renjith krishnan graphic

It takes teamwork to design cancer surveillance products that speak to all users.

Why rewrite the book?

There is no question that cancer statistics are readily available from a variety of sources but are those numbers fulfilling user requirements?

Over a year ago, C-SPAN started talking with data users about the kind of cancer survival information they wanted to access and how they wanted that information presented. Despite being quite new territory for the surveillance community, this approach yielded valuable insight into the type of report users preferred to work with. As C-SPAN Central in Manitoba engaged the users, C-SPAN's Methodological Working Group tapped the analytic community and began developing a cohesive, standard way of calculating survivorship measures, as well as providing detailed documentation and programming code to facilitate maximum uptake.

After extensive engagement with policy makers, advocates and analysts, C-SPAN distilled the feedback and used it to create its first product – *Cancer Survival in Canada: A focus on cancer overall and the four most common disease types (lung, colorectal, breast and prostate)* – a Q&A style report reflective of the targeted audience's input. Each section is designed to support rapid knowledge transfer, and may be pressed into service as a briefing note or quick overview when information on cancer survival is required.

We often get comfortable doing things the way we always have, and for me, this project has really involved outside of the box thinking. Developing standardized survival tools through the efforts of the Methodology Working Group was relatively familiar territory, but engaging data users and writing a report based on their feedback presented a real departure from the comfort and safety of traditional epidemiological conventions.

To produce a cancer survival report in this new way, a lot of time and energy is required to interact with the various groups. The C-SPAN team learned that genuine engagement means being as flexible as possible and taking the show on the road via face-to-face meetings, Tele-health, conference calls or webinars. I really enjoyed meeting with all of the stakeholders and listening to their take on the information we are currently providing and what we could do to make it better fit their needs.

Early feedback on this first report has been gratifying in two ways – first, that our user groups took the time to work with our drafts and promptly provide comments and suggestions, and secondly, that the drafts weren't far from the mark. Another project benefit has been the establishment of a rapport that supports the frank exchange of ideas and the ability to critically examine what works well and what doesn't. Simple questions such as why the graphs went east to west instead of the more intuitive west to east, gave me pause for thought – as an epidemiologist, I'd always done it that way. For ease of use, users said they wanted the graphs to reflect the country's geographic order.
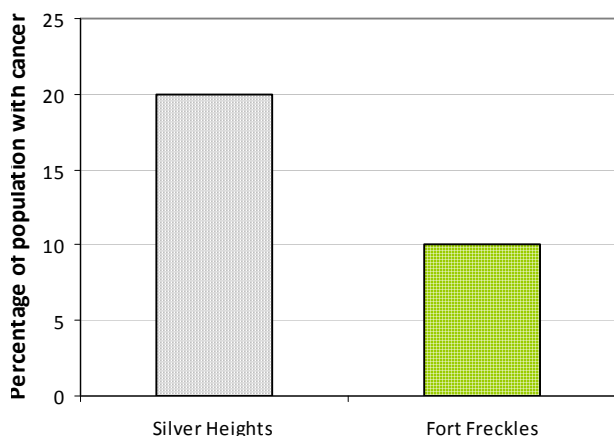
We're still learning, but early indications are that we are well on the right track! We are pleased with the results from our purposeful new engagement strategy - patient advocates said they wanted to "see themselves" in survival reports, with language that was accessible; policy makers wanted detailed information – fast. Now back to work …

Dr. Donna Turner
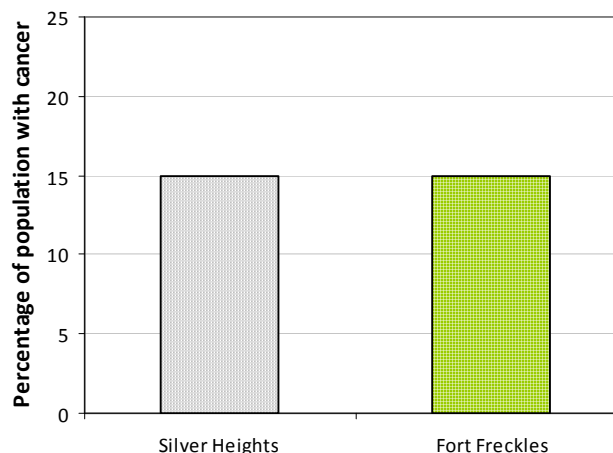donna.turner@cancercare.mb.ca

Crude Prevalence

Percentage of population with cancer

Silver Heights   Fort Freckles

Age-Standardized Prevalence

Percentage of population with cancer

Silver Heights   Fort Freckles

Health planners for the fictitious communities of Silver Heights and Fort Freckles want to properly prepare for cancer services. However, debate is ongoing about whether or not to age-standardize the prevalence measure.

Prevalence: What's in a rate?

When people talk about a population's cancer statistics, they often talk about incidence (new cases) and mortality (deaths). It's pretty well recognized that rates are better than simple counts and to accommodate for the effect of age in a population's risk for cancer, we often age standardize the rates to allow for direct comparison – that is, accounting for the effect of the population's age structure on the risk of developing or dying from cancer.

