

EXPANSE

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A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK



User engagement provided a fresh perspective on presenting cancer statistics.

New approach = results

As with any journey, an end is inevitable and though funding for the Cancer Survival and Prevalence Analytic Network (C-SPAN) finishes this spring, the lessons learned will serve to inspire for years to come.

Funded by the Canadian Partnership Against Cancer since 2009, the C-SPAN team has been dedicated to consulting with data users from all walks – data analysts, statisticians, policy makers, decision makers and patient advocates – in order to develop, design and produce cancer surveillance reports that fit the requirements of various users, as well as incorporating standardized methods to calculate prevalence and survival statistics that compare globally.

Despite increasing interest in survival and prevalence statistics, these figures have not been routinely produced by Canada's cancer registries. Though calculation of these measures is less straightforward than the readily produced incidence and mortality figures, it is not insurmountable. However, many cancer registries have not had the analytic capacity to apply the relevant methodologies and produce useful, comparable cancer survival and prevalence estimates for their populations. Even where this capacity exists, the results of the analysis have not always been shared in a format that is accessible or understandable by the many potential users of this information.

Enter C-SPAN – a collaborative effort with the aim of developing an environment to improve the effectiveness and efficiency of producing this information and promoting the use of standard analytic tools to ensure that both straightforward requirements, as well as the more complex, are met. This work is important because it leads to improved application of cancer surveillance data across the country.

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We've done it! C-SPAN's deliverables are nearly complete and the journey has been an extraordinary one. In this last column, I'll reflect on what we learned and the legacy created by the Cancer Surveillance and Epidemiology Networks.

A definite high point for me was truly connecting with people in their fields of expertise and working together to respond to a need. The team was able to tap into this knowledge and effectively apply it to the methods and concepts used to produce our reports. By cultivating expertise from across the country, C-SPAN was able to conduct thorough discussions around key issues such as choosing a standard population (relative survival) and whether to use first or all primaries. Heading into this, it was expected these basic topics would be easy to check off the list, but that wasn't the case.

The C-SPAN team was surprised to learn that things we thought were "standard", actually weren't. A series of intense engagement gave the team the chance to collect information and get to the heart of what was needed to produce standardized comprehensive reports. Our *Conversations with C-SPAN* sessions with our users helped the team to clearly understand who a particular audience is, what is needed and what format is required. It was a humbling and refreshing experience and it provided the necessary perspective to learn not only about the data users, but about ourselves as data experts as well.

By distilling all the information from our users gathered over many hours of consultations, and combining it with the expertise of our programmers and analysts, the C-SPAN team brought it all together to produce cancer surveillance reports in a new way. First impression feedback has been very positive and it demonstrates that users are ready for reports that embrace the quality of traditional publications in conjunction with user-friendly design and formatting. It has been most gratifying to see this style already being embraced and pressed into service by other agencies. Our users will be pleased.

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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.

Quick guide for survival & prevalence terms

The clock is ticking and you need to provide accurate data – fast. C-SPAN's reports have been designed to provide comprehensive information in a user-friendly format no matter what province you are in. Our soon-to-be released reports – *Cancer Survival in Canada* and *Cancer Prevalence in Canada* – have province-specific chapters in addition to the overall Canadian figures that offer a clear look at what the survival and prevalence statistics particular to each province are and how they compare with the rest of the country.

Here's a handy guide to understanding key cancer surveillance terms:

Survival

Crude survival:

- ▶ how many individuals diagnosed with cancer are alive after five years?
- ▶ endpoint is death from any cause

Disease-specific survival:

- ▶ how many individuals diagnosed with cancer have not died specifically of cancer after five years?
- ▶ endpoint is death from cancer only

Disease-free survival:

- ▶ how many individuals are alive and have not had a recurrence of the cancer after five years?
- ▶ "survivors" exclude people with a recurrence of their disease

Relative survival:

- ▶ compares the survival experience of individuals with cancer to individuals without cancer (of the same age)
- ▶ is a way of comparing survival of people who have cancer with those who don't - it shows how much cancer shortens life
- ▶ has become the standard survival measure in the population-based setting
- ▶ compares the survival experience of individuals with cancer to individuals without cancer (of the same age)

Prevalence

- ▶ a different "survivorship" statistic that can be used for health planning, resource allocation, and an estimate of cancer survivorship
- ▶ the number (or %) of people alive on a certain date in a population who previously had a diagnosis of the disease
- ▶ includes new (incidence) and pre-existing cases incorporates both past incidence and survival

Limited-Duration Prevalence:

