

**REPORT 3 / RAPPORT 3  
DUE DATE / DATE LIMITE: APRIL 30 AVRIL 2006**

**Request for Applications (RFA): Toward Canadian Benchmarks for Health Services Wait Times – Evidence, Application and Research Priorities**

**Appel de demandes: Établir des points de repères canadiens concernant les temps d'attente dans les services de santé - Preuves, application et priorités de recherche**

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<b>TITLE OF YOUR RESEARCH GRANT / TITRE DE VOTRE SUBVENTION DE RECHERCHE:</b> <b>Moving Evidence to Application : A Three Province Cancer Collaborative</b>
<b>CO-PRINCIPAL INVESTIGATORS AND CO-INVESTIGATORS:</b> Describe significant changes, if any that have occurred (e.g. include changes to the research team, list new co-investigators, collaborations, collaborations that are no longer in place, etc.).  <b>CO-CHERCHEURS PRINCIPAUX ET CO-CHERCHEURS :</b> Décrivez brièvement les changements importants qui sont survenus, s'il y a lieu (p. ex. changements à l'équipe de recherche, liste des nouveaux co-chercheurs, nouvelles et anciennes collaborations, etc.).  Marcy Winget, Nominated Principal Applicant, Alberta Cancer Board Donna Turner, co-Principal Applicant, CancerCare Manitoba Jon Tonita, co-Principal Applicant, Saskatchewan Cancer Agency Heather Bryant, co-Principal Applicant, Alberta Cancer Board George Browman, co-Applicant, Alberta Cancer Board Mark Taylor, co-Applicant, St. Boniface General Hospital, Winnipeg Riaz Alvi, co-Applicant, Saskatchewan Cancer Agency Mohamed Mohamed, Collaborator, Saskatchewan Cancer Agency Bill Morton, Collaborator, Saskatchewan Cancer Agency Zoann Nugent, Collaborator, CancerCare Manitoba  No changes have occurred
<b>CONSENT :</b> Following the 30 day period after the receipt of your report and with your consent, CIHR may post this report and/or its executive summary on the CIHR website and/or use the information therein to prepare communication materials, such as news releases. As such, do you consent to the use and disclosure of this report? <b>Yes</b> <input checked="" type="checkbox"/> <b>No</b> <input type="checkbox"/> .

**CONSENTEMENT:**

Suite à la période de 30 jours après avoir reçu votre rapport et avec votre consentement, les IRSC pourraient afficher ce rapport et/ou son résumé sur le site web des IRSC et/ou utiliser l'information contenue dans ce rapport/résumé afin de préparer des matériaux de communication, tels des communiqués de presse. Par conséquent, est-ce que vous consentez à l'utilisation et à la divulgation des renseignements contenus dans ce rapport? **Oui**  **Non** .

**A) SUMMARY OF RESEARCH RESULTS:**

Provide, in one page or less, a bulleted list of the report's main messages, for objective #4 of the RFA, followed by a two to three page executive summary of your report.

**Note:** The bulleted list and executive summary should summarize the detailed answers provided for questions B) below.

**A) RÉSUMÉ DES RÉSULTATS DE RECHERCHE :**

Veillez fournir, en une page ou moins, une liste (style télégraphique) des messages principaux de votre rapport, pour le quatrième objectif de cet Appel de demande, suivi d'un résumé de deux à trois pages de votre rapport.

**Note :** La liste et le résumé devraient résumer les réponses détaillées aux questions B) ci-dessous.

**Main Messages**

- The additional references we have identified and reviewed since Report 2 have supported conclusions drawn in Report 2.
- Although we attempted to evaluate the entire cancer care continuum, most studies focus only on time to radiotherapy or surgery. Data regarding the pre-diagnostic and post-treatment intervals are virtually non-existent.
- Because studies have not been conducted that quantify time between care steps along the entire patient care continuum, cancer care providers both inside and outside provincial cancer care systems do not actually know where current roadblocks to care are, relative to other steps, therefore, optimal long-term decision making cannot be made.
- Studies at the population level are needed to identify the current care intervals that are roadblocks so that proper allocation of resources can be made, appropriate service delivery changes can be identified, constructive changes implemented, and long-term planning made.
- One reason studies to evaluate the cancer continuum have not been conducted is because the data to do so are not readily available. Developing infrastructure to link existing data and designing and implementing appropriate quality assurance around the key data elements is needed. These activities require engagement of stakeholders and care deliverers both inside and outside the cancer system. Resources to develop such an infrastructure are needed
- Infrastructure that allows electronic capture and analysis of key data points is essential in order to identify and respond to local key resource problems in a timely and accurate manner. Resources to support development of this infrastructure are needed for all provinces.
- Infrastructure that allows electronic capture and analysis of key data points needed for comparing the cancer system across provinces is essential in order to identify and respond to provincial and nation problems in a timely and accurate manner. Resources to support development of this infrastructure are needed for all provinces.
- Coming to a common understanding across provinces regarding definitions and reporting of time between cancer care steps is not easy. Face-to-face discussions involving individuals familiar with the data and databases are required because nuances in the data and in the “common understanding” will likely result in differences in data ultimately pulled and compared. Unless

details regarding the data are discussed, it is likely that the “comparable data” will not actually be comparable.

- We have developed a successful methodology for defining and reporting comparable measures across our three provinces for time between critical cancer care steps that could be expanded to include all Canadian provinces and territories; we recommend expansion to incorporate two or three provinces/territories per year. Resources and infrastructure are needed to support and further expand this effort.

## **Executive Summary**

In Report 2, one of our conclusions was that evidence did not currently exist that could be used to create evidence-based benchmarks for time to various cancer care services. The most feasible way to obtain such evidence would require a series of population-based studies that account for all known and possible prognostic factors; conducting such studies would take considerable time and resources and would probably not be able to identify a threshold after which a treatment or other service was no longer effective. We further stated that due to the complexities of cancer (e.g., it is more than one disease, there are multiple treatments and valid service pathways for patients, etc.), finding evidence-based thresholds for select points along the patient care continuum is probably not a good use of resources. Instead, we suggested that population-based studies are needed to help cancer care providers identify ways to improve cancer care and to monitor cancer care treatment at the population level. We stand by these conclusions and expand upon them in this final report.

The cancer control system is complex; the range of services is broad and includes screening, diagnostics, treatment, post-treatment surveillance and end-of-life care, additionally, some services are obtained outside cancer agencies, some inside cancer agencies and some may be obtained inside or outside a cancer agency. In order to properly evaluate the system, therefore, information on the entire continuum is needed to identify where the current roadblocks are for cancer care, understand why they exist, and implement changes that will solve current problems and prevent future potential ones. One of the goals of this project was, therefore, to identify reports and scientific publications that addressed any and all aspects of the cancer control system. Unfortunately, information regarding the cancer control continuum is critically lacking, both in Canada and elsewhere. Almost all studies in Canada have focused on time from one point (usually diagnosis or referral) to treatment (radiation or surgery) and are usually done in patients treated at one hospital or cancer facility rather than at the provincial population level. Cancer care providers both inside and outside provincial cancer care systems, therefore, do not actually know where current roadblocks to care are, relative to other care steps, therefore, optimal long-term decision making cannot be made. This is the single-most critical gap in current research we identified that is needed in order to make long-term strategic decisions regarding resource allocation and system delivery changes that will improve the overall cancer control system.

We believe that the dearth of studies that account for the patient care continuum is largely due to the fact that cancer care services are very fragmented making it extremely difficult, if not impossible, to obtain the data needed to conduct such a study. Efforts to reduce the fragmentation of the delivery of cancer care and related services will undoubtedly improve the quality and timeliness of the care. Improving links between cancer agencies and physicians outside cancer agencies but who are involved in delivery of cancer care services and other stakeholders is a starting point for improvements. Additionally, a single authority responsible for evaluating the overall cancer control system from the population-level is

needed. In order to perform system evaluation at the population-level, data that measure quality of care need to be collected regularly and be accessible for routine evaluation. Cancer Care Ontario has made significant steps in this direction; other provinces in Canada may be able to borrow from them. Cancer health service researchers in Canada should also make publication of their studies and findings a bigger priority than it currently appears to be in order to maximize the sharing of knowledge.

There is a need to fund and implement the technological infrastructure to allow for surveillance of time-to-care measures over time and across care steps so that problems are identified early, provinces can share their experiences and learn from each other, and resources are put towards care steps that are the real roadblocks, not just those that receive the most press. Infrastructure for such surveillance systems will allow appropriate and immediate action to be taken to rectify problems when they are small before they become major. The cost for such infrastructure may seem high at the beginning but will more than pay for itself by preventing future problems and allowing for continuous high quality care. Defining and measuring time between care steps and setting benchmarks should be done in the context of measuring and evaluating the quality of a cancer care system that accounts for the entire cancer control continuum, not only radiation and surgery.

In order to move forward with standardizing definitions, measurement, and reporting of time-to-care for intervals for cancer patients across Canada, opportunities for open dialogue between cancer agencies, such as we have had in this project, are necessary. Even when “simple” intervals such as diagnosis to first treatment, are agreed on, extensive dialogue and exchange of information is necessary to ensure understanding and comparability of data. If/When differences in length of intervals are seen across provinces, even more discussion is needed to confirm whether the differences are due to differences in understanding (i.e., the data are not actually comparable) or if the differences are real. If real, investigation and further discussion is needed to determine the reason for the difference and identify changes that can be made to minimize or ameliorate differences. Infrastructure and resources need to be put into place to allow such an iterative set of processes to take place in order to ensure equitable and timely care within and across provinces. Input and participation from data analysts/programmers are essential parts of this infrastructure and process to successfully standardize definitions, measurement and reporting of cancer care intervals nationally.

