Linking Manitoba Cancer Data:
An opportunity for partnerships and new insights

A summary of the report, *Cancer Data Linkage in Manitoba: Expanding the Infrastructure for Research,* by Lisa Lix, Mark Smith, Marshall Pitz, Rashid Ahmed, Harvey Quon, Jane Griffith, Donna Turner, Say Hong, Heather Prior, Ankona Banerjee, Ina Koseva, and Christina Kulbaba.

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Have you ever thought about how the healthcare system keeps track of every new patient with cancer? Since the 1930s, CancerCare Manitoba has been collecting information from each new cancer patient in the province. These data are stored in the **Manitoba Cancer Registry,** which is one of the most complete cancer data collections in the world!

The information collected from cancer patients includes their age and sex, type of cancer and treatment, and how advanced the cancer was when it was detected. These data can be used to study trends in how often cancer occurs and how it is treated in Manitoba.

"The Manitoba Cancer Registry is one of the most complete cancer data collections in the world!"

The findings from these studies are useful to doctors and policy makers for planning and providing care for cancer patients. However, when studies are based on data from a single source (such as a cancer registry), it's hard to see the big picture. Manitoba has many other health-related databases that can add to our understanding of cancer care.

Virtually every time Manitobans come into contact with the healthcare system, data is collected. The Manitoba Centre for Health Policy (MCHP) gets a copy of these data and stores it in the Population Health Research Data Repository. Before the data are sent to MCHP, the personal information in these files is removed or scrambled to protect the privacy of the people involved. The data in the Repository can be linked across different areas of the healthcare system. This means we can follow Manitobans as they access healthcare, monitor how sick they are, and track how often they visit doctors and hospitals without ever knowing "who" they are.

"Linking the Manitoba Cancer Registry to the MCHP Data Repository opens the door to new opportunities for cancer research."

Until now, the Manitoba Cancer Registry has been separate from MCHP's Repository. But linking the Cancer Registry to the MCHP Data Repository opens the door to new opportunities for cancer research. And so, a partnership was formed between CancerCare Manitoba and MCHP. The Cancer Registry data was brought into the Repository and linked with other databases. This data linkage will improve cancer research in Manitoba.

With each new database that is brought into the Repository, the first step for MCHP researchers is to describe the completeness and quality of the data. Several features of the new database are explored, such as how well it matches up with databases already in the Repository, and whether there are any missing or invalid numbers in the new database. Looking at *Figure 1,* we can see how complete the data in the Cancer Registry are.

The data shown in this figure were collected from 1984 to 2011. The only feature that is not complete over this time period is cancer stage (how advanced the cancer was). This is because cancer stage data was only added to the Manitoba Cancer Registry starting in 2004. A small number of cancers cannot be staged, and this means that some stage information is missing – but overall, this data is mostly complete for the time period in which it was collected. Cancer stage data is useful for looking at treatment outcomes, like how long people live after being treated.

Figure 1.
Completeness of the Manitoba Cancer Registry Data
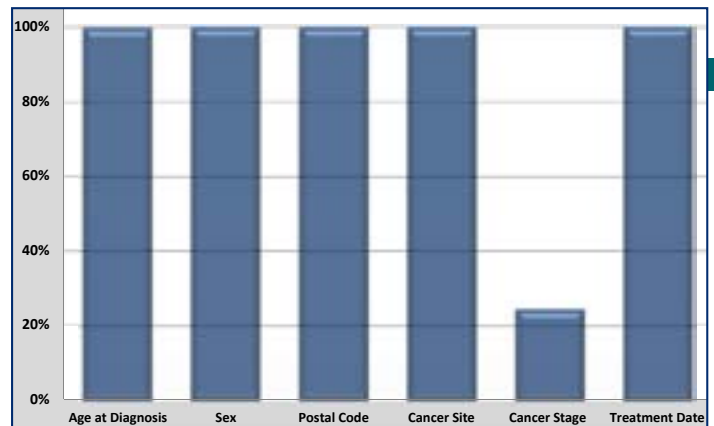
Once we confirmed the data were of high quality, we began to look at how we could use the linked cancer data to better understand cancer care in Manitoba.

"So, what is the pattern of emergency room (ER) visits among cancer patients?"

In this study, we looked at how often cancer patients visited the ER around the time their cancer was detected. We compared the ER visit pattern of cancer patients to a similar group who were cancer-free during three time periods - before, during and after diagnosis.

We expected that there would be more visits to the ER for cancer patients close to the time of cancer diagnosis, because people would be sicker.

"Lung cancer patients came to the ER more often than the cancer-free group."

Lung cancer

The results for lung cancer are shown in *Figure 2*. Lung cancer patients came to the ER more often than the cancer-free group in all three time periods.

There was a spike in the number of ER visits around the time of diagnosis (about 10 times more visits), but more frequent visits were also seen in the before and after periods. This might have occurred because pinpointing the cause of lung cancer symptoms can be difficult.

