had some degree of access in all seven instances where there was an EHR, nurses and pharmacists had access in only four instances.

Of the seven communities linked to the regional centre, community professionals were able to enter clinical data relating to the patients’ care in only three. In the remaining four, they had read-only access, i.e., the system did not allow entry of clinical information from the community professionals treating and taking care of the patients to enable tracking of treatment progress and complications by oncologists at the tertiary centre.

**TABLE 3 Information Included in the Electronic Health Record**

Distant Community	General Medical Info	Lab & Imaging	Pathology	Drug Treatment Protocols	Order Entry	Drug Treatment Checkpoints	Protocols for Managing Complications	Nursing Processes	All Meds	TOTAL
1	✓	✓	✓	✓						4
2	No Integrated Electronic Health Record									
3	✓	✓	✓	✓	✓				✓	6
4	✓	✓	✓							3
5	✓	✓	✓	✓	✓	✓	✓			7
6	✓	✓	✓	✓	✓	✓		✓	✓	7
7	No Integrated Electronic Health Record									
8	No Integrated Electronic Health Record									
9	No Integrated Electronic Health Record									
10	✓	✓	✓							3
11	✓	✓	✓							3

Blank indicates a response of “No”

TABLE 4 **Community Clinic Staff with Access to the EHR**

Distant Community	Physician		Onc Nurse	Other Nurse	Pharmacist	Clerk	TOTAL
1		GPO#* GP	✓		✓	✓	5
2	No Integrated Electronic Health Record						
3		GP**	✓	✓	✓		4
4		GPO#*					1
5	Internist*	GPO#* GP*	✓		✓		5
6		GPO# GP	✓		✓		4
7	No Integrated Electronic Health Record						
8	No Integrated Electronic Health Record						
9	No Integrated Electronic Health Record						
10	Internist*	GPO#*					2
11	Onc MD*	GPO#*					2

Blank indicates a response of “No”

\* Read-only access

\*\* Trained in chemotherapy administration

GPO # = general practitioner with special training in oncology

### Discussion

It might be argued that the EHR should, in the first instance, contain all clinical information related to all the conditions of the patient. We have taken the position that treatment of cancer is so complex and influenced by so many different factors that, as a first step, it is necessary to have an EHR uniquely configured for delivery of cancer treatment, care, and follow-up. Also, we considered it should be readily accessible to all of the physicians and allied health care personnel responsible for care of the patient, not just the specialists at the tertiary cancer center.

The present survey indicates the importance of detailed evaluation to accurately determine the true capabilities of EHRs, in instances where they are said to be present. The survey was conducted on relatively few communities but, as stated earlier, the results are in accord with other studies of the scant availability of EHRs in management of care. To ensure accuracy, the survey results were verified in most cases by the person who completed the survey and in two cases directly with a professional in the community.

The results of the survey indicate the very limited application of EHRs in managing the care of cancer patients in communities distant from major cancer centres. Only seven of the 11 community oncology clinics sampled had access to an integrated EHR system linking them to the tertiary centre. In those seven clinics, not all health care personnel could read the EHR, and in only three were clinic professionals allowed to enter clinical data into the record. It means the tertiary centre oncologists who originally devised

the treatment plans were not able to follow whether treatment was being given, or what complications were encountered, and could not use the EHR’s real-time capacity to advise community personnel.

The most highly developed and user-friendly EHR system linking communities to a tertiary cancer centre was the one used in Manitoba and Alberta: the ARIA system, previously known as OPTX 2000. It was developed more than 10 years ago by the cancer agency in Manitoba, and has since been commercialized and taken over by an American firm for wide use in the US. None of the other provinces surveyed had the equivalent combination of capability, interactivity, and coverage of this system.

Although no statistical studies appear to have been done on the impact of EHRs on the final outcomes of cancer treatment in distant communities, i.e., effect on survival, a number

of studies suggest that when such a system is operational and is interactive, other important aspects are impacted. For example, fewer medication errors occur, resulting in a reduction of adverse drug events,<sup>6,7,8</sup> increased adherence to guideline-based treatment occurs in favor of the patient<sup>7,8,9</sup> and efficiencies are introduced in the form of decreased utilization of care.<sup>7</sup> When combined with more accurate charting, important drug-drug interactions may also be readily detected and, where necessary, adjustments can be made.

A particularly dramatic example of the utility of the EHR occurred in the city of New Orleans after Hurricane Katrina. When records were in an electronic format, only three per cent of oncology patients had difficulty obtaining their records when they returned six weeks after the hurricane, whereas 100 per cent of those without such a record stated they had difficulty.<sup>10</sup> Perhaps the best example of the use of the EHR is the initiative taken by the Veteran’s Administration (VA) in the US. A system ([www.myhealth.va.gov/](http://www.myhealth.va.gov/)) has been developed enabling veterans to tap into their personal health records including medical history, lab results and appointment scheduling, Secure messaging with physicians is also allowed, and those messages are posted to the EHR as progress notes.