## B) RESEARCH RESULTS - OBJECTIVE 4:

Describe in detail the extent to which the fourth objective of the RFA has been achieved. Specifically, please address the following point:

- 1) The gap analysis and identification of priority areas and questions for future research (particularly with respect to the types of relationships between wait times and health status/quality of life described in objective #1) that are likely to yield research evidence of use to provinces and territories in considering additional wait time benchmarks.

**B) RÉSULTATS DE RECHERCHE – OBJECTIF 4:** Décrivez, de façon détaillée, jusqu'à quel point le quatrième objectif de l'appel de demandes a été atteint. Abordez plus particulièrement le point suivant:

- 1) L'analyse des écarts et les définitions des domaines et des questions prioritaires pour des recherches futures (particulièrement en ce qui a trait aux types de liens entre les temps d'attente et l'état de santé-la qualité de vie décrits dans l'objectif 1) qui devraient produire des résultats utiles pour les provinces et les territoires dans l'étude d'autres paramètres sur les temps d'attente.

### Update of literature review

Before detailing the gap analysis we would like to provide an update regarding the literature review. In Report 1, we described our search strategy, selection criteria, and methodology used for identifying potentially relevant sources of information to address the questions of the grant. Table 1 gives an update of the search results by database. All databases were searched a second time, except for HealthStar, from the end of the initial search period listed in Report 1 through December 31, 2005. HealthStar was not searched a second time since the initial search had such a low yield and none of the references were potentially relevant upon initial review. Several references were found in more than one of the database searches therefore the number of references identified is less than the number unique. In the initial search, a total of 1005 unique references were identified and in the second search there were 271 unique references identified for a total of 1276. These were reviewed and categorized as described in Report 1.

**Table 1: Update of Databases Searched and Numbers of Articles, Letters, and Editorials Identified**

Database searched	Medline	Cinahl	HealthStar	Embase	Web of Science	Total
<b>Search 1</b>						
# identified	730	100	6	297	Unknown	<b>1131+</b>
# unique	730	56	5	80	134	<b>1005</b>
<b>Search 2</b>						
# identified	143	22	Not done	151	92	<b>408</b>
# unique	Unknown	Unknown	Not done	Unknown	Unknown	<b>271</b>

Table 2 lists the numbers of identified, possibly relevant, and ultimately relevant references by the type of reference (i.e., article, editorial, etc.). These numbers are slightly higher than those in Table 1 because additional references were identified from the references of potentially relevant articles in Searches 1 and 2 as well as reports found from the grey literature. There were sixteen references that were categorized as potentially relevant that we were not able to obtain and therefore did not review. Five of

these were letters, three were abstracts in the proceedings from a meeting or conference, one was a book, and seven we were not able to classify by the information available. Based on the titles and types of references, however, it is very unlikely that any of these have unique information that we did not obtain in one of the relevant references we reviewed.

**Table 2: Number of References Identified and Relevant by Reference Type**

<b>Number</b>	<b>Articles</b>	<b>Reports/ Other</b>	<b>Letters/ editorials</b>	<b>Websites</b>
<b>Identified</b>	1154	47	54	32
<b>Possibly relevant</b>	287	42	46	8
<b>Relevant</b>	88	19	25	7

One of the criteria we used for determining whether a reference was potentially relevant in the first phase of the review was that it seemed to address at least one of the following topics: benchmarks, evidence for benchmarks, relationships with patient outcomes, wait-time definitions, wait-times experienced, or background information related to issues on cancer wait-times or benchmarks. Later on, we added an additional category, evaluation of service delivery systems (with respect to time and/or quality of care), that we thought important to include in order to be able to comment comprehensively on future research needs. The final categorization of the relevant articles is shown in Table 3 divided by country of investigation, Canada or outside Canada. This division is made because a lot of information gained by health services research from other countries is difficult to translate to Canada. There are many reasons for this difficulty including differences in service delivery practices, payment for services, cultures, behaviors, and populations. In this report, we therefore, focus on findings of studies that have been done within Canada, highlight findings from studies outside of Canada which may translate to Canada, and identify additional areas of research needed relating to benchmarks and time to cancer-related health care services in Canada. Relevant articles may appear in more than one category, for instance many of the evaluation of service delivery articles also contain wait times experienced and are therefore included in both categories.

**Table 3: Number of Relevant References by Category and Country**

	<b>Canada</b>	<b>Outside Canada</b>
<b>Benchmarks/Evidence</b>	1	15
<b>Relationships</b>	3	36
<b>Wait Times Experienced</b>	13	41
<b>Evaluation of Service Delivery</b>	7	31
<b>Background</b>	4	20

### **Update and Summary of Benchmarks and Evidence for Them**

We did not identify any additional benchmarks or sources providing evidence for existing benchmarks that were not included in Report 2. There is one article, however, we reviewed after Report 2 that we have categorized as a benchmark article that was conducted in Canada<sup>(22)</sup>. This reference is unique from the other benchmark references which are all reports from experts groups or cancer associations. Although information is based on expert opinion, this reference is for a study conducted to identify similarities and differences in professional opinion between the United States and Canada with respect to maximally acceptable time from referral to first radiation treatment based on six hypothetical patient

cases. Amongst the radiation oncologists surveyed in Canada, the maximum acceptable time for the six hypothetical cases was considered to be 20 days (median) and amongst those in the United States was 15 days. These numbers are fairly consistent with the Canadian Association of Radiation Oncology recommendations of 20 working days (one month) from referral to radiation for non-emergency cases, considering there were emergency cases included in the hypothetical examples.

### **Update and Summary of Relationships**

In Report 2, the studies we identified that fell into the ‘relationships’ category looked at prognostic factors for survival, rate of tumor growth, and timing of radiation therapy when given in combination with chemotherapy. All of these studies focused on lung cancer. We have since identified and reviewed a few additional articles that fall into the ‘relationship’ category and the above subcategories. An additional study that looked at possible reasons for survival differences between lung cancer patients in Denmark compared to those in other Nordic countries<sup>(91)</sup> found that the main reason for the difference was worse stage at diagnosis in Denmark than those in Norway and Finland. This is consistent with the studies described in and conclusions drawn in Report 2: stage is the most predictive single factor of survival. A report of a study and literature review on prognostic factors for colorectal cancer<sup>(81)</sup> conducted in Italy found that factors of stage (nodal involvement and metastases), bowel obstruction, and male gender were all predictors of poorer survival. Again, stage was the most significant predictor of survival. Time to treatment or time to any other cancer service was not evaluated in either of these studies<sup>(81, 91)</sup> or any of the studies included in the literature review by Ratto et al.<sup>(81)</sup>.

A study not previously included in Report 2 that was conducted in Japan<sup>(58)</sup> compared lung tumor growth rates amongst those screened annually over three years to identify factors that predict fast growth. Sixty-one patients were included in the analysis for which faster tumor growth was associated with smokers, those for whom nodules were visible on chest radiograph, and histologies of small cell and squamous cell carcinoma (compared to adenocarcinoma). These findings are consistent with the results of similar studies described in Report 2, as are the wide range of growth rates found within any of these subgroups, thereby making it difficult to predict tumor growth rate at the level of the individual.

With respect to articles relating to timing of radiation treatment given in conjunction with chemotherapy, one additional article was identified and reviewed<sup>(43)</sup>. In report 2, two out of four of the randomized controlled clinical trials that evaluated timing of radiation therapy found that if given in conjunction with chemotherapy early on (e.g., in the first cycle of chemotherapy) patient survival was better than if radiation therapy was given later on (e.g., cycle 3 or later). The additional article reviewed also found favorable survival for patients who received the ‘early radiation’ compared to those who received the ‘late radiation.’ It is difficult to draw any clear conclusion from these trials, however, as they all used different definitions for ‘early’ and ‘late’ radiation. It is reasonable to think that timing of radiation in conjunction with chemotherapy should matter in light of the increased rates of tumor growth seen in the studies that have evaluated rates of tumor growth post-initial treatment, particularly if the radiation reduces the number of potentially replicating tumor cells as one might predict.

We identified three studies conducted in Canada that evaluated patient outcome with respect to time to radiotherapy. One was a literature review conducted by Huang, et al,<sup>(18)</sup> with the purpose of determining whether time to radiotherapy impacts survival. Most of the studies identified by the authors were in breast cancer and head and neck cancer patients. For these patients there is evidence that increasing time to initiation of radiotherapy is associated with a decrease in local recurrence rate, concluding that time to treatment should be as short as is reasonably possible. Huang et al, did not find any studies that were

conducted on colorectal cancer patients and only five that were conducted in lung cancer patients. Consistent with our findings reported in Report 2, disease stage was a confounding factor in these five retrospective studies. Again, the two critical factors are 1) accounting for stage in analyses, and 2) identifying the fast-growing tumors and treating those quickly.

