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A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK



Where's Bob? Like a family portrait, completeness is key for prevalence data.

A snapshot in time

Cancer prevalence is a measure of the number of people in a population living with a diagnosis of cancer at a given time (the index date). Knowledge of cancer prevalence is important for assessing health care needs.

In theory, the concept of estimating prevalence is quite simple. We are essentially taking a snapshot of the burden of cancer at a particular time. However, it is not as simple as asking everyone to stand still for a moment while you take the photo. For instance, what happens if Uncle Bob sneaks off to the bathroom while the picture is being taken, and what if we cannot really see cousin Jill because she is standing in the back and slightly out of focus? Like any other measurements of disease, our estimates are only as good as the data on which they are based.

The case of Uncle Bob is analogous to what we refer to as "lost-to-follow-up". Linking mortality data to cancer registry data will help to account for some cases for which there is no follow-up information.

continued on page 3...

The North American Association of Central Cancer Registries (NAACCR) is an anchor for the Canadian and American cancer surveillance communities, connecting data collectors with information users. The annual conference, held in Quebec City this past June, provided the perfect venue for us to present C-SPAN's work to our colleagues. The main theme, *Renewed Collaboration: A Modern Paradigm for Cancer Surveillance*, proved an excellent fit.

Throughout the week, the message was clear - more than ever, cancer control requires more timely and comprehensive surveillance information. Those in the position to introduce policies and programs need data: good data, in a clear format, and fast! For those in the surveillance community, this validation of the importance of our life's work is welcome news. But at the same time, it's a little daunting to realize that we may have to change the way we work to meet the emerging demands.

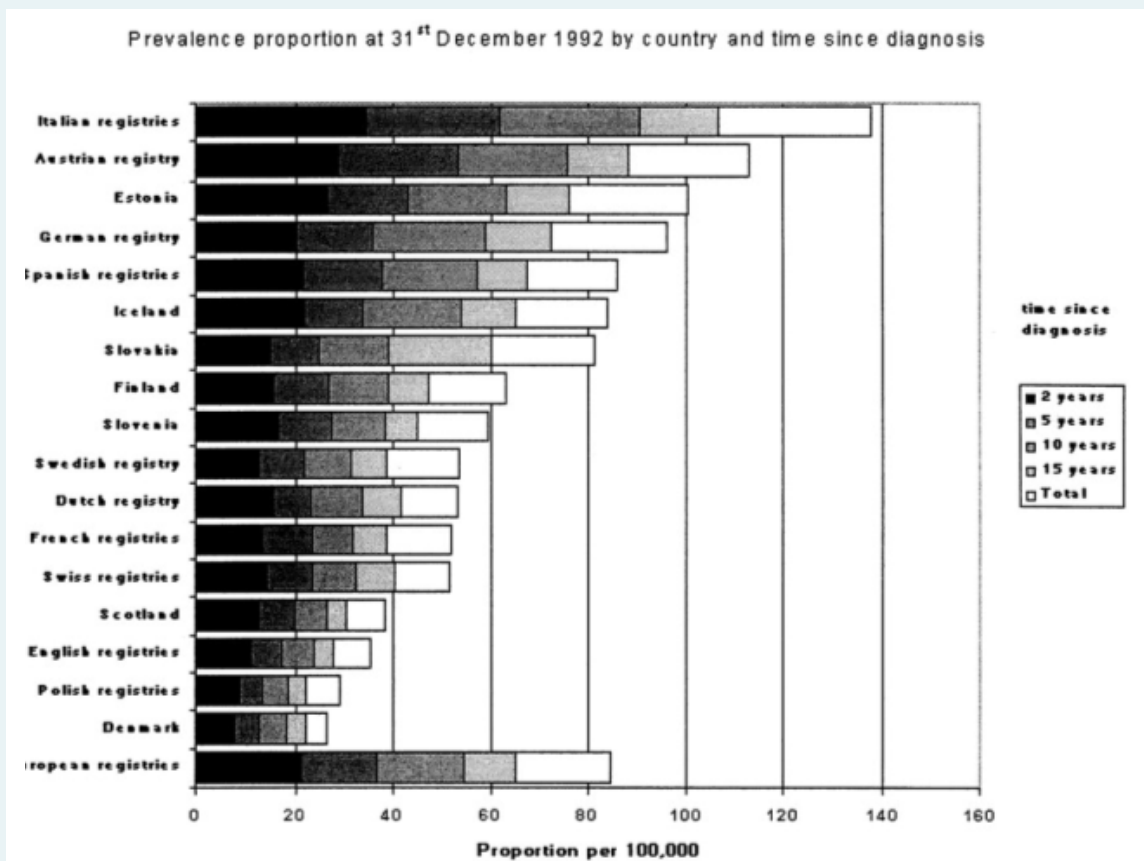
The call to collaborative action was highlighted by several keynote speakers and breakout sessions. For instance, Dr. Jon Kerner, a leader in cancer control-related knowledge translation (with the Canadian Partnership Against Cancer), spoke enthusiastically about the need for the surveillance community to engage with policy influencers. When asked what one thing someone in cancer surveillance could do to advance users' knowledge, he advised, "Take a policymaker to lunch!" He went on to explain that developing personal relationships with policy influencers to tell the surveillance stories is often more effective than simply "dumping your data" on the decision maker.

The philosophy of expanded partnerships resonates with us at C-SPAN. A focus on collaboration and the ultimate use (and users) of cancer surveillance products is the way to go, despite the challenges of doing our business differently. But it's this kind of innovative thinking that puts C-SPAN and the other Cancer Surveillance and Epidemiology Networks in the position to advance cancer control through an enhanced cancer surveillance system.

