EXSPANSE

VOLUME 2 ISSUE 3 WINTER 2010

A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK



From left, Cancer Care Nova Scotia's Surveillance and Epidemiology Unit members include Hao Wang, Gordon Walsh, Ron Dewar, Nathalie St.-Jacques and Vickey Bu.

Progress at home, abroad

The Cancer Survival and Prevalence Analytic Network (C-SPAN) is gaining ground on the development of standardized approaches to the analysis of survival and prevalence data and the effort is already starting to pay off. Recently C-SPAN Methodology Advisory Working Group member Ron Dewar was pressed for local data and he turned to C-SPAN for help. "Our communications people asked me to replicate a recent Statistics Canada report using Nova Scotia data and to do it quickly," said Dewar, an epidemiologist with Cancer Care Nova Scotia's Surveillance and Epidemiology Unit. "Naturally, my first reaction was to run for the door. Then I thought, well, why not? Using C-SPAN's standards programs, I ran the cohort (1992-1994) and period (2005-2007) analyses with agestandardization for the four major sites and presto - we could say that Nova Scotia follows national patterns, both in terms of improvements over time, and in terms of the current fiveyear age-standardized relative survival ratios." Readers of this newsletter will know that C-SPAN has worked to harness the experience and knowledge that already exists in Canada's cancer surveillance community; distilling the best thinking into national standards for calculating survival and prevalence. The approach is hitting the mark. "My previous experience and work on survival analysis was in England and Scotland where health information is very centralized. Working with the C-SPAN methodology group has been a total change, but it is hugely productive," said Lorraine Shack, Research Program Leader, Public Health Innovation and Decision Support, Alberta Health Services and Associate Professor, Department of Preventative Oncology and Community Health Sciences (joint appointment), University of Calgary. "The collaboration, KE (knowledge exchange) and process has been wonderful." See page 3... Timing is everything and the timing couldn't be more right for focusing on survival statistics, as they are gaining attention around the world.

The EUROCARE Project - a project documenting variations in cancer survival between European countries - led to changes in the UK's approach to cancer control. The CONCORD Study expanded EUROCARE's concept internationally, applying standard quality-control procedures and identical analytic methods for all datasets, further inspiring consideration of variations in cancer control programs worldwide. Both studies earned a lot of press and showed the differences that exist between the countries.

With the second phase of CONCORD pending, there is interest in trying to understand *why* we see variations. Led by the UK, Canadian, Australian and European policy makers have pooled data for the International Cancer Benchmarking Project. With publication imminent, this project aims to help identify which factors improve cancer survival rates, including early detection programs, stage distribution and treatment capacity.

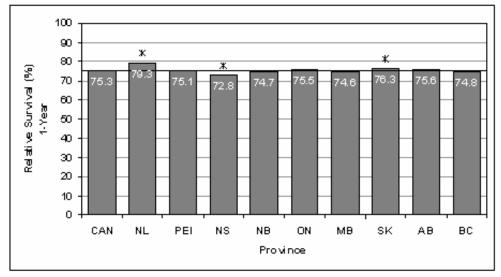
The concept of C-SPAN fits perfectly with these projects and the potential for change based on survival efforts for *any* jurisdiction is great. To use surveillance information to influence strategies, we not only need to see the differences in cancer survival, but look at what is underneath. If we can understand the factors that drive the data, we can improve the outlook for future cancer patients.

Dr. Donna Turner

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Figure 1, One-Year Survival (%), All Cancer Patients

Age-adjusted relative survival for patients diagnosed with cancer (2003-2005), by province



^{*} indicates significant difference from the national average (b<0.05).</p>

Source: Canadian Cancer Registry, 2010; Statistics Canada, Health Statistics Division.

Notes:

- Survival statistics shown here are relative survival ratios, which show survival for patients
 diagnosed with cancer compared to people of the same age who do not have cancer.
- The period approach was used to estimate relative survival.
- If a patient has more than one cancer diagnosed, only the first one was used (first primary).
- 4. Newfoundland and Labrador's survival may be overestimated due to under reporting of cases to the cancer registry. The missed cases have poorer survival, so the survival statistics presented must be interpreted with caution.
- Due to differences in defining the date of diagnosis and missing death information, the estimate for Canada excludes Quebec.

The ability to produce a comprehensive national report relies on the ability to access the appropriate data. The ability to impart and present what the data means requires an understanding of the intended audience. Engaging Canada's senior analysts and users of cancer survival reports has led to progress in meeting C-SPAN's objectives and deliverables. Frequently, audience has been a topic during these meetings and it is clear there are different needs.