In another Canadian study<sup>(23)</sup> the authors developed a model based on clinical data for the tonsillar region to predict loss of local tumor control with increasing time to radiation. The model developed estimates that the local control rate would decrease 10% per month in a typical series of patients with carcinoma of the tonsillar region. This estimate will vary depending on the rate of growth of the cancer but given this, the authors conclude that time from referral to radiation should be as short as is reasonably possible. A study conducted by Johnson, et al,<sup>(19)</sup> conducted in Nova Scotia, evaluated the relationships between time to radiotherapy and age, gender, income, distance to cancer center, and extent of disease as well as changes in time to radiotherapy over an eight-year period. Time to radiotherapy was not associated with age, gender, or income, but was with extent of disease (more extensive disease, shorter the interval to treatment). Interestingly the time from diagnosis to radiotherapy did not change over the 8-year interval evaluated for colorectal cancer patients but increased from five weeks to seven weeks for lung cancer patients. The interval of diagnosis to first consult was longer for those who lived more than 165 km from a cancer center but the interval consult to radiation was shorter so that the overall interval diagnosis to radiotherapy did not differ by distance to cancer center. This was probably because patients who lived far away stayed near the cancer center once they came in for their consult and subsequent scheduling took into account that they were not local residents so they were seen faster. This study<sup>(19)</sup> suggests that access to radiotherapy is equitable for patients living in Nova Scotia and that stage of disease at diagnosis is the major factor related to time from diagnosis to first treatment.

We did not identify any studies that evaluated patient outcomes with timing of surgery, chemotherapy (except when in conjunction with radiation), diagnosis or any other cancer care step.

### **Update and Summary of Wait-Times Experienced**

One of the goals of this project was to consider benchmarks for wait-times that relate to any part of the patient care continuum for lung and colorectal cancer patients rather than focusing on one piece of the continuum such as treatment. The cancer control system is complex; the range of services is broad and includes screening, diagnostics, treatment, post-treatment surveillance and end-of-life care.

Additionally, some services are obtained outside cancer agencies, some inside cancer agencies and some may be obtained inside or outside a cancer agency. In order to properly evaluate the system, therefore, information on the entire continuum is needed to identify where the current roadblocks are for cancer care, understand why they exist, and implement changes that will solve current problems and prevent future potential ones. Putting into place “benchmarks” for specific points in time along the care continuum will not solve problems in the short or long-run unless there is an understanding of the underlying issues of the larger picture. As part of the literature review, we therefore, identified references that quantified time between care steps for any portion of the patient care continuum for lung and colorectal cancer patients in order to assess the current “health” of the cancer control system.

We identified twelve references from Canadian sources that quantified the time from one care step to another for lung and/or colorectal cancer patients. Nine of these are listed in Table 4 with the highlights of the study, care interval measured, and the time reported in the study. Of the three references not listed in Table 4, one was a news article<sup>(29)</sup> written in 1999 describing the dire situation for cancer patients in

Quebec, some of whom were being sent to the United States to receive radiation treatment and others who were waiting five months to receive it. The data sources for the information were not given nor was the starting time point of the interval “time to radiation” defined in the news article. Another reference was a letter<sup>(11)</sup> in response to one of the references in Table 4<sup>(27)</sup>. The third reference not included in Table 4 was an update<sup>(14)</sup> to previously published, more detailed results<sup>(11)</sup> that are listed in Table 4. Of the nine studies in Table 4, only one<sup>(25)</sup> quantified time between care steps prior to diagnosis; five focused on intervals around radiotherapy<sup>(10, 11, 12, 19, 21)</sup> and three focused on intervals around surgery<sup>(24, 27, 28)</sup>. Five were conducted in Ontario<sup>(10, 11, 21, 27, 28)</sup> and only one was population-based<sup>(19)</sup> at the level of the province. It is difficult to compare these studies directly primarily because definitions of intervals and inclusion criteria varied widely. A few general comments and observations can be made, however. Of the studies that quantified and compared length of care intervals across time, some found care intervals increased with year of diagnosis<sup>(19, 21, 28)</sup> while others did not<sup>(12, 19)</sup>. The study conducted by Craighead, et al<sup>(12)</sup>, reported a decrease in length of intervals because short-term and long-term initiatives were put into place when increases in time from diagnosis to radiotherapy were observed in monthly reports. These observations were only possible because the institution had recently implemented an infrastructure that allowed electronic capture and analysis of key data points; the advantages of electronic data capture and retrieval systems cannot be overstated. Without this type of infrastructure, there is no way of identifying and responding to key resource problems in a timely and accurate manner.

Two studies<sup>(25, 28)</sup> identified predictors for length of time between care steps. Simunovic, et al<sup>(28)</sup>, found that other than year of diagnosis, only age and presence of co-morbidities contributed to longer times from first surgical consult to surgery. This finding is consistent with expectations of care as older patients and those with co-morbidities often need more preoperative tests, consults or preparation for operation than younger, healthier patients. Gender, income, type of hospital (teaching), volume of patients, rural/urban residence were not related to time to surgery. Porter, et al<sup>(25)</sup> was the only study conducted in Canada that measured length of care intervals prior to diagnosis. In this study, tumor location in the rectum was associated with longer time from first physician visit to diagnosis and, consistent with many other studies, advanced stage at diagnosis was associated with a shorter time interval from diagnosis to surgery. In addition to quantifying time between care steps, the authors also conducted a patient satisfaction questionnaire to determine which care steps were most strongly associated with patient satisfaction. The interval of diagnosis to surgery (inclusion criteria were colorectal cancer patients that had had surgery) had the strongest association with patient satisfaction even though the interval from first visit with physician for symptoms to diagnosis was the longest and had the greatest variation. The findings of this study suggest that greater resources are needed during the pre-diagnostic period even though the period patients are most concerned with is post-diagnosis. This suggests a need for more resources, at least partially towards patient and physician education, to shorten the pre-diagnostic period.

Additional conclusions drawn by the authors of the above references that are important to consider in the context of resource planning and priorities are:

- Start for "wait" should be when first abnormality is detected, attention to only CARO guidelines is misleading because it's only a portion of the health care window.
- Time-to-care intervals should be assessed within and across the full set of staging activities and treatment modalities required for each diagnosis.
- An increase in time-to-care may not be a major concern if there is a change in protocol as an appropriate response to new knowledge.

- Time to radiotherapy is consistent with what is expected given treatment protocols for various types and stages of disease (in Nova Scotia).
- Obtaining objective workload data is fundamental to identifying resource needs.
- Similarly, quantifying patient trajectories at the population level that encompass the entire patient care experience is necessary in order to identify the roadblocks in the overall cancer control system.
- Patients are most concerned with time from diagnosis to treatment even though the longer time interval and the one with the most variation seems to be in the period prior to diagnosis.

We agree with the above conclusions and add that there is a need to set up infrastructure to allow for surveillance of time-to-care measures over time and across care steps so that problems are identified early, provinces can share their experiences and learn from each other, and resources are put towards care steps that are the real roadblocks, not just those that receive the most press. All of the above address the issue that defining and measuring time between care steps and setting benchmarks should be done in the context of measuring and evaluating the quality of a cancer care system that accounts for the entire cancer control continuum, not only radiation and surgery.

**Table 4 - Wait time intervals in Canadian studies**

<b>Author, City or Province Year</b>	<b>Study type Sample size</b>	<b>Cancer site and selection criteria</b>	<b>Intervals measured</b>	<b>Times experienced</b>
Chow <sup>(11)</sup> Toronto 1996-1998	Retrospective survey of referring physicians Physicians:64	All cancers referred to a rapid response RT program for palliation	1st consult appt to palliative RT	80% given treatment on same day
Craighead <sup>(12)</sup> Regina 1991-1992	Prospective	All cancer patients referred for radiation	Diagnosis to radiation  Consult to radiation	<b>Range in days</b> 1991: 50-65 1992: 30-32  1991: 35-60 1992: 21-24
ICES Report <sup>(10)</sup> Ontario – 1999-2000	Retrospective Regional cancer centers Colorectal:1040 Lung: 1527	Cancer patients who received first radiation within one year of diagnosis	Referral to consult  Consult to radiation  Referral to radiation	<b>Median (IQR) days</b> Colorectal:22(12,33) Lung:14 (8, 26)  Colorectal:40(23,64) Lung: 32 (16, 53)  Colorectal:69(48,92) Lung: 52 (34, 77)
Johnston <sup>(19)</sup> Nova Scotia 1992-2000	Retrospective Colorectal: 598 Lung: 2025	Prostate, colorectal, lung, and breast cancer patients who received RT within a year of	Diagnosis to radiation  Diagnosis to consult	<b>Median (IQR) wks:</b> Colorectal:16 (9, 21) Lung: 6 (4, 11)  Colorectal: 7 (4, 11) Lung: 3 (2, 6)

		diagnosis	Consult to radiation	Colorectal: 6 (3, 10) Lung: 2 (1, 4)
Mackillop <sup>(21)</sup> Ontario 1982-1991	Retrospective Lung: 5445	All cancer patients who received radiotherapy at any of seven cancer centers in Ontario	Diagnosis to radiation  Diagnosis to referral  Referral to consult  Consult to radiation	Median 27.3 days  Median 8 days  1982: >80% within 2 weeks 1991: ~80% within 2 weeks  1982: >80% within 2 weeks 1991:<40% within 2 weeks
Olson <sup>(24)</sup> Edmonton 1999	Prospective Colorectal: 21	Colorectal and breast cancer patients who received surgery at the Royal Alex Hospital	Referral to surgical consult  Surgical consult to surgery	Mean 17d  Mean 15 days (14pts) if no further work up needed prior to surgery; 34 days for the 7pts who required scope prior to surgery
Porter <sup>(25)</sup> Halifax 2001	Prospective 110	Colorectal cancer patients who received surgery	Symptoms to 1 <sup>st</sup> physician visit  Physician visit to diagnosis  Diagnosis to surgery  Surgery to chemotherapy	<b>Median (IQR) days</b> 32 (10, 75)  88 (44, 218)  19 (10,44)  54 (47, 72)
Simunovic <sup>(27)</sup> Ontario 2000	Prospective Colorectal:100 Lung: 123	Patients who had a surgical consult Jan. 31-May 31, 2000 for any cancer	Referral to surgery  Referral to consult  Consult to decision to treat	<b>Median</b> Colorectal: 29 days Lung: 26 days All cancers: 37days  All cancers: 11days  All cancers: 0 days

