

EXSPANSE

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A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK



In Manitoba, Dr. Donna Turner, left, and Katherine Fradette, anchor the C-SPAN team.

exSPANding horizons

Cancer surveillance is the cornerstone of cancer control. Despite widespread agreement about the basic concepts, there is currently no one standard approach for actually calculating statistics like incidence, mortality, prevalence, and survival in Canada. However, the Cancer Survival and Prevalence Analytical Network (C-SPAN) is aiming to change that for cancer survival and prevalence statistics - two very important population-based measures used to understand the patterns and impact of survivorship. "Our goal is to produce a comprehensive suite of analytical output relevant to cancer survival and prevalence, two measures important to quantifying the burden of cancer in Canadians," said Dr. Donna Turner, epidemiologist and principal investigator of C-SPAN. "We know there is a disconnect between those who analyze the data and those who want to use it to manage and steer the cancer system." The lack of uniformity in cancer surveillance calculations leads to challenges when surveillance

data are compared and interpreted, and frustrates those wanting to use "hard evidence" to address inequities and influence policy.

C-SPAN is one of four Surveillance and Epidemiology Networks funded by the Surveillance Action Group of the Canadian Partnership Against Cancer. To make its concept work, C-SPAN membership includes the "traditional" players, statisticians from cancer and health organizations across the country, but decision makers, policy makers and patient advocates are also at the table. While the idea of producing cancer survival and prevalence statistics, tables and graphs isn't new, the approach is. "C-SPAN is working to connect the surveillance community with those who influence cancer policy, including regional/provincial policy makers and decision makers, clinicians and patients," explained Dr. Turner.

See page 3 ...

Welcome to exSPANse. This forum is intended to engage a broad audience from data analysts to policy influencers. This marks the beginning of a new era in cancer surveillance: we are now intentionally reaching out to the end users to design our reports to fit with what the users tell us they need.

For years cancer surveillance analysts have been providing a wide range of statistics to the health community assuming that these carefully researched reports would be used to develop programs to control cancer. But now we are asking ourselves to challenge these assumptions: are these reports hitting the mark? Is the population benefiting from what the data are telling us? Are we all working with comparable analytic tools? And do we explain well enough why sometimes the statistics can justifiably vary?

We have strong players in the analytic community and there is a desire to draw from this small, but vibrant pool of expertise to create a cohesive, standard way of calculating key survivorship measures. Our approach will contribute significantly to making cancer survival and prevalence statistics comparable and will be a step forward in meeting long-recognized challenges in analytic capacity across jurisdictions. This really is an exciting venture and I invite you to share your ideas or questions along the way. Together, we can blaze new trails which will ultimately lead to improved approaches to and use of cancer surveillance information across the country.