Representing patients, families and survivors, Manitoba members of the Canadian Cancer Action Network explained to C-SPAN members that they need information they can easily share with those affected by cancer as well as information they can take into the boardroom. They want jargon-free, well-explained and highly visual pieces that reflects the patient experience for those who are on the cancer journey, but they also require the hard facts and numbers to use with the policy makers.

Initial response to a draft survival graph (see above, Figure 1) presented during the ongoing *Conversation with C-SPAN* series with patient advocates indicates the changes to titling, highlighting significant differences and including the numbers within the bars are hitting the mark. "I love the redesigned example. I can look at it and see exactly what I want," said an advocate.

The graph also prompted questions about why data on Canada's territories are missing. In fact, often because these numbers are so small, the information is suppressed because of concerns about the reliability of any resulting analysis. Stating why the numbers are absent would go a long way to increase understanding. The east-to-west presentation of provinces was also queried as it is counter intuitive - after all, BC is on the west (left) coast, not the east!

The C-SPAN team is continuing to consult with user audiences to determine how to build better data products.

Contact us with your thoughts at roberta.koscielnv@cancercare.mb.ca.

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.

Winter 2010 Topic:

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

C-SPAN's Methodology Working Group

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C-SPAN Member Biosketch

Zoann Nugent

Agency: CancerCare Manitoba

Job title/Position Senior Health Outcomes Analyst

Education & Training

BSc (Hon) and MSc, Biology, University of New Brunswick PhD, Population Genetics, Liverpool University Diploma in Applied Statistics in Medicine, Green College, Oxford

Area of interest

Zoann's personal favourite problems to tackle involve analysis of cancer rates in people with previous cancer diagnoses and comparison of mechanical diagnostic methods. Most of her current research is on the impact of colonoscopy on colon cancer diagnosis.

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From page one...

Examples like these are music to the ears of C-SPAN Principal Investigator Dr. Donna Turner. "One of our biggest hopes for this project was that we'd be able to support rapid response to local queries through standardized approaches," said Dr. Turner. "It is great to see we are making progress."

Replacing accepted practices with new methods is not a quick or easy process. The C-SPAN Methodology Working Group has spent hours debating decision points and consulting experts in Canada as well as the international scene, and the experience has been very rewarding. "The opportunity to bring analysts together from across North America to determine the best calculations and interpretations is really exciting and the information coming out of these meetings has provided a sound foundation for new applications," said analytic lead Janet Nowatzki.

Other agencies such as NAACCR (North American Association of Central Cancer Registries), have recognized the expertise pooled by C-SPAN and have tapped into it as its own survival analysis working groups wrestle with similar issues. "C-SPAN members have a lot to contribute and thanks to the support of the Canadian Partnership Against Cancer, Canadians have been able to take on leadership roles," said Dr. Turner.

Dancing with the Stats

Standard populations for age-standardizations

Choice of standard population for age-standardizing relative survival estimates is currently a hot topic in the analytic community.

When considering standard populations, we must carefully review the strengths of each option as well as the intended use of the estimates. One option is to use a standard so standardized values are close to crude values specifically to aid in the communication of results. But is this really necessary? This is at the subject of some debate!

In some publications, site-specific age distributions are used for age-standardizing, which keep age-standardized and crude estimates close. It allows for comparison across jurisdictions, but not across cancer sites. Although informal comparisons between cancer sites will likely still occur, technically they are not legitimate. This raises the question: are there other approaches? Ideally, we would like to be able to compare results across jurisdiction, time period, and cancer site.

As an alternative, Corazziari et al (2004) propose three standard cancer patient populations appropriate for

cancers with differing incidence patterns: a) increasing with age; b) broadly constant with age; or c) those mainly affecting young adults¹. This supports inter-site comparisons while providing options to accommodate analyses of cancers with different age distributions.

Recent discussions among C-SPAN analysts focused on whether the standard populations described by Corazziari et al are appropriate for use in a Canadian context. Although we haven't always done this before, this is an important consideration, as the Corazziari weights have been used by the CONCORD study and by the International Cancer Benchmarking Project. Indeed, international advisors are urging North Americans to adopt these weights.

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¹Corazziari I, Quinn M, & Capocaccia R. Standard cancer patient population for age standardising survival ratios. *European Journal of Cancer* 2004, 40, 2307-2316.

Items under Discussion

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

- 1. Cancer site groupings: When calculating any cancer-related statistics, including survival and prevalence estimates, it is important to think about cancer site groupings. The Principal Investigators from the analytic networks have been discussing appropriate conventions, comparing SEER groupings with those used by Statistics Canada as well as those used for the Canadian Cancer Statistics publications.
- **2.** Weights to use when age standardizing: Discussion continues around standardizing relative survival estimates to the general population versus standardizing to the population distribution of the particular diagnosis (ex. breast cancer). *See above: Dancing with the Stats.*

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.

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.