			Treatment decision to surgery	All cancers: 20 days, 32.5% seen within 14 days
			Surgery to receipt of path report	All cancers: 8 days
Simunovic <sup>(28)</sup> Ontario 1993-2000	Retrospective Colorectal: 24,790 Lung: 7716	All lung, colorectal, breast, and prostate cancer patients that had surgery 1993-2000	First surgical consult to surgery	<b>Median</b> 1993- Colorectal: 13 days Lung: 25  1994 - Colorectal: 14 days Lung: 26 days  1995 - Colorectal: 14 days Lung: 28 days  1996 - Colorectal: 14 days Lung: 27 days  1997- Colorectal: 15 days Lung: 29 days  1998- Colorectal: 16 days Lung: 32 days  1999 - Colorectal: 19 days Lung: 33 days  2000 - Colorectal: 19 days Lung: 34 days

### Studies Outside of Canada

Although our focus for studies that measured time-to-care intervals were those conducted in Canada, we also identified 41 references<sup>(32, 34-36, 38-40, 42, 45, 46, 50, 52-54, 56, 57, 59, 63-66, 68-75, 77-80, 82-86, 88, 95, 96)</sup> from other countries. As mentioned previously, it is difficult to translate much of the information to Canada but there are some lessons that we can learn, particularly from audits that have been conducted to report on patient experiences since implementation of the United Kingdom's National Health Service two-week rule<sup>(21)</sup>. The two-week rule states that time from referral from general practitioner to specialist must occur within two weeks for suspected cancer cases. There were seventeen references we identified that reported effects of the two-week rule, three were news<sup>(74)</sup> or letters<sup>(79, 86)</sup> and the rest were audits or reviews of audits. Of the fourteen audits or audit reviews, ten<sup>(36, 39, 42, 45, 50, 54, 56, 73, 95, 96)</sup> were specific to suspected colorectal cancer referrals, three<sup>(46, 69, 75)</sup> were specific to suspected lung cancer referrals, and one was a literature review<sup>(70)</sup> that included all audits of suspected cancer referrals. These audits are not an exhaustive list of all the audits conducted nor are they an exhaustive list of all the audits reported on

the two-week rule; we did not do an exhaustive search to identify all of them as this was out of scope of this project. There are, however, some lessons that can be gleaned from these reports that apply to Canada, these are listed below.

Lessons learned from the UK two-week rule:

- The guidelines for suspected lung and colorectal cancer are not specific, resulting in most referrals under the two-week rule as having non-cancerous conditions and a large percentage of cancer cases referred as standard referrals.
- Time-to-care intervals have increased for standard referrals since implementation of the two-week rule. Modeling studies predict this effect of the two-week rule and show that it is more efficient to implement a system that allows for equally timely access to services for all rather than a small subpopulation. This is largely due to the large random fluctuation in numbers of cases that will come through an institution's system in a given week, because cancer is a rare disease and because symptoms are not specific, making appropriate resource planning difficult.
- Infrastructure is needed to capture the data elements needed to measure time-to-care intervals that does not necessarily exist and putting the infrastructure into place requires time and resources.
- Setting and mandating unrealistic benchmarks or targets for time-to-care intervals may encourage some "playing" with numbers so they look good in reports to government; numbers across institutions are, therefore, not necessarily comparable in such reports .
- Proper allocation and redistribution of funds to improve diagnostic services and improving cancer care once diagnosis has been made, rather than reducing out-patient waiting times, would be of greater benefit to the patient.

## **Update and Summary of Evaluation of Service Delivery Systems**

As part of our desire to assess the current status of the cancer system with respect to time between cancer care steps via the literature and to inform our gap analysis, we identified references that evaluated service delivery systems that were implemented in order to decrease time-to-cancer-care services or improve quality of care for patients in some way. Again, we focus on the studies conducted in Canada.

### **Studies in Canada**

As indicated in Table 3, there were only seven studies identified in the literature review that were conducted in Canada that evaluated any aspect of the cancer health care delivery system. Six of them are summarized in Tables 5 and 6. The seventh<sup>(14)</sup> is an update of the delivery system reported by Chow, et al,<sup>(11)</sup> so is not listed separately. There were three studies, listed in Table 5, that were conducted to evaluate or identify appropriate implementation of a new delivery system. One of these<sup>(11)</sup> was a fast-track service for patients needing urgent radiation for palliative reasons, one was a modeling study<sup>(15)</sup> that used clinical data to identify changes needed to improve staff retention and patient flow, and the third<sup>(20)</sup> described the process by which a new scheduling system was developed and implemented to improve patient flow and optimize staffing resources for out-patient chemotherapy.

**Table 5: Studies Evaluating Service Delivery - Canada**

<b>Author, City Year</b>	<b>Study type Sample size</b>	<b>Clinic goal</b>	<b>Conclusions</b>
Chow <sup>(11)</sup> Toronto 1996-1998	Retrospective survey of referring physicians' opinions of service	To provide quick access to RT for patients with true medical emergencies (e.g., spinal cord depression) and for those whose life expectancy is < 12 months.	Major strength according to referring physicians is prompt service. Major weaknesses are: poor access for palliative patients in general, difficulty in contacting radiation oncologist, poor communication of info regard treatment received and lengthy time to receive dictation notes
Dickof <sup>(15)</sup> Regina, SK 2001	Modeling based on data from everyone who rec'd RT at the Allan Blair Cancer Center '91-99	Use statistical modeling to improve clinic efficiency	Must build a responsive/flexible system that includes: 1-understand treatment system, 2-move to processes with short service times, 3-use multiple service queues when possible, 4-improve scheduling (decentralize it to allow flex), 5-maintain morale. Cross-train, decrease amount of time to train, enrich jobs, provide good working hours.
Langhorn <sup>(20)</sup> London, ON 2001	Description of methodology used to create a new scheduling system	Decrease in-clinic waiting time for chemotherapy outpatients	Problem: Available nursing hours was limiting resource in determining number of patients and types of treatment that could safely be given on a given day. Solution: Developed a new scheduling system that accounted for nursing intensity of each necessary task.

The other three Canadian references<sup>(13, 16, 17)</sup> identified that address cancer service delivery service were either case studies or systematic reviews based on historical documents and/or expert panels. They were focused on identifying reasons for current problems and identifying solutions for long-term resolution. All of them were conducted in Ontario. An additional reference categorized as background<sup>(30)</sup> describes in detail the restructuring of cancer services in Ontario that has resulted from the processes described in Greenberg, et al<sup>(16)</sup>. The focus was to develop an evaluation process and indicators that focused at the cancer system-level, not just a few areas in detail (ie, radiation), as in the past. The overall conclusion from Greenberg, et al<sup>(16)</sup> is that Cancer Care Ontario has identified and developed indicators that address improvement of the cancer system and are appropriate measures to evaluate progress.

**Table 6: Case Studies/Reviews Evaluating Service Delivery - Canada**

Author, City Year	Study type Sample size	Care step(s) evaluated	Conclusions
Hayter <sup>(17)</sup> Ontario 1920-1997	Systematic review	All cancer services	Current problems date back to policies made 60 years ago. Central problems are: 1- fragmentation of care; 2- variation in treatment practice; 3- inequitable access to care.
D'Souza <sup>(13)</sup> Toronto 1998-1999	Case study of Princess Margaret Hospital Input from 10 people	Radiation therapy	Current problems due to: 1-increasing # of cases (aging population), 2-increasing utilization of service, 3- human resource shortage due to low salaries  Solutions: Short-term: Re-referral to location without or shorter wait-lists. Long term: Sustained commitment to human resources
Greenberg <sup>(16)</sup> Ontario 2005	Systematic review of Cancer Care Ontario 34 panelists to determine system indicators	All cancer services	Previously, CCO only responsible for radiotherapy and about half of chemo delivered in Ontario-about 25% of cancer expenditures.  Restructured so now CCO doesn't deliver care, it purchases it and is responsible for ensuring quality for all cancer patients.

**Conclusions:**

In total, there were seventeen unique references identified by our literature review written by Canadians that addressed time-to-cancer care services or evaluated those services. Only ten of these were studies that collected data on actual patient experiences, the rest were either modeling studies, opinions of authors or summaries of opinions of other experts. Our search methodology should have identified all reports that quantified time-to-care intervals, although it may not have identified all evaluations of service delivery models as there are additional search criteria that could have been used. Since the “evaluation of service delivery” category was added after Report 2, we did not have time to conduct another extensive review to ensure we captured all possible sources for this category. The fact that we identified 31 references<sup>(32, 37, 41, 44-49, 51, 54-57, 60-62, 67-69, 72, 73, 76, 85, 87, 89, 90, 92-95)</sup> for this category from outside of Canada, however, suggests that the search criteria used captured a reasonable number of relevant studies.