Prevalence is a bit different. It's used to determine the total number of people who are living with a particular disease, incorporating the new incident cases as well as those diagnosed in previous years.

It is generally used by planners to ensure that the right health care services are available. We need different prevalence "windows", for example the number of people who have just been diagnosed and are in the active treatment phase, or the number who have been diagnosed in the past ten years, which includes those who may be in different follow-up phases but are part of the cancer survivor voice and call to action.

Sometimes people will ask about being provided with age-standardized prevalence rates, but this might be in error. In fact, to get a complete understanding of what percentage of the population has cancer in order to plan

appropriately, it is necessary to keep the effect of age *in* the equation. So it's very likely that the plain old crude rate is what's really required.

For example, image that in the fictitious communities of Silver Heights and Fort Freckles, local health planners want to ensure the best care and services for their residents who may be cancer patients or survivors.

The graphs above both show prevalence information for these communities: the one on the left uses crude data and the other uses age-standardized data. By leaving the impact of age in, the proportion of the population that requires resources is realized. By age-standardizing this information, this vital detail is stripped out and the information that is left provides a less helpful picture of the population's need for services.

C-SPAN recognizes that different people may want different presentations of cancer prevalence data. Age-standardized rates will be provided, but only in the appendix: most of the main sections will feature the plain (crude) prevalence, showing the percent of the population with cancer.

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C-SPAN Member Biosketch

Bin Zhang

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Job title/Position
Epidemiologist

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Education & Training
PhD, Epidemiology and Biostatistics, McGill University

Area of interest
Bin's research interests have been in the areas of pharmaco-epidemiology, environmental pollution, human health, particularly in cancer epidemiology and etiology related to environmental hormone disruptors, genetic susceptibility, gene-environmental interaction, as well as the development of new statistical methods for longitudinal cohort studies and evaluation methodologies for complex datasets.

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From page 1 ...

The resulting national report sports a new look for cancer surveillance reporting and incorporates features users were asking for: clean, clear and consistent titles and footnotes, highlighting what is significant (trends for example), using real numbers and explaining technical terminology and statistical concepts.

It also provides a cancer profile specific to each province which makes comparisons across the country possible. With these new analytic tools and user-friendly templates in hand, organizations will be able to access more detailed information and share it more easily with their stakeholders.

"The information presented in the report is really just the tip of the iceberg," said epidemiologist and C-SPAN principal investigator Dr. Donna Turner. "C-SPAN has developed protocols and programs that will allow data to be analyzed at any grouping or geography desired, which means specific regions will be able to get a more personalized picture of what cancer survival looks like in their community."

Serving as first evidence of how a process like this can work, the C-SPAN team has incorporated early feedback and is now pressing ahead to produce similar reports for another six cancer disease sites as well as a national prevalence report.

Cutting the Bias

Diane stitched together some words about Ontario's immortals

"*The only thing wrong with immortality is that it tends to go on forever.*" Herb Caen, 1916-1997.

In order for cancer registry data to be used for survival analyses, current vital status is required. While active follow-up with direct patient contact is considered the gold standard, most cancer registries use at least some passive follow-up methods such as linkages with death files. Several Canadian provinces use their health insurance files to identify patients who are no longer insured and can be assumed to have moved out of province.

The Ontario cancer registration system uses only passive methods and relies on records created by others for their own purposes. Over 97% of deaths are confirmed by a death certificate; additional death information comes from other sources such as treatment centres or the Canadian Cancer Registry. Ontario's health insurance database cannot be used to identify people who have moved away, hence those not known to be dead are assumed to be alive. This means that patients whose deaths are missed seem to live forever; we have nicknamed those aged 100+ who are still alive 'immortals'.

Of the 105,700 cases diagnosed 1964-1969 in Ontario, 14% are assumed to be alive and 41% of those (5.8% total) are currently aged 100+. Immortality varies by site, with high percentages observed for prostate (11.6%) and bladder (11.2%); lower percentages are observed for rapidly fatal cancers such as pancreas (2.7%) and liver (0.5%). There are also geographic patterns to immortality, with the highest rates observed for those with unknown residence at diagnosis (35%), which could mean that they were never Ontario residents.

More immortals are found in Kenora, a small Ontario border city, where deaths may have occurred in Manitoba, and in Toronto and York, where immigrants may have returned to their homelands. When residence is known, a high percentage of immortals are diagnosed on the basis of surgery without histology (hospital records only); it is possible that these cancer diagnoses are incorrect.

Ontario's immortals are being examined further in order to better understand their impact on survival estimates and the most appropriate method for handling them in analyses.

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Items under Discussion

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

1. Conditional survival: The Methodology Working Group is exploring the issues involved in conditional survival – that is, if patients survive to time X, what is their probability of surviving to time Y? But there's a hitch. It turns out the term "five-year conditional survival" could mean a) the probability of surviving to five years after diagnosis given you survive one year (e.g., the approach used in the International Cancer Benchmarking Partnership), or b) the probability of surviving five **more** years given you survive one year or two years or three years and so on. C-SPAN plans to do both. Which do you prefer?

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