My HealtheVet is a model for empowering patients to take an active role in their healthcare and for improving care while lowering costs. The configuration provides feedback and encourages positive behavior. The secure messaging strengthens relationships between physicians and patients and streamlines work-

flow. Demand on the VA's Release of Information offices is reduced, as well as unnecessary trips to VA medical facilities by veterans who have difficulty traveling. Finally, the capability for online scheduling reduces the number of missed appointments and calls to the appointment desks.

A Canadian example would be the Odette Cancer centre at Sunnybrook Medical Centre in Toronto. Cancer patients have secure access to their electronic health records, are able to share this information with caregivers whenever they deem necessary, and can closely monitor their own progress.

If patients can access their bank statements from anywhere in the world, why not their health records? It can be expected that putting internet-based EHRs in the hands of individual patients will greatly improve cancer treatment and care. They will be able, in the comfort of their own homes, to become more aware of the delays arising in referrals and tests, can look up the implications of these delays, and better prepare themselves to become active participants in their own care during visits to their oncologists. Existing silos in cancer investigation and treatment will eventually be connected as a result of patient initiatives resulting in:

- a. Uniformly higher quality of treatment and care for all cancer patients;
- b. Improved quality of life as distress, due to lack of information, is reduced;
- c. Improved timeliness of care and reduced waiting times especially by allowing patients to make their own appointments;
- d. Improved safety by reducing accidents in administering chemotherapy drugs;
- e. Stretching of oncology budgets by reducing wasteful repetitions of tests and x-rays;
- f. Reduction in the myriad of costly systems necessary to maintain confidentiality of paper records during the sharing information among appropriate caregivers.

In addition to providing better patient treatment and care, deployment of an EHR facilitates system-oriented uses such as:

- Audits of treatment outcomes and complications in individual clinics;
- Post-market surveillance of newer cancer drugs to determine their true effectiveness in the general population;
- Rapid identification of patients who, in retrospect, may have been exposed to errors (e.g., recent problems with breast cancer tests);
- Screening patients who may be candidates for clinical trials;
- Linking health records to cancer registries to rapidly determine trends and the effects of improvements in cancer control.

## **Barriers**

Choosing, implementing and integrating an oncology EHR system into a hospital system is resource-intensive. However, roadmaps are available from clinics that have successfully managed the transition. In a major community network involving 4,800 US physicians, electronic health records were linked among various clinics. Oncologists within the network quickly noted advantages from improved efficiencies and response speed.<sup>11</sup> The salutary effects this could have on the prolonged waiting times bedeviling Canadian patients can only be imagined.

There have obviously been major barriers to developing and adopting an integrated interactive oncology EHR system in Canada, otherwise such a system would have been in operation long ago. Many were identified by respondents to the present survey (data not shown). We did not investigate these barriers, but the literature is replete with examples:

### **Parochialism**

One of the biggest impediments; manifested as unwillingness to share clinical information. Includes reluctance to give universal access to capable and responsible users.

### **Lack of funding**

Really a reflection of a lack of willingness by health care administrators to place a high priority on developing an integrated EHR. Lack of willingness is partly a failure to appreciate the far-reaching implications of EHRs on treatment and care. Education of administrators could address this issue, combined with pressure by physicians and public pressure on governing institutional boards.

### **Privacy and security regulations**

Often over-interpreted to an unreasonable degree. This stifles development. Application of newer security systems and common sense would be in order.

### **Overblown concerns regarding the integrity of the system**

Higher priority given to the security concerns of IT personnel than to safe and efficient patient care. Witness the fact that even where they existed, the majority of EHR systems surveyed were read-only in the community clinics. Treating physicians were thus unable to interact with the system and inform their colleagues back at the tertiary centre about what they were doing. To overcome this barrier, greater participation is required by health care professionals, especially physicians, in development and oversight of institutional policies.

### **Resistance to change**

Healthcare workers recalcitrant to the idea of electronic charts, or the need to upgrade and maintain their computing skills, or reluctant to participate in the data

entry process. To overcome these obstacles, leadership is required from health care professionals, particularly physicians, experienced in the use of EHRs.

### Incompatibility of different systems

Community cancer clinics located in hospitals that have clinical information databases not readily accessible or compatible with their tertiary cancer centres. Again, greater participation by health care professionals is required in development of EHR standards, institutional policies, and resource allocation.

### Lack of a national strategy for the development of an integrated EHR in oncology

The American Society of Clinical Oncology (ASCO) is striving to help cancer care providers in the US move towards medical and patient-accessible EHRs.<sup>12</sup> ASCO has proposed a standard oncology EHR and holds an annual event where practitioners evaluate commercial EHR packages and discuss findings and conclusions about these systems.