We believe that many more studies have been conducted by Canadians than we identified but that these have not been published in the scientific literature or written up as reports in the grey literature. Our findings, however, suggest that there is a shortage of studies that evaluate time-to-cancer care services outside of radiation and surgery. This is largely due to the fact that there is fragmentation in cancer services making it extremely difficult, if not impossible, to obtain data across service deliverers. Hayter, et al<sup>(17)</sup> concluded that fragmentation of care was one of the primary sources for variation in access, appropriateness, and quality of cancer care in Ontario. He recommended a new vision for the cancer system that involves general practitioners, surgeons and regional cancer clinics that integrates education,

prevention, screening, diagnosis and treatment. We agree with this recommendation as the issue of fragmented cancer care exists in all the Canadian provinces and territories and all aspects of the control system need to be integrated in order to properly evaluate it as a whole. Efforts to create electronic medical records that are accessible to appropriate authorities and identifying a single authority responsible for evaluating data that measures quality of care is necessary. Cancer Care Ontario has made significant steps in this direction and other provinces in Canada should borrow from them. Cancer health service researchers in Canada should also make publication of their studies and findings a bigger priority than it currently appears to be in order to maximize the sharing of knowledge.

### **Results and Conclusions From the Feasibility Study to Standardize Time-to-Care Definitions, Measurements, and Reporting for Cancer Care Services**

One of the aims of this project was to conduct a feasibility study to standardize definitions, measurements, and reporting of time-to-care intervals for cancer patients across the provinces of Alberta, Saskatchewan, and Manitoba as a first step towards standardizing across Canada. Over the past several years, cancer agencies in Canada have been asked to produce time-to-care reports<sup>(1, 2, 4-9)</sup> for various care intervals, with ever-changing definitions and metrics (e.g., mean, 50<sup>th</sup> percentile, 90<sup>th</sup> percentile, etc.) that every province interprets differently and has varying ability to obtain due to differences in data that are readily available. Data are, therefore, not comparable across provinces, and in many cases are not comparable within a province over time because the requested data have changed from year-to-year<sup>(8, 9)</sup>. In spite of this, since the data end up in one report, the tendency is for readers and users of the report to compare the data across provinces. In addition to differences in the data that are collected and readily available, there are also many differences in the ways each province administers cancer care even within provinces at the different cancer treatment facilities. The question then becomes, “Is it possible to standardize time-to-care measurements and reporting for cancer patients across provinces and, if so, what intervals can be compared?” Our feasibility study set out to answer that question. The rationale for including the three Prairie Provinces is that we all use the same software, Varian MedOncology (VMO), to capture scheduling data as part of our electronic medical record, thus eliminating data comparability restrictions due to software differences. Researchers, senior management, clinicians, nurses, data analysts, and programmers from each of the three provinces were included in a series of workshops to identify and agree upon intervals that should be standardized and comparable at a national level and to present and discuss the results. In our June 2005 workshop, we agreed that ensuring high quality care should be the primary reason behind national standardization efforts. We further agreed that time from diagnosis to first treatment within a cancer facility was the interval that: 1) cancer agencies have control over, 2) measures quality of care at a high level, and 3) the dates are collected in our three cancer agencies in a consistent manner. The interval from diagnosis to first treatment, thus became the primary interest and efforts of the feasibility study. Consensus was also reached to evaluate and compare data each agency had regarding dates for health care services considered to be secondary by the group: dates of surgery, referral to cancer agency, and first consult with medical oncologist. We predicted that for *most* patients, these services would occur between the time of diagnosis and first radiation or chemotherapy. These time points were considered secondary because it was clear in early discussions that the dates for these services were not collected consistently and/or accessible to all three cancer agencies in a comparable manner. Since surgery is a major form of treatment and because dates of referral and consults are frequently requested as part of time-to-care intervals, we thought they were important time points for us to evaluate as a group in order to flush out the difficulties and limitations of these dates across our three provinces. Once the major decisions described above were made, a subgroup, comprised of researchers and data analysts, worked together closely to define the populations, identify comparable data representing the agreed-upon intervals, and

identify ways of presenting the data for further discussion in the study workshops. In the remainder of this section our populations and key results are presented graphically and described.

The patients included in this feasibility study are lung and colorectal patients diagnosed in Alberta, Saskatchewan, or Manitoba in 2004. Tables 7 and 8 present demographics of the lung and colorectal cancer patients, respectively, from each of the provinces. The populations are very similar with respect to age and gender distribution as well as percentage living in rural vs. urban regions at time of diagnosis.

**Table 7: Demographics of Lung Cancer Cases Diagnosed in 2004**

Province	Sample	Age			Gender		Region <sup>3</sup>	
		<=69	70-79	>=80	M	F	Urban	Rural
Manitoba	All cases <sup>1</sup>	385	282	182	446	403	492	357
	Eligible <sup>2</sup>	289	183	115	295	292	347	240
Saskatchewan	All cases	276	237	124	347	290	374	263
	Eligible	220	149	76	247	198	190	255
Alberta	All cases	815	529	227	834	737	998	573
	Eligible	634	365	140	600	539	772	367

<sup>1</sup>All cases - All patients that have topology of C33-C34, C260 diagnosed in 2004

<sup>2</sup>Eligible- Eligible for treatment: All provincial resident patients with a first primary invasive cancer C33-C34, diagnosed in 2004 excluding leukemias, and patients that died within a week of diagnosis

<sup>3</sup>Region – Urban defined as living in health region with major cancer facility (i.e., Edmonton, Calgary, Regina, Saskatoon, or Winnipeg)

In our initial discussions regarding patient inclusion we thought it important to exclude certain patients for the following reasons: 1) patients who had had more than one primary invasive cancer because treatments are not linked to diagnosis in our databases, 2) patients with non-invasive cancers because the type of care is not the same for these patients, 3) patients who were not residents of the province at the time of diagnosis because access to cancer facilities were not thought to be comparable to in-province patients and, 4) patients who were diagnosed at the time of death or soon after diagnosis because these patients do not have the opportunity to receive treatment.

**Table 8: Demographics of Colorectal Cancer Cases Diagnosed in 2004**

Province	Sample	Age			Gender		Region <sup>3</sup>	
		<=69	70-79	>=80	M	F	Urban	Rural
Manitoba	All cases <sup>1</sup>	366	241	203	431	379	447	363
	Eligible <sup>2</sup>	290	187	125	320	282	348	254
Saskatchewan	All cases	335	253	194	426	356	287	495
	Eligible	252	169	110	277	254	187	344
Alberta	All cases	794	525	366	944	741	1075	610
	Eligible	593	339	225	649	508	769	388

<sup>1</sup>All cases - All patients that have topology of C18-C21, C260 diagnosed in 2004

<sup>2</sup>Eligible- Eligible for treatment: All provincial resident patients with a first primary invasive cancer C18-C21, C260 diagnosed in 2004 excluding leukemias, and patients that died within a week of diagnosis

<sup>3</sup>Region – Defined as in Table 7

Table 9 lists each of these exclusion criteria and the number (percent) of patients excluded by cancer site for each province. These exclusion criteria eliminated 25-30% of all the cases. The criterion that accounted for the majority of exclusions, approximately 65%, was history of multiple invasive cancers. Because such a large percentage of patients were excluded with the exclusion criteria initially thought reasonable, analyses were done two ways. One excludes those patients with any of the criteria listed in Table 9, and the other excludes only those patients who died within a week of diagnosis. The majority of the results shown in this report are from the latter, more inclusive category. Tables 7 and 8 present the demographics for the entire population as well as for the population that excludes patients with any of the criteria listed in Table 9. The exclusion criteria did not result in a change of the distribution of the population with respect to age, gender, or residence.

**Table 9: Sample Selection for Feasibility Study**

	Alberta		Saskatchewan		Manitoba	
	Colorectal	Lung	Colorectal	Lung	Colorectal	Lung
	N(%)	N(%)	N(%)	N(%)	N(%)	N(%)
Diagnosed in 2004(a,b)	1685	1571	782	637	810	849
Non provincial residents	75	91	10	5	25	33
Remaining	1610(96)	1480(94)	772(99)	632(99)	785(97)	816(96)
Non-invasive tumor	87	3	75	2	34	13
Remaining	1523(90)	1477(94)	697(89)	630(99)	751(93)	803(95)
ICD-0-3 cell type (c)	11	4	3	1	0	1
Remaining	1512(90)	1473(94)	694(89)	629(99)	751(93)	802(94)
Multiple cancers (d)	339	281	139	114	130	166
Remaining	1173(70)	1192(76)	555(76)	515(81)	621(77)	636(75)
Dead at diagnosis	5	25	16	49	12	26
Remaining	1168(69)	1167(74)	539(74)	466(73)	609(75)	610(72)
Dead within one week of diagnosis	11	28	8	21	7	23
Remaining	1157(69)	1139(73)	531(73)	445(70)	602(74)	587(69)

a- Definitive diagnosis date using Canadian Cancer Registry coding rules.