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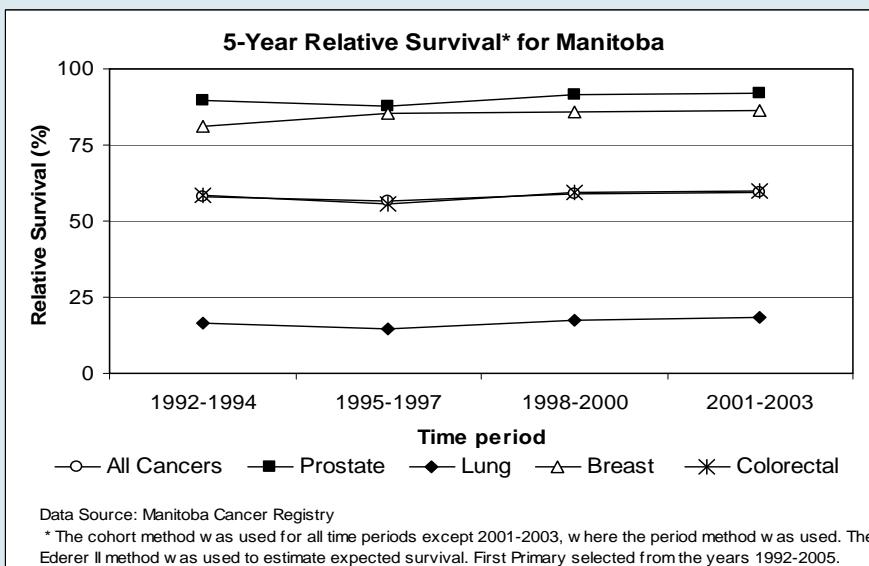
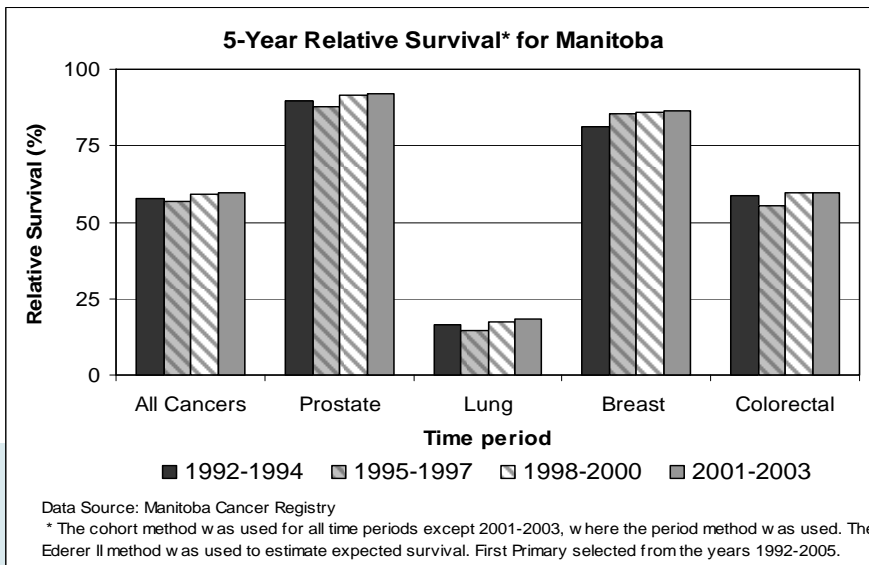
By the Numbers - Policy on 2

This section is designed to engage, educate and learn from the end-users of cancer surveillance information so that we can create products that work for you.

5-Year Relative Survival* (%) for Manitoba				
	1992-1994	1995-1997	1998-2000	2001-2003
All Cancer	57.8	56.7	59.0	59.5
Prostate	89.6	87.8	91.6	92.1
Lung	16.5	14.4	17.5	18.5
Breast	81.1	81.1	85.8	86.4
Colorectal	58.7	55.5	59.4	59.8

Data Source: Manitoba Cancer Registry

* The cohort method was used for all time periods except 2001-2003, where the period method was used. The Ederer II method was used to estimate expected survival. First Primary selected from the years 1992 through 2005.



That old graph magic

We know that clear, concise information is crucial to cancer control planning and that the right presentation is needed to realize the data's full potential.

For example, the graphs on this page are all presenting the same information using different formats. Here's where we need you help!

- Which way do you prefer to see the information presented the table, the line graph or the bar graph?
- Do have any suggestions about how we can make information like this more accessible to you?

We'll be reaching out in a variety of ways. Watch for more on this topic in upcoming editions of exSPANse.

Have a question for *By the Numbers*? Email: roberta.koscielny@cancercare.mb.ca

INTRODUCING ...

C-SPAN's Methodology Working Group

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C-SPAN Member Biosketch



Larry F. Ellison

Job title/Position:

Senior Analyst/Epidemiologist,
Cancer Statistics Section, Health
Statistics Division

Agency: Statistics Canada,
Ottawa ON

Education:

- Undergraduate degree, Statistics, Carleton University
- Graduate degree, Epidemiology, University of Ottawa

Area of interest:

Larry is currently involved in analyzing and describing surveillance data from the Canadian Cancer Registry. He has a particular interest in survival analysis and methodology.

