PERSPECTIVES

EFFICIENCY AT THE HEART OF THE QUEBEC HEALTH CARE SYSTEM

Could reliable data on breast cancer actually save lives?

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One in eight women will be diagnosed with breast cancer over the course of her life. In Canada, breast cancer is the second most common cause of cancer mortality among women aged 30 to 49. Delays in diagnosis can exacerbate the disease and increase inequalities. Waiting times for diagnosis are conspicuously longer in Quebec than in Ontario and Alberta, which report the shortest waiting times in Canada. An outdated cancer registry and a lack of standardized care contribute to the delays in Quebec. In this article, the authors explore the capabilities, performance, and innovations in breast cancer diagnosis in Quebec and compare them with those in other provinces. They argue that Quebec could and *should do* better by strengthening its commitment to policy innovation and developing effective methods for collecting comprehensive, standardized, up-to-date, and accessible data. These efforts are essential both for planning the provision of care and for advancing research.

Breast cancer screening saves lives by enabling earlier diagnoses. Delayed diagnoses increase the risk of finding cancer at an advanced stage, requiring more intensive treatments and leading to a poorer prognosis. The five-year survival rate is 99.8% for stage I cancers, compared to 92% for stage II, 74% for stage III, and only 23.2% for cancers diagnosed at stage IV (Canadian Cancer Statistics, 2023). Furthermore, the more intensive the treatment, the greater the cost. According to a study by Canadian researchers, the cost of treatment for stage IV cancer can be up to 11 times greater than for stage I cancer (Wilkinson et al., 2023).

Everywhere in Canada (except Nunavut), mammograms are offered as part of formal breast cancer screening programs. Eligibility requirements vary from one jurisdiction to another but are generally based on age and whether or not a woman is deemed "high-risk." Participation in organized screening programs is voluntary, and the decision whether or not to undergo a mammogram depends on how much the individual knows about the program and the various aspects of the screening process. Notwithstanding the universality of these screening programs, participation rates vary across regions and groups of women. Women from marginalized communities, indigenous, or from immigrant backgrounds display lower participation rates, which can exacerbate preexisting inequalities (Kumachev et al., 2016; and Raynault et al., 2020).

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The eligibility criteria to Quebec's screening program are outdated

Women eligible to participate in the Quebec Breast Cancer Screening Program (Programme québécois de dépistage du cancer du sein, PQDCS) qualify for a free mammogram every two years at a Designated Screening Centre (DSC). Upon turning 50, they receive a letter from the government informing them of their eligibility and inviting them to book an appointment at a DSC. In the event that the mammogram shows an abnormal result, the DSC refers the patient to a Designated Reference Centre for Investigation (Centre de Référence d'Investigation Désigné, CRID), which carries out further testing and establishes the diagnosis.

In 2024, Quebec extended its mammography screening program to women aged 70 to 74. Previously, the program was limited to those aged 50 to 69. This was a long-awaited move, bringing Quebec in line with all the other provinces, which have offered screening up to age 74 for decades. By accounting for medical advances and demographic changes this update better accommodates current needs.

In a recent press release, the Canadian Cancer Society is "urging provinces and territories to lower the start age for breast screening programs to 40 for individuals at an average risk of developing breast cancer." (Canadian Cancer Society, 2024). British Columbia, Nova Scotia, and Prince Edward Island have been offering screening starting at age 40 for several years. This autumn, Manitoba announced that by the end of 2025, the eligibility age will be lowered from 50 to 45, with the ultimate goal of cutting it to 40.

This guideline is consistent with recent research using Canadian data, which indicates that women who do not access screening in their 40s are diagnosed with breast cancers at more advanced stages. Women in provinces that do not offer a screening program for those aged 40 to 49, such as Quebec, are 23% more likely to be diagnosed with stage IV breast cancer than those in jurisdictions offering a screening program for 40- to 49-year-olds. In provinces that eliminated their screening program for 40- to 49-year-olds, the number of stage IV cancers in women in their fifties increased by 10% in six years (Wilkinson et al., 2022).