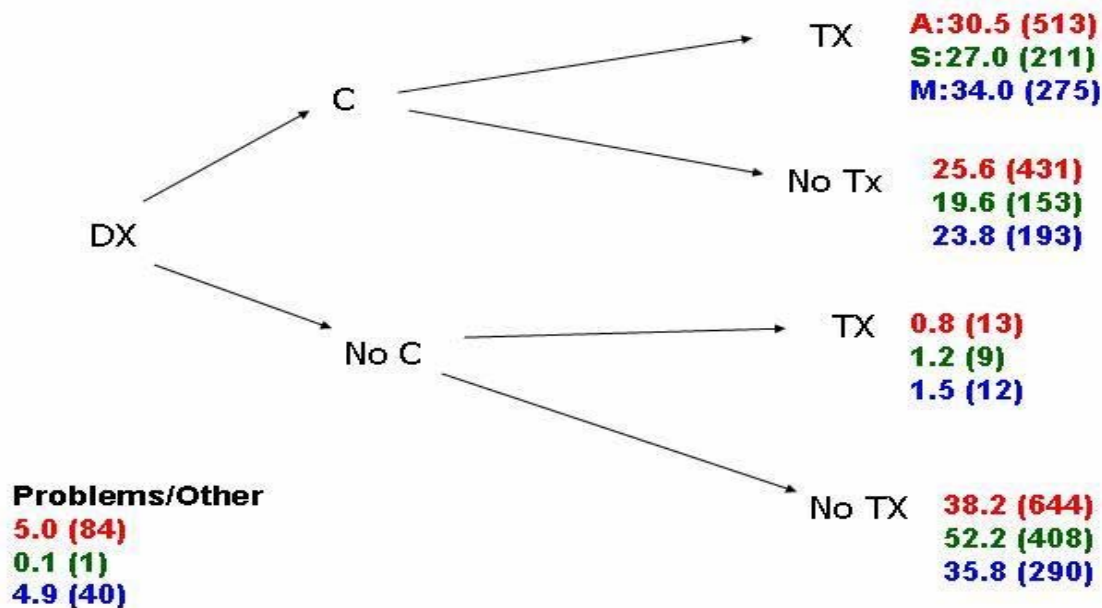
b- ICD-10 coding definitions: Colorectal – C18, C19, C20, C21, C260; Lung – C33, C34.

c- Excluded leukemias, lymphomas, mesothelioma and Kaposi's sarcoma.

d- Does not include non-melanoma skin cancer, does include in-situ breast and bladder.

As a first step in our analysis, we created diagrams of patients' "standard paths to care"<sup>(26)</sup> to illustrate the health care steps utilized by patients included in the study. Figures 1 and 2 show the simplest diagram that we created, it includes all possible pathways from diagnosis to consult with an oncologist (yes/no) to radiation/chemotherapy (yes/no). The percentage (number) of patients who experienced each pathway for each province is given. In each of these figures, the red numbers correspond to Alberta, the green numbers correspond to Saskatchewan and the blue numbers correspond to Manitoba. The numbers listed under "Other" indicate the percentage and number of patients who did not fall into any of the pathways depicted. These are primarily due to errors in the data, for instance, patients for whom the first consult date occurred after the radiation or chemotherapy. In practice this order could not happen because a meeting to discuss the treatment plan with the patient (i.e., a consult) must occur prior to a patient receiving treatment. These pathways do not take into account whether or not a patient had surgery, that is, patients who had radiation or chemotherapy, regardless of whether or not they had surgery, are in the DX-C-TX arm of the diagram. In this way, all patients colorectal and lung cancer patients are accounted for in Figures 1 and 2, respectively. We created diagrams depicting patient trajectories that included the secondary care points, surgery or referral to a cancer facility but do not include them in this report because the interval and time from diagnosis to first treatment is our primary outcome. Furthermore, although date of first consult with an oncologist was defined as a secondary time point, we discovered that the three cancer agencies collect and maintain that information in a comparable way so we were able to easily include it. Dates for surgery and referral, however, are not currently available for all three cancer agencies and the comparability for the two agencies for which each set of dates are available, is still being assessed.

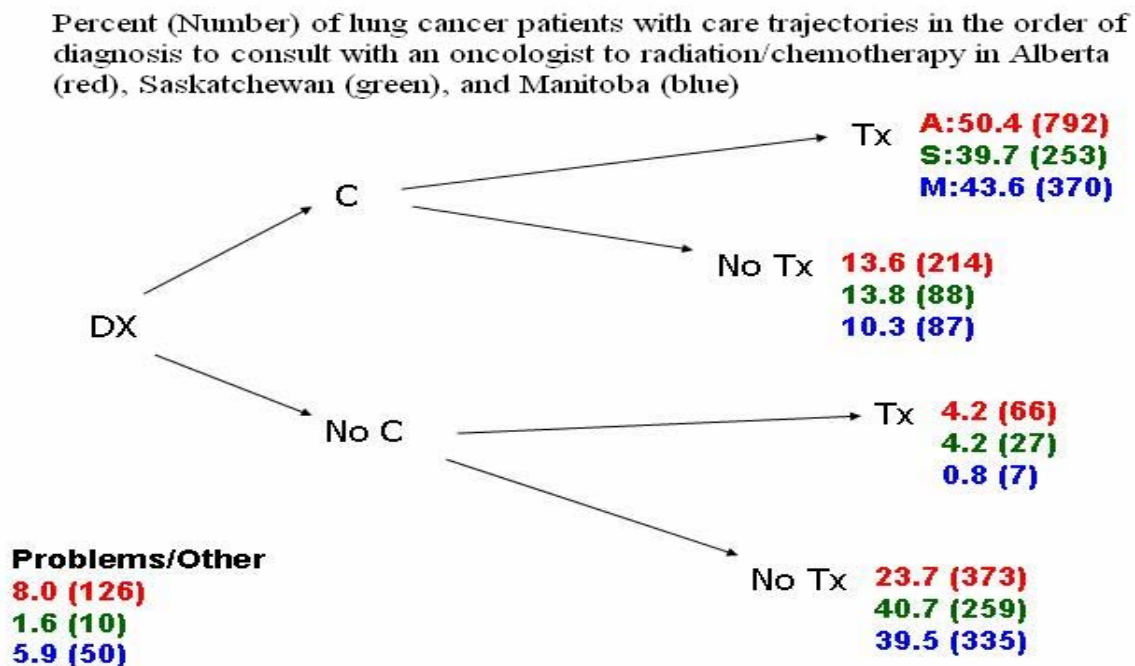
Percent (Number) of colorectal cancer patients with care trajectories in the order of diagnosis to consult with an oncologist to radiation/chemotherapy in Alberta (red), Saskatchewan (green), and Manitoba (blue)



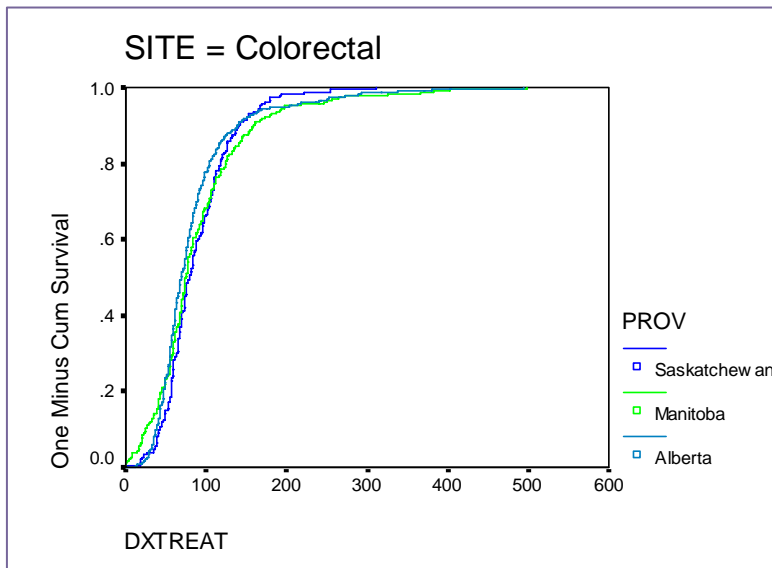
**Figure 1:** Colorectal cancer patient trajectories from diagnosis (DX) to first consult with an oncologist or not (C or No C) to first chemotherapy/radiation or not (Tx or No Tx).

As can be seen in Figures 1 and 2, the percentages of patients in each pathway are very similar across the three provinces indicating a similar level of utilization of cancer agency facilities for oncology consults and radiation or chemotherapy amongst colorectal and lung cancer patients, respectively. In these populations, roughly 30% of colorectal cancer patients had a consult with an oncologist and later received radiation or chemotherapy, 20% had a consult but did not receive treatment, and about 40% did not come into a cancer facility at all. In contrast, about 45% of lung cancer patients had a consult with an oncologist and received radiation or chemotherapy, 13% had a consult but did not receive treatment, and about 30% did not come into a cancer facility at all. The larger percentage of colorectal cancer patients who did not have a consult with an oncologist and/or receive radiation or chemotherapy relative to lung cancer patients is reflective of the fact that many colorectal cancer patients are “cured” with surgery alone. Lung cancer patients, on the other hand, tend to have advanced unresectable disease at diagnosis and a larger percentage receive palliative care only.