An example of how barriers can combine to prevent the deployment of an EHR system to support community based cancer treatment is provided by the fate of a proposal to serve outlying communities in Ontario put forward almost twenty years ago.<sup>13</sup> The proposal would have used the Oncology Patient Information System (OPIS), was approved in principle by the Ontario Legislature, the Ontario Medical Association, and the Board of the Ontario Cancer Research and Treatment Foundation (OCTRF). The then-Deputy Minister of Health asked for a plan to implement it. The plan was aborted due to internal considerations at the OCTRF.

## PART 2:

# Resources in Community Cancer Clinics

### Methods

Exploring the health service resources in smaller communities must be done with caution, as unrealistic expectations cannot be imposed on these hospitals. It is not our intent to suggest supersizing the health facilities of every community, or establishing tertiary cancer centres in small towns.

Nonetheless, communities caring for the multifaceted needs of cancer patients have certain obligations, especially where non-specialists are providing specialist care. These obligations include suitable organizational structures to ensure patient safety and quality of care. The survey did not attempt to assess the entire spectrum of cancer care in small communities, but focused instead on the delivery of drug therapy and multi-disciplinary care, including allied health professionals.

We considered the service elements essential for the delivery of drug therapy and care should include:

1. a community-based physician versed in drug therapy treatment
2. a nurse trained in drug therapy administration
3. a dedicated pharmacist
4. access to psychosocial counseling
5. access to nutritional counseling
6. a dedicated area for chemotherapy administration,
7. a dedicated clinic area for seeing patients
8. the existence of community-based organized support groups
9. access to telemedicine support

TABLE 5 **Resources Available to the Community Oncology Clinic**

Distant community	Physician on site	Who administers drug therapy	Pharmacist	Psycho-social counseling	Nutrition counseling	Patient support groups	Designated oncology clinic	Designated area for drug therapy	Tele-medicine	TOTAL
1	✓	Oncology Nurse	✓	✓	✓	✓	✓	✓	✓	9
2	✓	IV Nurse	✓	✓	✓		✓	✓	✓	8
3	✓	Oncology Nurse	✓	✓	✓	✓	✓	✓	✓	9
4	✓	IV Nurse	✓				✓	✓		5
5	✓	Oncology Nurse	✓			✓		✓	✓	6
6	✓	Oncology Nurse	✓		✓	✓	✓	✓	✓	8
7	✓	IV Nurse	✓	✓				✓	✓	6
8	✓	Oncology Nurse	✓			✓	✓	✓	✓	7
9	✓	Oncology Nurse	✓	✓	✓	✓	✓	✓	✓	9
10	✓	Oncology Nurse	✓	✓	✓	✓	✓	✓	✓	9
11	✓	Oncology Nurse	✓	✓	✓	✓	✓	✓	✓	9

Blank indicates a response of "No"

## Results

Table 5 indicates the organizational readiness of the 11 sampled clinics to deliver cancer treatment and care, regardless of their access to an EHR system. Five of these community clinics met all nine of the clinical resource requirements we considered essential for community cancer care. Of the remainder, two had eight, one had seven, two had six and one had five.

## Discussion

As judged from Table 5, the capabilities of the community clinics for delivering cancer treatments were quite impressive. However, the lack of an interactive EHR system in almost all of them raises the probability that patients' treatment plans in these communities are not getting the input from the specialists at the tertiary centres that would obtain if they were in direct proximity to regional cancer centers. This, in turn, might mean that the patients in these communities are not getting the state-of-the-art treatments and tests they need.

## Conclusions and Recommendations

- Health professionals at the community cancer clinic should be allowed to enter data into the EHRs.
- Physicians who have responsibility for day-to-day care such as family doctors, surgeons, and emergency room physicians should also have access to existing EHRs on their cancer patients.
- A national strategy should be devised and implemented to facilitate linking of oncology EHRs with community clinics in each province.
- Development of this national strategy should be facilitated by the Canadian Partnership Against Cancer (CPAC) in collaboration with Canada Health Infoway.
- Patients should be given immediate and continuing access to their own health record in conjunction with access to an electronic library of explanatory notes to enable them to make best use of the information in their record.
- Standard EHR specifications for cancer care should be adopted by Canadian institutions, to enable patient records to be interchangeable among different systems.
- Although such standards are necessary for exchanging EHRs, the terminology used may vary among practitioners. To accommodate differences in terminology, SNOMED CT (Systematized Nomenclature for MEDicine–Clinical Terminology) could be used. This is an internationally recognized and comprehensive multilingual clinical terminology tool which provides the information framework for clinical decision making for electronic medical records. SNOMED CT terminology is included with the standardized pan-Canadian EHR being supported by Canada Health Infoway.

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