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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.



This European example was part of the presentation made to Manitoba users to discover likes and dislikes regarding graph styles for displaying prevalence information.

In Brief: Manitoba results from C-SPAN's Focus on Knowledge of Prevalence Survey

The home province of Manitoba was first up as the C-SPAN team began presenting prevalence information to gauge how users respond to different ways of displaying the data.

As these first few sessions unfolded, it became clear people want detailed information – fast. Giving users options to peruse tables added to an appendix rather than pulling all the data into one product is a way of creating the best of both worlds – succinctly described graphs along with the availability of actual numbers.

Clarity is key and even simply setting the format to display provinces West-to-East (rather than our traditional East-to-West) makes a big difference in user friendliness.

What else did we learn? Well, according to our survey, the majority of Manitoba participants had encountered some prevalence terms and concepts.

However, not all participants had the same level of understanding.

For example: 40% of participants correctly identified the two statements describing 5% cancer prevalence. In regards to the participants' knowledge about cancer prevalence in Canada, many participants overestimated the levels in Canada, and most were unsure about which region had the highest cancer prevalence.

These findings reveal that though there is some knowledge among data users about cancer prevalence terms and levels in Canada, there is still a need for further education and knowledge translation.

The second wave of *Conversations with C-SPAN* continues to roll across the country gathering more feedback and ideas to create an optimum product and set new national standards.

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C-SPAN Member Biosketch

Ryan Woods

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Biostatistical
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Education & Training:

BSc Mathematics from University of Guelph
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Area of interest:

Ryan provides statistical support to a number of groups within BCCA. At present he is working with the Breast and Colorectal Cancer Outcomes Units (both groups doing outcomes research within their respective tumour groups), a large clinical trial on using HPV testing as a means of screening for cervical cancer, and a variety of projects that fall under the agency's "cancer surveillance" mandate.

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from page one...

For the remaining cases with no follow-up information, and no death record, it may be safe to assume that cases where a patient has moved out of Canada are offset by the immigration of cancer patients into Canada.

The case of cousin Jill is analogous to situations in which we have incomplete information. For example, Death-Certificate-Only (DCO) cases lack details, particularly the date of diagnosis, making it difficult to ascertain which cases should actually be included in our snapshot. As well, missing year of birth or missing gender make it difficult to categorize cases.

In estimating cancer prevalence, we can hope that data issues account for a small portion of cancer cases. The assumptions that are used to account for incomplete information must be justified and documented. Creating tools based on agreed-upon standards for prevalence analysis will allow comparisons between provinces and will support C-SPAN's goal of increasing analytic capacity across Canada.

Dancing with the Stats

How stable are your estimates?

Recently during a balancing exercise in a dance class, I talked to my students about stability and maintaining a strong core and how this relates to accuracy of movement. Interestingly I have also been thinking about issues of stability at work, but this time regarding relative survival estimates. Much like dance, stability is important and in statistics, it relates to certainty. To interpret any statistical estimate, it is important to have a measure of stability.

In the process of running the C-SPAN relative survival programs on data from the Canadian Cancer Registry (CCR), the issue of stability of estimates arose regarding small cell sizes and possible cell suppression. With relative survival estimates, identity is masked, so the issue of small cell size centers on stability of the estimate, not on issues of confidentiality. Currently, there are different standards of practice for ensuring stability, including setting limits on cell size and suppressing estimates based on standard errors.

Our current C-SPAN programs calculate confidence intervals for the relative survival estimates. Based on recommendations from the Methodology Working Group, we will be including a flag to indicate if the standard error is above certain levels (0.05, 0.10).

Instead of automatically suppressing estimates based on level of standard error, the flags will aid analysts in making their own interpretations of the relative survival estimates.

Calculating asymmetric confidence intervals for age-standardized survival rates versus crude survival rates is a bit like going from ballet to break-dance; the process is not smooth. With complex relative survival models that include covariates (the Estève model, see Estève, 1990), the variance is on a log-log survival scale, whereas the weights for age standardization are on the natural survival scale. However, using the variance on the log-log survival scale and a log-log transformation, asymmetric confidence intervals can be attained. Alternatively, a simpler approach used in Europe involves assuming the Normal approximation on the logarithmic scale when computing the confidence intervals (see Corazzari et al., 2004). C-SPAN's Methodology Working Group is currently discussing these methods.

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Corazzari I, Quinn M, Capocaccia R. Standard cancer patient population for age standardising survival ratios. *Eur J Cancer* 2004; 40:2307-2316.

Estève J, Benhamou E, Croasdale M, Raymond L. Relative survival and the estimation of net survival: elements for further discussion. *Statist Med* 1990; 9:529-538.

Items under Discussion... Survival Analysis Webinar

We are pleased to invite you to a webinar hosted by the CPAC-funded Cancer Survival and Prevalence Analytic Network (CSPAN). The webinar: "An Introduction to Survival Analysis", will be held **Thursday, September 30 from noon - 3 pm Eastern**.

This session is the first in a series of webinars on survival analysis aimed at a wide range of analysts - from the most junior to the more senior. The series will cover topics ranging from the introduction of the basic concepts and terminology of cancer survival statistics, to the decision points and programs created through the C-SPAN initiative, which may serve as a standard for cancer surveillance analysts in Canada.

Please feel free to share this notice with interested colleagues. If you have questions, or would like to join us for this webinar, please email madeline.kells@cancercare.mb.ca.

We want to hear from you. Please contact *exSPANse* with your comments or story ideas by emailing 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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