- ▶ represents the number (or %) of people alive on a certain day who had a diagnosis of the disease within a determined time frame
- ▶ commonly looks at two-, five-, ten- or 15-year prevalence
- ▶ is the standard way of calculating prevalence using population-based cancer registry data

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C-SPAN Member Biosketch

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Job title/Position

Provincial Leader, Epidemiology

Education & Training

- ▶ MSc, Community Health and Epidemiology, University of Saskatchewan, Saskatoon, SK.
- ▶ Bachelor of Arts (Advanced), Sociology, University of Saskatchewan
- ▶ Bachelor of Science (Advanced), Physiology, University of Saskatchewan

Area of interest

Riaz is interested in cancer surveillance, indicator development, program evaluation, using epidemiologic methods to evaluate programs offered by the Saskatchewan Cancer Agency, risk factor surveillance, and cancer in indigenous populations. Membership includes C-SPAN, CRC-Net and C-Proj and CPAC's Surveillance Advisory Group, CSEB board member, and a Canadian Coordinating Committee of the Canadian Alliance of Regional Risk Factor Surveillance member.

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From page 1 ...

Cancer is changing the Canadian landscape; it is the leading cause of premature loss of life, despite significant improvements in cancer prevention, treatment and survival. Numbers are high partly because of an aging population. According to 2011 statistics, Canadians aged 50 and older represent 88% of all new cancer cases and 95% of cancer deaths. Estimates for 2011 include approximately 74,700 new cancer cases (42% of all cases) and 44,600 cancer deaths (59% of all deaths) in Canadians aged 70 and up.¹ Increasingly, surveillance statistics are needed to anchor and justify cancer programs and policy.

To achieve its task, C-SPAN worked to connect the surveillance community with those who influence cancer policy - regional/provincial policy makers and decision makers, clinicians and patient advocates. Gathering information from these interactions was essential in learning how to work together to improve the design of traditional cancer surveillance reports. Now nearing completion, C-SPAN has created a suite of surveillance products in forms that are usable by the target audiences, as well as building the foundation for sustainable analytic capacity with regards to the production of survival and prevalence statistics across Canada.

Reference

1. Canadian Cancer Society's Steering Committee on Cancer Statistics. *Canadian Cancer Statistics 2011*. Toronto, ON: Canadian Cancer Society; 2011.

Hitchhiking along Epi Road

Epidemiologist Alain Demers recounts his C-SPAN journey

As I write these words, the C-SPAN Central team in Winnipeg is busy making final edits to the top ten prevalence report and readying it for a March submission. Right now, we are discussing the content and format of the conditional survival report that should be finalized soon - an event that makes all of us rejoice!

Compared to other team members, I have been with C-SPAN for a relatively short time. Last summer I was looking to hitchhike onto some interesting epi work and was excited when Donna Turner invited me on board. Some would say it was good timing because many of her team members were busy bringing new lives to our planet. So far, I have to admit that the ride has been an interesting one.

I knew that C-SPAN was departing from the traditional report format to showcase its results, a move that has the potential to broaden the use of cancer statistics among stakeholders. The feeling that we can do something better with cancer data was really appealing to me and I was glad to be part of this work.



Over these few months, I took the tremendous efforts of many like Ron Dewar from Nova Scotia, Ryan Woods from British Columbia, Larry Ellison from Statistics Canada and Diane Nishri from Ontario (just to name a few), mixed in the numerous consultations and observations from users and layered it into this format so it could slowly stew and develop.

I did come across a few surprises, one being the sheer size of these reports. I wasn't completely prepared for the magnitude of the task, but after jumping in and working with C-SPAN Central and imaginative people like Oliver Bucher and Madeline Kells, putting together reports numbering hundreds of pages went quite smoothly.

The editing process was an eye-opening experience and that's when I saw - in action - how teamwork is really key. Everyone on this project, from analysts to communications and administrative staff, were employing their skill sets to shape the reports to what users said they wanted.

I hope you will enjoy discovering these results in this innovative format. I am certain that you will find the final results to be interesting, informative and some of them even unexpected, but I'm not saying anymore...

Alain Demers

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Editor's Note

Editing *exSPANse* has been a great experience. Much like C-SPAN's reports, *exSPANse* was designed to be a hybrid - a publication written to satisfy a professional audience (analysts and policy makers) as well as a public one.

The C-SPAN Central team (see left) has been very open to new ways of providing information and Methodology Working Group members have proved to be fine columnists. Thanks for sharing your expertise!

- Roberta Koscielny