

# EXSPANSE

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A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK



*Dr. Donna Turner, right, consults with Canadian Cancer Action Network members*

## Conversations with C-SPAN

Though they use different lenses to look at the same data, policy makers/ influencers and advocates rely on cancer surveillance information to support their decisions and future plans.

“Understanding the information produced is of the utmost importance. It is fine to have data, but if it is not easily understood and not consistent across the country, it is of little value to anyone,” said Pam King, a Canadian Cancer Action Network (CCAN) member.

In a series of ongoing meetings and teleconferences dubbed *Conversations with C-SPAN*, the C-SPAN team is reaching out to these groups to solicit their opinions regarding presentation of cancer survival information. The feedback from these sessions has been compiled and a clear picture is emerging about the future of Canadian cancer surveillance statistics.

“‘Keep it simple’ and requests to highlight the trends were key themes coming up in our conversations,” said Dr. Turner, adding people were very candid about their likes and dislikes regarding the presentation of information. “Many noted a comfort level with the classic table and agreed line graphs show trends over time well, but bar graphs won support as being most accessible to a wide audience.” And no detail was too small.

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**My sincere thanks** to everyone who participated in the *Conversations with C-SPAN* sessions and for those who completed the *Focus on Survival Survey*. Your feedback and engagement are key to the success of this project and, as we enter the next phase, we now have the benefit of your wisdom to assist in the creation of new cancer surveillance products.

Looking at the results (*see page two for details*), it was clear that people have encountered cancer survival data and concepts before, however, there are varying degrees of how clearly these terms and concepts are understood. As expected, those in the business of cancer – cancer agency senior leadership – had a pretty firm grasp on the information, but those who do not solely focus on cancer had some difficulty.

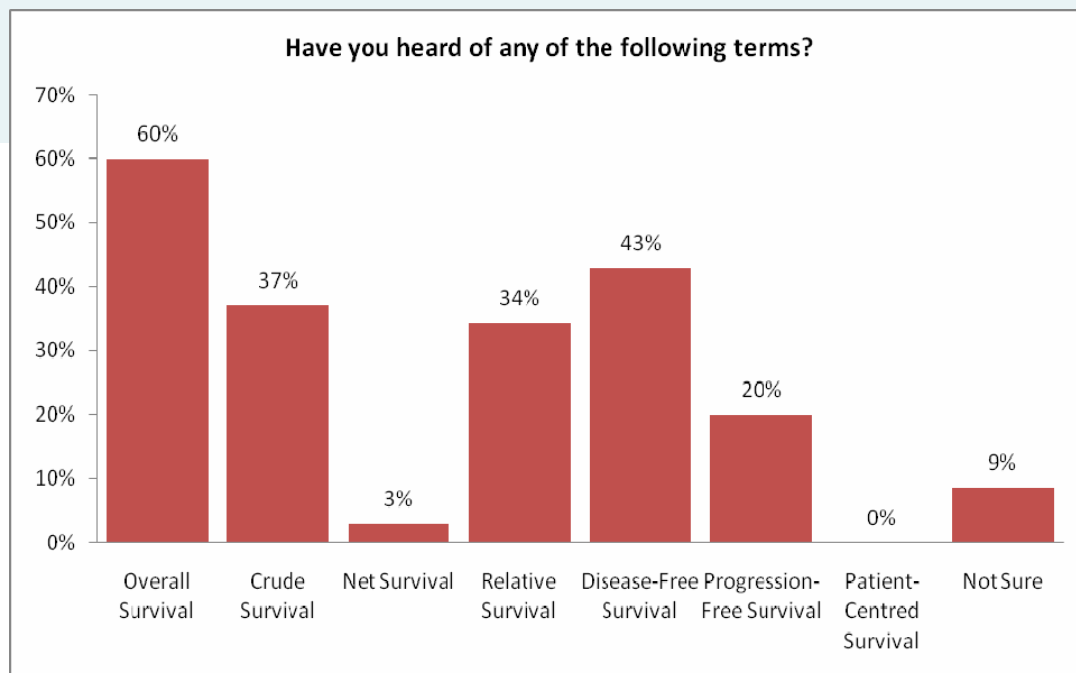
There were a few surprises though. The survey revealed a lack of knowledge surrounding current Canadian cancer survival rates. Interestingly, people thought that British Columbia or Ontario have the best survival rates, but this isn’t always true. In the case of lung cancer survival, for example, Manitoba has the highest rates. Another area of interest was the fact that the term ‘relative survival’, a way of comparing survival of people who have cancer with those who don’t, is not always well understood.

With the initial engagement sessions now complete, we plan to reconnect with you to share a first draft of the new output based on your feedback. In addition to presenting our analysis to you, we’re excited to be introducing the next phase of the project – prevalence statistics.

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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.



Percent of survey respondents who noted familiarity with the above terms. 'Patient-centered survival' is 'ghost' term and not a real concept.

### In Brief: Results from C-SPAN's "Focus on Survival" Survey

The goal of C-SPAN's Focus on Survival Survey was to better understand how end users interpret cancer survival statistics and create a baseline from which to make improvements.

Over 40 participants completed the survey. Participants included partners in Manitoba as well as CEOs from cancer agencies across the country.

Twenty percent identified themselves as policy makers and 46% identified as decision makers (managers). Patient advocates accounted for 6% and 34% identified as "other" including consultant, planner, or government.