From page 1 ...

"Information needs to be effectively understood and used by these folks as they monitor and inform cancer control activities. To date, we statistical types have analyzed data and written reports hoping that those who need this information will be as enthusiastic as we are about the data. But we now realize uptake only happens by design. We are learning that the basic principles of knowledge translation have not been well applied in cancer surveillance."

In fact, the Surveillance and Epidemiology Networks have learned a lot about knowledge translation. Working with experts in the KT field, they crafted the *Knowledge Translation (KT) Framework for Canadian Cancer Surveillance*, which emphasizes basic requirements of KT, including the engagement of the ultimate users of a project's findings.

C-SPAN has two major audiences - policy influencers and the analyst community. Dr. Turner hopes to work closely with both groups to build capacity for the production and use of cancer survival and prevalence statistics.

"It's a new era for cancer surveillance," said Dr. Turner. "We're excited to be venturing into this new territory with new partners."

Career highlight to date:

Meeting his wife-to-be, Joellyn Ellison (née Hotes), at the North American Association of Central Cancer Registries (NAACCR) 2001 annual conference in Miami Beach, Florida.

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Fradette's Frying Pan -

Serving up today's hot analytic issues

Developing standardized survival and prevalence tools, so that output produced by different people in different provinces can be easily compared, is not as easy as it may sound.

C-SPAN's final goal is to produce cancer survivorship information and share it with a wide audience. This simply cannot be achieved without teamwork! We need teamwork to create agreed-upon standards for survival and prevalence analysis so that analysts from across the country feel confident using the analytic tools we create. In short, we want the products of C-SPAN's efforts to not only be relevant to you, we want them to belong to you.

The C-SPAN methodology group (*see page 3*) met for the first time in September and have gathered monthly since. Many interesting methodological issues around survival analysis have already been raised around the table. For example, the group has explored questions like which population life tables should be used and what is the effect of using different lengths of follow-up intervals on relative survival estimates?

An important ongoing discussion also surrounds whether we should include only first primaries in survival analysis or whether multiple primaries should be considered.

We are so fortunate to have highly experienced analysts from across the country contributing their expertise to our network, and we would like to see the collaboration reach even further.

Hopefully, by encouraging connections in the analytic community, years of knowledge and skill can be shared and new perspectives and fresh questions can shed new light on old ideas. So in addition to the uniform application of tools, we can help each other do our jobs even better.

Please contact me with your thoughts and ideas about cancer surveillance, especially as they relate to survivorship, and I will be sure to share them with our group. Your input will help to make our products better. After all, they belong to you!

Katherine Fradette

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Items under Discussion

This regular feature will highlight topics that have come up for discussion that require further action or updates.

1) First primary versus multiple primary – In survival analysis, analysts typically only include the first primary cancer diagnosis in a person's lifetime despite any diagnosis of a later primary cancer. Researchers are now looking at incorporating all diagnoses into survival analyses and the implications of doing this.

2) The difference between the North American SEER (Survival Epidemiology and End Results) and IARC (International Association for Research in Cancer) coding rules – Right now, the provinces do not all use the same coding systems, which makes comparing information a challenge, especially when looking at multiple primaries.

We want to hear from you. Please contact exSPANse with your comments or story ideas by emailing roberta.koscielny@cancercare.mb.ca.



CANCER SURVEILLANCE AND EPIDEMIOLOGY NETWORKS
RÉSEAUX DE SURVEILLANCE ET D'ÉPIDÉMIOLOGIE DU CANCER



This newsletter is a quarterly update of the C-SPAN project, a unique initiative focusing on the production of cancer survival and prevalence statistics in Canada. We aim to reach everyone who generates, analyzes or uses these measures of cancer survivorship.

Production of this newsletter has been made possible by support from the Canadian Partnership Against Cancer through a Surveillance Action Group initiative, and CancerCare Manitoba. The views expressed represent those of the C-SPAN team.