After creating diagrams of the patient trajectories, as depicted in Figures 1 and 2, we calculated the times between each of the care intervals, starting with the diagnosis to first consult to first treatment pathways, that is, the overall time from diagnosis to first treatment was calculated as well as the intermediary intervals, time from diagnosis to consult and time from consult to first treatment. Initially we calculated means, medians, quartiles, and 90<sup>th</sup> percentile points but we found that the large number of numbers that resulted made it difficult to digest the information and that often, conclusions differed depending on the metric (e.g., median or 90<sup>th</sup> percentile) used to compare the provinces. We, therefore, created time-to-event graphs so that all the data could be seen from each province and different curves could be overlaid one another for comparative purposes. Figures 3-6 are examples of some of the cumulative time-to-event graphs created.



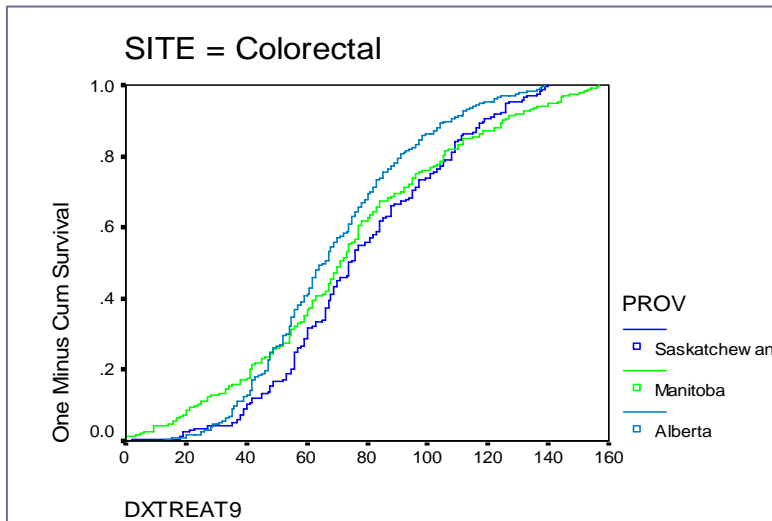
**Figure 2:** Lung cancer patient trajectories from diagnosis (DX) to first consult with an oncologist or not (C or No C) to first chemotherapy/radiation or not (Tx or No Tx).



**Figure 3:** Cumulative time from diagnosis to treatment for colorectal cancers diagnosed in 2004 by province of those who received radiotherapy or chemotherapy.

10% of patients. In order to understand why the top 10% of patients had such long intervals from diagnosis to first chemotherapy/radiation, we performed chart reviews on a sample of them. We found that these were patients who had unusual circumstances or extreme situations. Examples of these situations include: 1) multiple surgeries prior to treatment, 2) receipt of unconventional treatment outside of Canada and later received palliative treatment, 3) initially declined treatment but later had disease progression so received palliative treatment at that time, and 4) participated in clinical trials, the treatments for which are captured in separate databases to which we did not have access. Because these

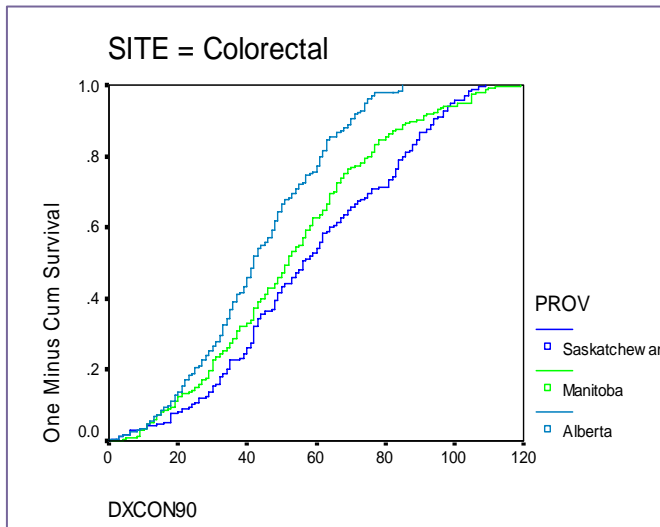
Figure 3, to the left, is an example of one of these graphs and shows the cumulative time from diagnosis to first chemotherapy or radiotherapy for patients who received either of these treatments, by province. The x-axis is the number of days from diagnosis to treatment and the y-axis represents the cumulative proportion of patients who had the event of interest. As an example, a little more than 80% of patients received radiation or chemotherapy within 100 days of being diagnosed, according to Figure 3. There are two main points to be made from this graph: 1) there is not any difference between the three provinces, and 2) 90% of the patients received treatment within about 150 days of diagnosis after which time the graph flattens out indicating large variability for the interval in the remaining



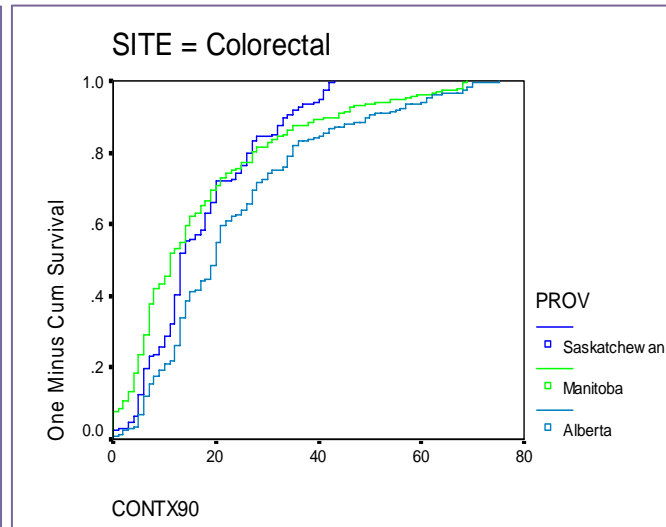
**Figure 4:** Cumulative time from diagnosis to treatment of the 90<sup>th</sup> percentile for colorectal cancers diagnosed in 2004 by province of those who received radiotherapy or chemotherapy.

patients represented unusual circumstances and because we had no way of accounting for them individually (e.g., we could not identify clinical trial patients or categorize treatment as having palliative or curative intent) we decided to exclude them from the graphs in order to better see the data for the 90% of patients who represent the more “typical” patient scenario. Figure 4, to the left, is identical to Figure 3 except only the bottom 90<sup>th</sup> percentile of patients are included. By deleting the 10% extreme scenarios, one can see there is more variation between the provinces than indicated in Figure 3, however there is no statistical difference between them. Roughly fifty percent of patients receive their first radiation or chemotherapy treatment within 65 to 75

days of diagnosis for colorectal cancer. Considering many of these patients receive surgery prior to radiation or chemotherapy, this time seems quite reasonable.



**Figure 5:** Cumulative time from diagnosis to consult of the 90<sup>th</sup> percentile for colorectal cancers diagnosed in 2004 by province of those who received radiotherapy or chemotherapy.



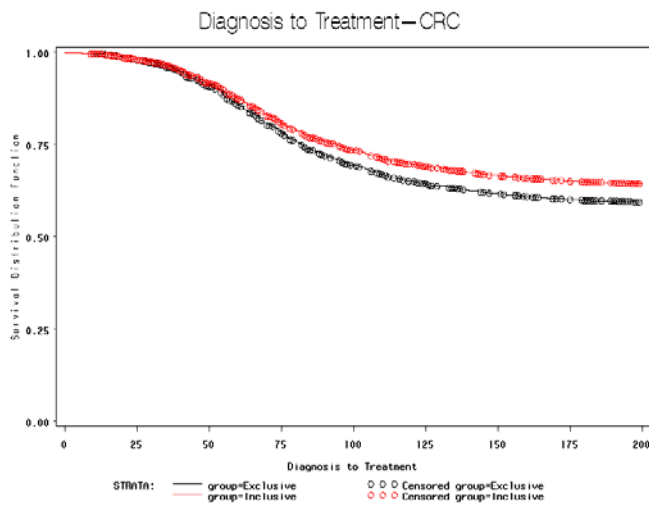
**Figure 6:** Cumulative time from consult to treatment of the 90<sup>th</sup> percentile for colorectal cancers diagnosed in 2004 by province of those who received radiotherapy or chemotherapy.

Figures 5 and 6 are graphs of the time from diagnosis to first consult at a cancer facility and time from first consult with an oncologist to first radiation/chemotherapy, respectively. As in Figure 4, only the bottom 90<sup>th</sup> percentile of patients are included. Although the overall interval of diagnosis to treatment is the same for the three provinces (Figures 3 and 4), time from diagnosis to consult is shorter in Alberta than in Saskatchewan and Manitoba (Figure 5) but time from first consult to first treatment is longer in Alberta than Saskatchewan and Manitoba (Figure 6). These similarities and differences were discussed in Workshops 2 and 3 and we believe that the differences in the subintervals are due to process differences. Based on discussions, it appears that the cancer agencies in Manitoba and Saskatchewan may have stricter scheduling requirements when they receive referrals than exist in Alberta, for instance all diagnostic tests and results must be received by the cancer agency prior to scheduling a consult with an oncologist. This could, theoretically, result in a longer diagnosis to consult interval but shorter consult to treatment interval for Saskatchewan and Manitoba vs. Alberta, as seen in Figures 5 and 6. Another possibility is that Alberta has better processes or more efficient resource utilization for the diagnosis to consult interval whereas Saskatchewan and Manitoba, analogously, have better efficiencies in the consult to first treatment interval suggesting there are ways each province could improve and perhaps learn from another. More detailed assessment is needed to confirm which of the scenarios is correct. Regardless of which scenario is correct, however, it is interesting that ultimately the diagnosis to treatment interval is the same across the three provinces.