Including younger women in screening programs entails significant costs, not only for processing the increased volume of patients but also for managing cases of false positives, which require additional tests and generate anxiety among patients. It is therefore not as simple a matter as expanding access to screening to the largest possible proportion of the adult population, but rather of refining selection criteria and using more precise, better-targeted imaging techniques. In particular, it seems essential that guidelines be tailored to specific populations at increased or high risk of developing breast cancer, notably due to their personal and family history, their breast density, or their genotype.

Ontario and Alberta have implemented simplified diagnostic programs for high-risk individuals to improve access to care, optimize targeting and imaging, and establish dedicated access points. Ontario, for example, systematically includes high-risk women over 30 in a screening program specifically designed for them. In Alberta, high-risk women are invited to undergo screening starting at the age of 25. In both provinces, they are offered screening annually rather than every two years. In addition to mammography, they undergo magnetic resonance imaging or ultrasound. These techniques have been shown to be more effective for women with higher breast density, who are often younger, or those with certain genetic predispositions to breast cancer (Heller and Moy, 2019).

Recent studies on genetic factors, in particular the presence of BRCA1 and BRCA2 mutations, have highlighted the importance of individually tailored screening guidelines. For women with BRCA1 or BRCA2 gene mutations, the probability of developing breast cancer in their lifetime can be as high as 85%, substantially higher than the 12.5% risk for the general female population (Kuchenbaecker et al., 2017).
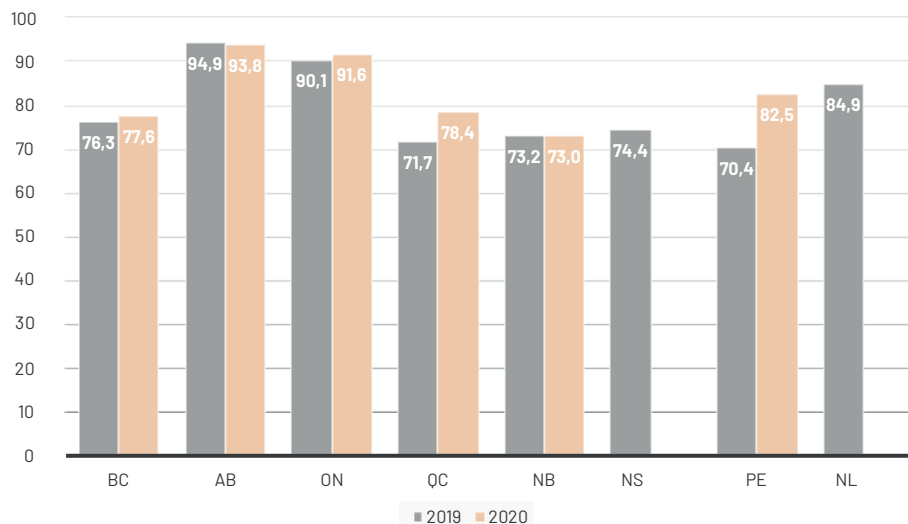
However, this approach is neglected in Quebec. The only exception has been the PERSPECTIVE research project. Conducted in the Capitale-Nationale and Lanaudière regions, it provides women aged between 40 and 69 with breast cancer screening recommendations tailored to their genetic profile. The project has recruited almost 2000 women—it will be important to monitor the results of the study (PERSPECTIVE, 2022).

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In Canada, Quebec ranks near the bottom in terms of diagnostic wait times

Not every woman with an abnormal screening result is diagnosed with breast cancer. Early detection and rapid diagnosis following an abnormal breast cancer screening result are essential for improving prognoses and increasing the likelihood of survival.

A confirmed diagnosis requires further diagnostic procedures, such as a biopsy or an imaging scan. The time elapsed between the patient receiving notification of an abnormal screening result and obtaining a definitive diagnosis depends on many factors. Canada has set a national performance target for wait times based on various indicators. For women with abnormal screening results, the target is that at least 90% will be diagnosed within five weeks if the diagnosis does not require a tissue biopsy. If a tissue biopsy is needed, the aim is for at least 90% of women to be diagnosed within seven weeks.