Figure 2.
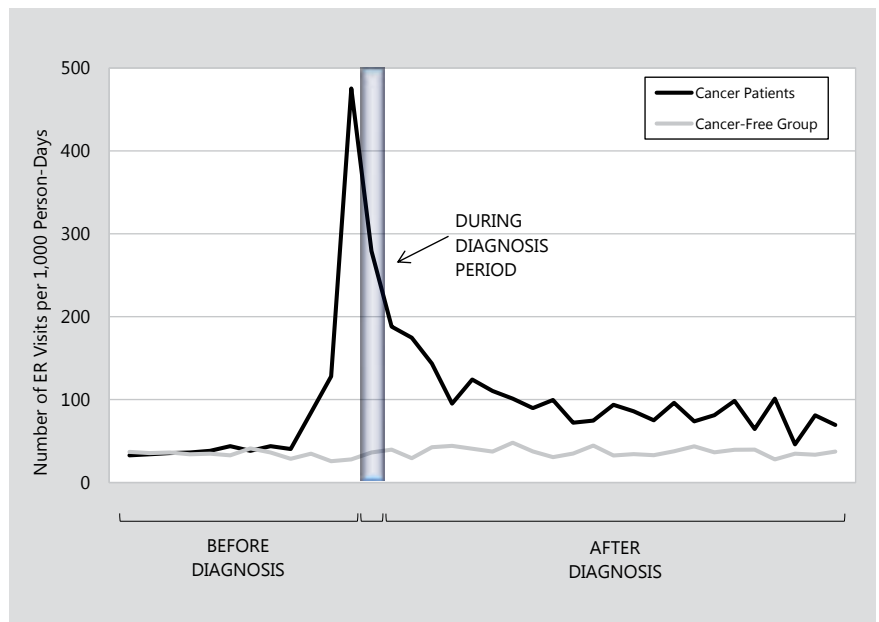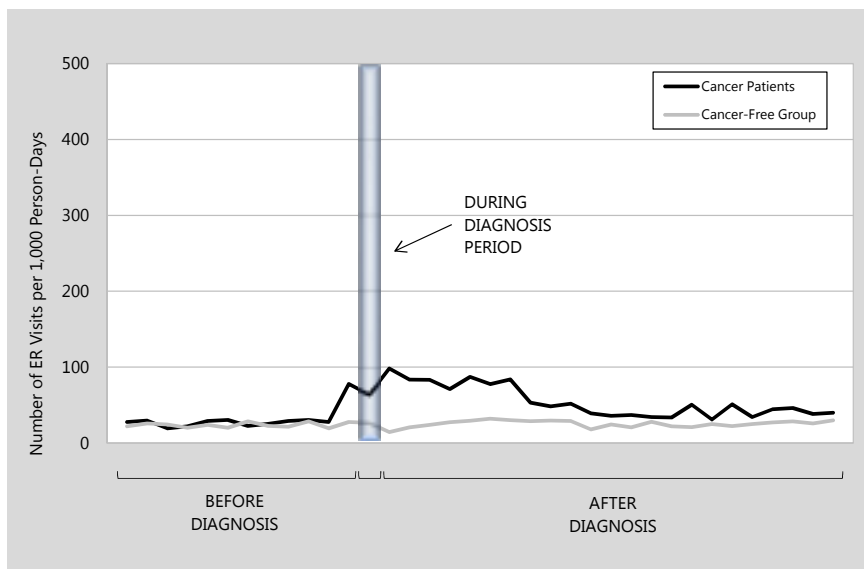**Emergency Room Visits for Lung Cancer Patients**

Figure 3.
Emergency Room Visits for Breast Cancer Patients

Breast cancer

The results for breast cancer are shown in *Figure 3*. Breast cancer patients made far fewer visits to the ER than lung cancer patients did, and many breast cancer patients don't need to visit the ER at all.

Overall though, breast cancer patients still visited the ER more often than the cancer-free group during (about four times more visits) and after diagnosis.

"Can we predict how cancer patients will use the healthcare system, and how long they are likely to live?"

These predictions were based on **comorbidity**, the number or type of illnesses (besides cancer) that a cancer patient has, like diabetes or high blood pressure.

It's logical to assume that the sicker you are (the more comorbidities you have), the more often you are going to need healthcare. People with comorbidities often die sooner than people without them. It's common for cancer patients to have comorbidities, and for the number to increase over time.

And so, measuring comorbidities could be helpful to predict how often cancer patients access the healthcare system, and how long they are likely to live.

We compared six measures of comorbidity to see which was best at predicting these outcomes. Our results showed that some measures were better at predicting healthcare use for lung cancer patients, while others worked better for prostate cancer or breast cancer patients. In general, a measure called the Elixhauser index, a list of 31 comorbidities, worked very well for predicting both the number of contacts with the healthcare system and the number of years patients would live.

Overall, what did we gain from this project?

First of all, researchers from CancerCare Manitoba and MCHP worked together to share and learn about the Manitoba Cancer Registry data and the MCHP Repository. This partnership gives us access to high-quality data that can be used to study healthcare in a new way.

And secondly, we can better answer complex questions about care for cancer patients. The two studies described above are examples of this – but there are many other topics to explore. We could study the long-term patterns of care for cancer patients. Or, we could measure how effective different types of cancer treatment programs are, and whether they help people to live longer. The results from studies like these give policy makers a more complete picture of how cancer patients use the healthcare system and benefit from the care they receive.

In summary, adding the Cancer Registry to the Repository helps researchers, healthcare providers, and policy makers in Manitoba. Ultimately, this will mean improved care for cancer patients.

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