

EXSPANSE

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A REPORT FROM THE CANCER SURVIVAL & PREVALENCE ANALYTIC NETWORK



Manitoba programmers Giselle Mak, left, and Michelle Lu discuss data protocols.

Changing landscape

Fifty years ago the chance of surviving a cancer diagnosis was slimmer than it is today, and the chance of living long enough to be diagnosed with a second form of the disease was remote.

Over time, cancer detection and treatment have improved and five-year survival has improved considerably. The good news is that people are surviving longer; the bad news is that, as a result, survivors may develop another cancer - perhaps even three or more cancers in their lifetime.

This presents a unique issue for analysts looking at cancer survival because traditionally, survival has been measured using only the first primary - with this "one cancer per person" rule subsequent cancers are not counted. But now, because of today's longevity trends and the ability to record more tumours per individual, the importance of considering all primaries is becoming apparent.

Part of the reason analysts might want to consider including all primaries in survival analysis is to achieve comparability^{1,2}. Canadian Provincial and Territorial Cancer Registries range from the very well-established (50 years plus) to those that are relatively new in comparison. So some registries in Canada have a longer history than others and can look further back in time to determine whether or not a person had a previous cancer, while others are more limited.

For example, if an individual had their first cancer diagnosis in 1962 and a second diagnosis in 1985, a registry that started in 1956 would be aware of both of these cases.

However, a registry that started in 1975 would include the second cancer as the first primary because there would be no way to know about the earlier diagnosis.

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In our debut issue, I introduced the idea of consulting with the people who ultimately use cancer surveillance reports in a bid to learn more about how we can present and explain complex information as clearly as possible. C-SPAN has two audiences - the surveillance or "analytic" community, and the policy influencers (decision makers, policy makers and advocates).

By engaging each community early and throughout the process, we are building the trust and mutual respect necessary to improve the uptake of cancer surveillance information in Canada. C-SPAN's actions incorporate the principles of knowledge translation or KT which are driving forces in achieving our project's mandate.

As reflected in our cover article and *Fradette's Frying Pan*, work with the analysts has been moving ahead quickly. I am excited to share that the C-SPAN team is currently taking its first major steps towards the end user community through a series of interactive sessions with Manitoba policy influencer groups as well as a significant national organization representing the provinces and territories (Canadian Association of Provincial Cancer Agencies). These sessions allow us to get to know our policy-influencing partners and see how we can better meet their needs by requesting feedback on the ways of presenting cancer survival information.

This is an exciting new way of doing business, and I am looking forward to sharing some of the results with you in the next edition of *exSPANse*.

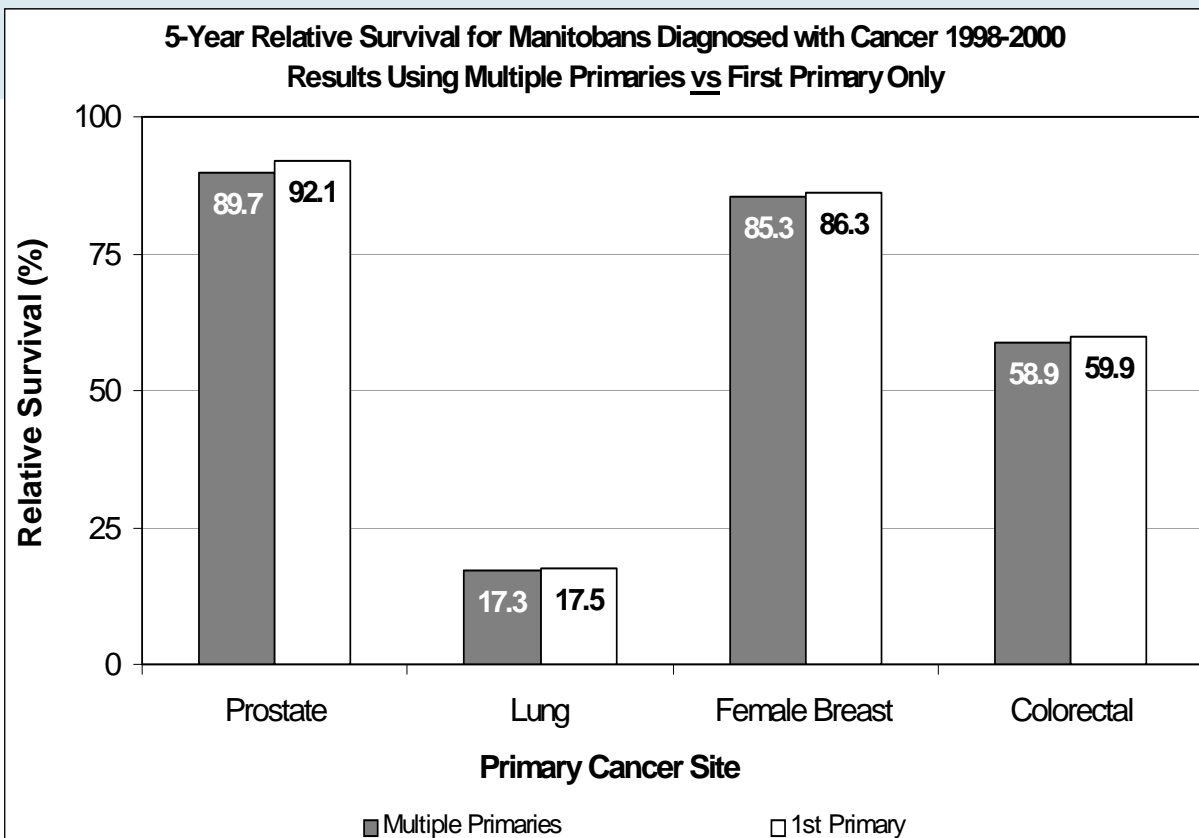
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By the Numbers - Policy on 2