According to Canada-wide data from the Canadian Partnership Against Cancer, the percentage of women with abnormal screening results who didn't require a biopsy and who received a definitive diagnosis within five weeks ranged from 70.4% in Prince Edward Island to 94.9% in Alberta in 2019. Alberta and Ontario were the only provinces to reach the national target in 2019 and 2020. In Quebec, this percentage was 78.4% in 2020.
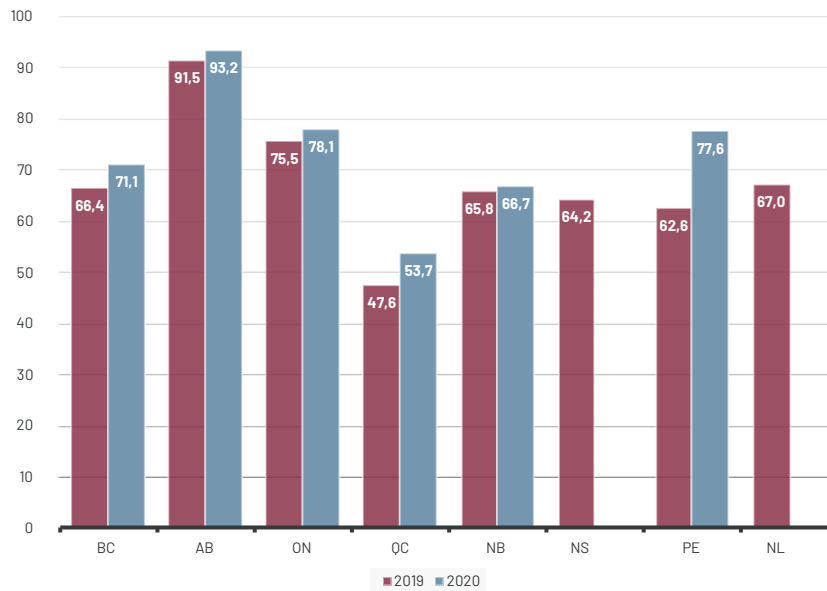
According to the most recent data from INSPQ, this result fell to 74.5% in 2022 (INSPQ, 2024).

In cases requiring a biopsy, the percentage of women with abnormal screening results who received a definitive diagnosis within seven weeks ranged from just 47.6% in Quebec in 2019 to 93.2% in Alberta in 2020. Alberta was the only province to reach the national goal in 2019 and 2020.

What was the impact of the COVID-19 pandemic? Unsurprisingly, the temporary suspension of breast cancer screening and diagnostic activities at the beginning of the pandemic had a noticeable impact on diagnostic procedures. Compared to the 2015-2019 average, reports of new breast cancer cases fell by about 30% in April and May of 2020. Note that this decline is not actually good news. Rather, it underlines that many detectable cancers were unfortunately missed owing to the interruption of screening programs.

Women who are ineligible to the screening program do not know where to go for care

Patients who receive abnormal mammography results and are part of a formal screening program are provided with support, and the process follows the provincial guidelines. Conversely, symptomatic women who are not eligible for the screening program navigate the system

Percentage of women with a definitive diagnosis not requiring tissue biopsy within 5 weeks.
Source : Canadian Partnership Against Cancer, Time to diagnosis

Percentage of women with a definitive diagnosis <u>requiring</u> tissue biopsy within 7 weeks.
Source : Canadian Partnership Against Cancer, Time to diagnosis

on their own to obtain treatment from various service providers. Despite being at a higher risk of actually having cancer because they are symptomatic, the need for multiple appointments with various healthcare professionals, high breast density, and atypical symptoms further compromise the chances of early detection.

The diagnostic process typically starts with the family doctor, at least among those who have one. Family doctors play a vital role in breast cancer diagnosis by offering advice, starting with the first contact and extending through to post-diagnostic care, especially in the absence of organized screening. The shortage of family doctors in Quebec is undoubtedly a major obstacle to diagnosis. It is important to note that over one million so-called "orphan" patients do not have a family doctor in Quebec.

In some cases, women who present symptoms must settle for online resources or turn to private clinics, which can be very expensive. Some women have even been known to check themselves into hospital emergency units.