Though respondents have encountered cancer surveillance information before, the survey indicates there is a need for greater clarification of cancer survival terms and concepts to ensure that end users have a clear understanding of the data they review and ultimately use. Additionally, respondents did have some understanding of five-year survival rates for the top cancer types. However, not everyone was aware of these statistics. For example, 40% correctly estimated that 50-60% of all cancer patients will reach five-years of survival after diagnosis.

Respondents were often not sure which of the

provinces or territories have the best cancer survival rates. Between 77% and 85% of respondents noted that they were 'not sure' about survival rates for each cancer type.

#### Definitions

*Overall or crude survival: the probability of survival following a diagnosis of cancer; includes death from any cause. Endpoint is death from any cause*

*Disease-specific survival: individuals diagnosed with cancer, that have not died specifically of cancer after five years. Endpoint is death from cancer only.*

*Net survival: the probability of surviving cancer in the absence of other causes of death. Common net survival measures include cause-specific survival and relative survival.*

*Disease-free survival: individuals that are alive and have not had a recurrence of the cancer after five years,*

*Progression-free survival: individuals whose cancer has not advanced.*

*Relative survival: compares the survival experience of individuals with cancer to individuals without cancer (of the same age).*

## C-SPAN's Methodology Working Group

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**Area of interest:** Jean-Marc's research interests are in public health, epidemiology, and biostatistics. He is involved in the evaluation of the Quebec Breast Cancer Screening Programme (PQDCS). He also works on population-based cancer studies to produce a variety of measures such as incidence, mortality, prevalence and survival of cancer in Quebec.

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Dr. Turner said conversation participants remarked on a wide range of usability topics, even the need for "photocopy-ability".

"This feedback is incredibly valuable," said Dr. Turner. "It will allow us to develop cancer surveillance products that are more meaningful and relevant to the audiences we serve." In the often fast-paced policy world, accessing information with the proper context is vital, especially when answers are needed quickly.

"As policy influencers we rely on evidence for guidance for decisions on policies, funding, investing, and directions to move forward," said Bernadette Preun, Assistant Deputy Minister, Regional Programs and Services, Manitoba Health, adding being asked to participate has been extremely worthwhile. "Well-described information with notes as to meaning are helpful."

Pam King said CCAN's mandate is to advocate for patients and their families and participation in this project has provided an excellent opportunity to speak for patients and their families in identifying what they would like to see.

To ensure the new products are meeting the needs, the C-SPAN team will be following up with participants to ensure the right elements have been incorporated either through in-person sessions, teleconferencing or via email.

# Dancing with the Stats

*Janet Nowatzki and the Analytic Team*

The Cancer Survival and Prevalence Analytic Network's goal (C-SPAN) is to cover two statistical measures, survival and prevalence. As readers of this column will know, to date we have focused on the analytic issues associated with relative survival; now we are shining a light on prevalence.

Meeting through teleconferences in March and again in early June, the Methodology Working Group outlined the analytic decision points around prevalence. While prevalence is generally thought of as the number of people living with cancer in a population, in practice it is common to limit the time period to a certain timeframe (e.g., 2-, 10- or 15-years).

Because of the limitations of the Canadian Cancer Registry, which only goes back to 1992, we are looking at producing 10-year limited duration prevalence. Programming code will allow the production of both counts and rates.

Current discussion has focused on the following points:

- use cases diagnosed between 1992 and 2005 (inclusive)
- only invasive cancers will be included, with the exception of in situ bladder cancers
- exclude non-melanoma skin cancers

- exclude death certificate only (DCO) cases, and/or cases where diagnosis date = death date (or worse, where diagnosis date occurs after death date!), and/or cases noted as "deceased" but missing death date
- restrict analysis to cases where age at diagnosis is between 15 and 99 years (inclusive), and gender is known

As with survival, C-SPAN has proposed that both tumour-specific and person-specific statistics be produced. An interesting exchange focused on the management of records with missing birthdates during the last Methodology Working Group. Thanks to work done by Larry Ellison, C-SPAN plans to incorporate an algorithm to impute missing birthdates based on distribution of birthdates among all cases.

Another important consideration is the effect of loss-to-follow up; while the Methodology Working Group supports the documentation of the magnitude of this limitation, current experience suggests that national death clearance is sufficient to produce robust estimates.

Stay tuned to this column for more details on prevalence as the programs unfold!

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## Items under Discussion

*The Methodology Working Group has discussed the following items that will affect the calculation and interpretation of prevalence:*

1. Loss to follow-up - When dealing with situations of loss to follow-up in the cancer registry data, censoring and/or statistical adjustment of prevalence is an option. However, the quality and completeness of death ascertainment in the Canadian cancer registries may be sufficient. In other words, if "not deceased" we can assume "alive" with little statistical consequence.
2. The limit on "limited-duration" prevalence - the focus will depend on the desired use of the statistic:
  - we could look at all patients who have ever been diagnosed, in which case we would want longer inclusion periods such as 10- to 15-year prevalence, **or**
  - we could focus on patients who are more recently diagnosed who are currently using health care at a high level, in which case we would want shorter periods such as 2- to 5-year prevalence.

**We want to hear from you. Please contact exSPANse with your comments or story ideas by emailing [roberta.koscielny@cancercare.mb.ca](mailto:roberta.koscielny@cancercare.mb.ca).**



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.

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