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:

The Effect of Only One (First) Cancer vs All Cancers on Survival Statistics: 5-Year Relative Survival for Manitobans Diagnosed with Cancer (1998-2000), by Cancer Type



Data Source: Manitoba Cancer Registry

The cohort method was used to estimate relative survival. The Ederer II method was used to estimate expected survival. First Primary was selected from the years 1956 through 2000.

People who use cancer survival data for planning and developing policy may assume all cancers are being included in the statistics. In fact, this is not the case: the standard approach used by cancer surveillance analysts around the world has been to take the first cancer diagnosis for any individual and calculate survival based on that primary cancer, even if a person has more than one cancer.

But times are changing. Increasingly, analysts are recognizing that important information is being discarded – we are losing the data that subsequent cancers provide, which in turn might influence the survival statistics. Current data show that 10% of everyone diagnosed with one cancer develops a second one.

So the good news is more people are surviving cancer. The bad news is that they are at risk of developing another cancer. Right now, this group makes up only 10% of cases, and though it is a small percentage, it is not insignificant and it is growing. In terms of survival statistics, if we use *all* the cancers, the survival estimates can change, as shown in the graph above. This is because people with cancers diagnosed later in life have [by definition] shorter survival, effectively reducing survival estimates.

What do you think? Should we use all cancers in our calculations instead of just the first primary?

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

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Another compelling reason C-SPAN analysts are looking at the possibility of moving away from the "one cancer per person" model is because patients and physicians live with and treat all cancers, not just the first diagnosis. So it seems reasonable when looking at cancer survival, to consider a person's entire cancer experience.

C-SPAN's discussion around inclusion of multiple primaries in Canadian survival analysis is in its initial stages. There are still collective decisions to be made and these will ultimately shape the future of Canadian cancer survival statistics.

References

1. Brenner H, Hakulinen T. Patients with previous cancer should not be excluded in international comparative cancer survival studies. *Int J Cancer* 2007;**121**(10):2274-8.
2. Rosso S, De Angelis R, Ciccolallo L, Carrani E, Soerjomataram I, Grande E, Zigon G, Brenner H. Multiple tumours in survival estimates. *Eur J Cancer* 2009;**45**(6):1080-94.



C-SPAN Member Biosketch:

Ron Dewar

Agency: Cancer Care Nova Scotia, Halifax NS

Job title/Position: Epidemiologist, Surveillance and Epidemiology Unit

Education & Training:

- Mathematics, University of Alberta
- Department of Statistics, University of Edinburgh
- MSc, Biostatistics and Epidemiology, McGill University

Ron's varied career included stints at the Dominion Bureau of Statistics (now Statistics Canada), the Alberta Cancer Registry, a central London teaching hospital, McGill University, and finally the Nova Scotia Cancer Registry.

Area of interest:

Ron met his wife in Montreal, and together welcomed four sons. Since then, Ron has lived and raised his family (and added a girl) in Halifax.

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Fradette's Frying Pan -

Serving up today's hot issues

The comparability of cancer registry data among different provinces is the topic of much discussion in recent C-SPAN Methodology Group meetings.

These exchanges have highlighted the fact that provinces are using different rules for coding primary cancers (e.g., variations of CCR (Canadian Cancer Registry), SEER (Survival and Epidemiology and End Results) and IARC (International Association for Research in Cancer) rules).

Because of these differences, there is a need to establish a method to convert data to a standard format when the goal is to produce nationally comparable estimates.

The consensus among the methodology group was that the best course of action would be for provinces to convert their data using IARC rules because this method generally results in the smallest number of primary cancers.

Two methods for converting data using IARC rules have been explored - the Multiple Primary Program in the IARCrgTools package, which can be

downloaded free of charge, and a SAS macro originally written by analysts at Alberta Health Services to convert registry data to the CCR's version of IARC's multiple primary rules.

Both are good options but because the Alberta macro was designed to replicate the CCR IARC file, the group has agreed to employ the Alberta macro as the conversion tool of choice. This will allow for more direct comparisons with estimates produced for the Canadian Cancer Statistics publications.

Some C-SPAN participating provinces have used the Alberta CCR/IARC conversion macro on their own data and find that it works well. Thanks to Alberta Health Services, C-SPAN will be posting the macro on our project web space along with other applications in the near future.

Until then, if you are interested in getting a copy of the macro for use in your province, please feel free to email me.

Katherine Fradette

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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) Tools to use to compare data – There are different tools analysts can use to 'IARCify' statistics (adapt local statistics to compare to International Association for Research in Cancer data). A quality tool evens the playing field and produces comparable national survival estimates. Alberta analysts have developed a specifically designed macro to transform data to match Canadian Cancer Registry IARC files and are providing it for other analysts to use.

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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