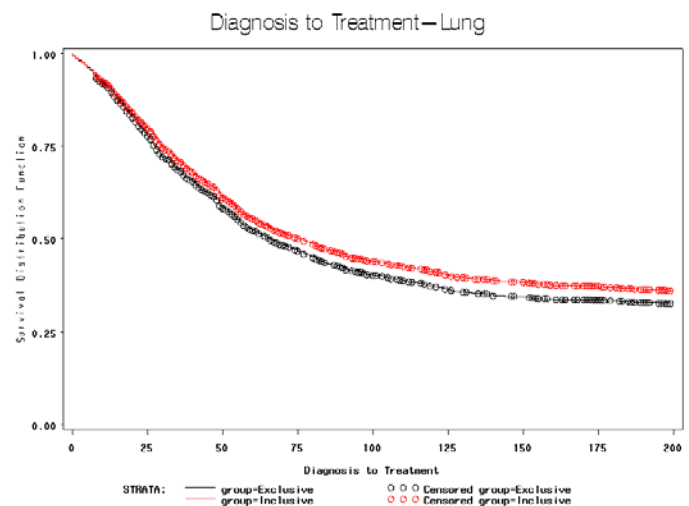
Although Figures 2- 6 are specific to colorectal cancer patients, the results and conclusions are essentially the same for lung cancer patients included in the study, although the specific times experienced by patients for each of the intervals are different. Lung cancer patients tend to have a shorter time from diagnosis to first radiation/chemotherapy and time from diagnosis to first oncology consult than the colorectal patients. This is largely explained by the fact that a larger percentage of the colorectal cancer patients receive surgery prior to first radiation/chemotherapy than lung cancer patients

and have to recover from surgery prior to receiving additional treatment. An additional difference between the colorectal and lung cancer patient intervals is that the differences between the provinces in time from diagnosis to first oncology consult for colorectal cancer patients does not exist for lung cancer patients, that is the length of the interval is the same across the provinces for lung cancer patients.

As mentioned previously, data were analyzed in two ways: all colorectal and lung cancers diagnosed in 2004 except those who died within a week of diagnosis (Group 1) and all diagnoses except those excluded according to the exclusion criteria listed in Table 9 (Group 2). Also mentioned previously, about 30% of the diagnosed patients were excluded as a result of the exclusion criteria. Since our “reasonable” exclusion criteria excluded so many of the diagnosed cases, we evaluated the effect the exclusion criteria had on time from diagnosis to first radiation/chemotherapy. Figures 7 and 8 are graphs of this sensitivity analysis for colorectal and lung cancer, respectively. The x-axis is the number of days from diagnosis to treatment and the y-axis is the proportion of patients that have not received radiation or chemotherapy. Group 1 is depicted by the red line and Group 2 is depicted by the black line in both Figures 7 and 8. Unlike Figures 2-6, Figures 7 and 8 include all patients regardless of their patient trajectory; all patients do not receive radiation or chemotherapy, therefore the curves never reach 0.



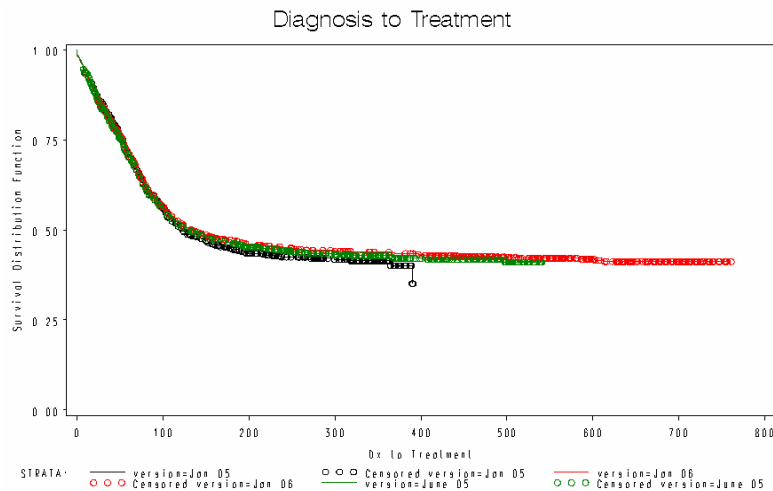
**Figure 7:** Cumulative time from diagnosis to treatment for all colorectal cancers diagnosed in 2004 (red) vs those who were “eligible for treatment” (see text for definition-black).



**Figure 8:** Cumulative time from diagnosis to treatment for all lung cancers diagnosed in 2004 (red) vs those who were “eligible for treatment” (see text for definition-black).

As seen in Figures 7 and 8, the exclusion criteria do not have a very big effect on the time from diagnosis to first radiation or chemotherapy. The curves separate a bit after about 25% of colorectal patients are treated and about 50% of lung cancer patients after which point the interval is a bit longer for the patients in Group 2 than for those in Group 1. This suggests that patients who are excluded are more likely to experience a longer time interval from diagnosis to radiation or chemotherapy but are also a bit less likely to receive either treatment.

For the feasibility study, date of diagnosis from our cancer registries was used to calculate all time intervals that included diagnosis. The reason for doing so is because our cancer registries all follow the same standardized criteria for coding diagnosis and date of diagnosis, furthermore, cancer registry data is of very high quality. It takes upwards of 18 months to complete all the details involved in coding cancer cases, however, far too long for timely production of time-to-care reports. We, therefore, conducted a sensitivity analysis using three snapshots over time of the data in the Manitoba Cancer Registry to determine the effect the accuracy and completeness of the cancer registry data has on time from diagnosis to first radiation or chemotherapy data. Figure 9 illustrates the results of this analysis graphically. The x-axis is the number of days from diagnosis to first radiation/chemotherapy and the y-axis is the proportion of patients that have not received radiation or chemotherapy, that is, the top of the y-axis indicates that 100% of the patients have not received their first radiation of chemotherapy treatment. The three snapshots used were taken in January 2005 (black curve), June 2005 (green curve), and January 2006 (red curve). As seen in Figure 9, there is virtually no difference in the time from diagnosis to treatment in the three different snapshots of the data. The only difference is in the length of the longest time interval, such that as time progresses, the length of the longest interval increases. This makes sense since more opportunity for patients to be treated increases with time. It is also consistent with the findings described earlier regarding patients with unusual circumstances that result in extremely



**Figure 9:** Cumulative time from diagnosis to treatment for all lung and colorectal cancers diagnosed in 2004. Manitoba Cancer Registry snapshots taken in January '06 (red), June '05 (green), January '05 (black)

long intervals from diagnosis to first treatment either because the interval really is long (e.g., patient initially declines treatment, progresses, and then receives palliative treatment) or because we are not able to capture the true first treatment (e.g., patients treated in clinical trials). Another point is that if the exact day of a cancer diagnosis is not known, the cancer registry will default to the first of the month of the date of the cancer diagnosis. For instance, if a patient was known to have been diagnosed in June (day unknown) and treated on 10 July, they would have a time from diagnosis to treatment of 40 days. However, if when the case was coded it turned out that the patient was diagnosed on 30 June, then using the partially-coded case would have overestimated the time to treatment

by 30 days. For this reason, we anticipated that the effect of the default to the first day of the month would be to bias the partially-coded snapshots, January 2005 and June 2005, to have longer times to treatment from diagnosis, however, this did not occur. One explanation for the lack of difference is that the registry does quite well in receiving accurate information regarding date of diagnosis on the majority of patients; it is a small minority for whom the day of diagnosis is initially unknown and, therefore, estimated. Since data snapshots were only available of the Manitoba Cancer Registry we do not know how generalizable this finding is.

## Conclusions

In order to move forward with standardizing definitions, measurement, and reporting of time-to-care for

intervals for cancer patients across Canada, opportunities for open dialogue between cancer agencies, such as we have had in this project, are necessary. Even when “simple” intervals such as diagnosis to first treatment, are agreed on, extensive dialogue and exchange of information is necessary to ensure understanding and comparability of data. If/When differences in length of intervals are seen across provinces, even more discussion is needed to confirm whether the difference is due to a difference in understanding (i.e., the data are not actually comparable) or if the difference is real. If real, investigation and further discussion is needed to determine the reason for the difference and identify changes that can be made to minimize or ameliorate differences. Infrastructure and resources need to be put into place to allow such an iterative set of processes to take place in order to ensure equitable and timely care within and across provinces. Input and participation from data analysts/programmers is an essential part of the infrastructure and process.

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**D) ADDITIONAL COMMENTS** (e.g. challenges you have faced and how you have addressed them, deviation(s) from your original research proposal...)

**D) COMMENTAIRES ADDITIONNELS** (p. ex. des obstacles que vous avez rencontrés et la façon dont vous les avez / que vous les surmontés, tout écart par rapport à votre proposition de recherche initiale...)

**SIGNATURE OF PRINCIPAL INVESTIGATOR:**  
**SIGNATURE DU CHERCHEUR PRINCIPAL DÉSIGNÉ :**

**DATE:**  
**DATE :**