« Excluding Quebec »

In recent years, Statistics Canada has created new datasets by linking information from assorted administrative files—notably the Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS)—with survey data, including data from the Canadian Cancer Registry (CCR). These linked datasets offer great analytical prospects for research, expanding our knowledge, and developing healthcare policy.

Unlike in the other provinces, in Quebec, the repository of these data—the ministère de la Santé et des Services sociaux (the Ministry of Health and Social Services)—has decided not to share its administrative health data with Statistics Canada. This situation has dismayed the research community for years. "*So-called 'national' data lack a wealth of information on Quebec patients, limiting the ability to extrapolate information. The cost of this decision is borne by all researchers, stakeholders, and actors in the field*" (translation) (Le Devoir, 2018).

Access to data is crucial for evaluating the efficacy of breast cancer screening and diagnostic processes. There are three principal sources of data.

Cancer Registry: The Canadian Cancer Registry (CCR) contains basic demographic information on each patient (e.g., age, sex), as well as more detailed information on tumour characteristics and diagnosis. The CCR provides healthcare workers and the community with standardized and comparable data on cancer incidence and cancer mortality to facilitate identifying risk factors, planning, monitoring, and evaluating cancer control programs, and promoting evidence-based research. Each province also has its own cancer registry.

Data from screening programs: All Canadian provinces, Yukon, and 15 communities in the Northwest Territories run an organized breast cancer screening program. Each program collects individual data on socio-demographic characteristics, risk factors, the screening test and its results, diagnostic tests and their results, and follow-up by a healthcare provider. These crucial data are, of course, not collected from symptomatic patients who are *not* eligible for provincial screening programs.

Administrative data: Provincial public health insurance programs, such as the Régie de l'assurance-maladie du Québec (RAMQ, the Quebec Health Insurance Board), the Ontario Health Insurance Plan (OHIP), and the Alberta Health Care Insurance Plan (AHCIP) have comprehensive and up-to-date data on healthcare, including physician billing, hospital records, emergency room visits, and prescribed drugs, in addition to demographic data.

Until very recently, the most up-to-date Quebec data included in the Canadian Cancer Registry was from 2010, as Quebec had not been participating in the CCR. Thus, analyses conducted at the national level were not truly representative of the Canadian population. A 2023 study on cancer incidence and associated mortality rates states, "Annual case counts and rate estimates are therefore not available for the following geographies: Canada and Quebec." (Statistics Canada, 2023).

Quebec cancer data for the 2011-2017 period have now been integrated into Canadian data. This makes it possible to study the change in the lifetime probability of developing and succumbing to breast cancer using more recent data for the Canadian population as a whole. Nonetheless, data on cancer cases diagnosed in Quebec after 2017 have still not been reported to the CCR, while data from the other provinces include 2019 (Brenner et al., 2024).

It is vital to obtain better access to data that is comprehensive, standardized, and up-to-date

There are several impediments to accessing comprehensive and reliable data. First, there is the issue of data being linked, or not, in Quebec. Data exist that track the time elapsed between the mammogram and the diagnosis. This performance measure makes it possible to assess the speed with which patients receive their diagnosis. There is also data on the percentage of all women eligible for the screening program who obtained abnormal mammogram results and were subsequently diagnosed with breast cancer. This is called the "positive predictive value." This indicator is important because a screening process with a high positive predictive value indicates a better program, which limits the need for unnecessary follow-up procedures and the stress they cause.

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Data from the Quebec screening program provide an overview of the breast cancer diagnosis pathway, but they are incomplete on their own. This is also the case for administrative data, which often does not include specific information such as cancer stage at the time of diagnosis. These gaps can be filled by linking screening program data with administrative data from the RAMQ and the Registre québécois du cancer (Quebec Cancer Registry), to make them more useful. Such linkages would notably allow to measure and document disparities between various groups of women and to promote equitable healthcare policies. These gaps in linked data for Quebec impede progress in research and make it difficult to conduct the analyses needed to evaluate and improve current and future policies.

