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.

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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.koscielny@cancercare.mb.ca.
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 adults. 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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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.