Another issue is that, in 2019, the Institut de la statistique du Québec (ISQ) was tasked by the Quebec government with making RAMQ information available for research. RAMQ manages databases that can provide valuable information on the processes of cancer diagnosis and the delivery of care. The data—including those on the cancer diagnosis process and the provision of treatment—can be accessed by making a request via the ISQ's Guichet d'accès aux données de recherche. However, the process of accessing data remains relatively demanding and expensive. For researchers affiliated with a university, it takes between six and nine months to process a request for microdata containing personal information.

There are many inspiring initiatives across Canada, including in Quebec

Evaluating healthcare programs and policies requires gathering and analyzing detailed data. Measuring indicators allows to observe, compare and monitor the strengths, weaknesses, and disparities of the breast cancer screening and diagnosis processes over time. Without these measures it is difficult to identify and improve underperforming sectors. Nonetheless, with Montreal raising as one of the world's leading centres of expertise in artificial intelligence, Quebec has talent and skills in data science and information technology that it can leverage to improve clinical decision-making.

Telepathology networks, for example, use the digitization of specimens and the transmission of images over a secure network to enable specialists to analyze and diagnose cases collaboratively and *remotely*. The aim is to connect remote communities to pathologists located in major metropolitan areas, possibly hundreds of kilometres away—or even in other provinces—thereby improving the quality of care and reducing diagnosis times (Têtu et al., 2012).

One example is the *Multi-Jurisdictional Telepathology Project*, which combines the efforts of pathologists in Manitoba, Newfoundland and Labrador, and Ontario. In Quebec, the OPTILAB project connects twelve clusters of laboratories and services, which have pooled their resources to optimize medical biology services. These are promising initiatives for reducing territorial inequalities. However, reservations expressed by certain organizations underline the need for rigorous assessments.

Telepathology practices are part of a wider strategy to improve access to diagnostic and optimize healthcare *for everyone*. In the same vein, the so-called "integrated care" approach seeks to unify and coordinate healthcare pathways, in line with the established consensus that such practices can improve the efficiency of the diagnostic process (Browers et al., 2009). In 2022, the MSSS announced the launch of an $11.2 million project to coordinate diagnostic pathways in oncology.

Investigation units will be set up in each of the 28 government-affiliated cancer centres, with the aim of reducing the time elapsed between the first symptom and diagnosis, allowing patient support to begin earlier. This initiative aims to improve the quality of cancer care, regularly monitor diagnosis times in imaging centres, and standardize practices. Although the project emcompasses all types of cancer, we can naturally infer its benefits for breast cancer diagnostic pathways. Because it also involves setting up data-sharing networks using information technologies, this project has clear synergies with the development of telepathology networks and the systematic collection of clinical data.

These initiatives to standardize and extend care leverage economies of scale to reduce the pressure on the healthcare system and contribute to more efficient diagnostic pathways. Taking this a step further, they can be enhanced by a "shared care" model in which nursing, clinical and paramedical professionals deliver cancer care with specialist support as necessary. By mitigating

the lack of access to specialists, this model used in tertiary and community cancer centres also facilitates patient support. In British Columbia, for example, nurse practitioners receive special training in oncology, enabling them to order diagnostic tests, diagnose cancer and detect recurrences, with oncologists available for consultation. Similar efforts have been successfully deployed in Alberta and Ontario.

For women eligible for the Quebec screening program—but also for those "outside the program"—Montreal has set up Referral Centres to facilitate specialist consultations on a family doctor's recommendation. Women without a family doctor can make an appointment with one to obtain a referral. These centres aim to guide women through the healthcare system, aligning their objectives with those of the shared care model.

Quebec can and must do better

Quebec has the capacity to implement innovative policies at every stage of the process, from optimizing participant recruitment into the screening programs to improving access to diagnostic services and providing patient support, not to mention implementing targeted communication and advertising strategies for screening. Ontario and Alberta have led the way in breast cancer screening and diagnosis innovation over the last decade. In Quebec, pilot projects such as OPTILAB, PERSPECTIVE, and the Referral Centres, showcase the dynamism of the province's scientific community in healthcare policy and its ability to innovate.

Quebec can and must do better by strethening its commitment to innovative policies. It must also prioritize the implementation of strategies to collect comprehensive, standardized, up-to-date, and accessible data. Access to reliable data on breast cancer is not just an academic exercise. It could save lives.

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