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IMPROVING BREAST CANCER DIAGNOSIS PATHWAYS IN QUEBEC

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RAPPORT DE PROJET



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Improving Breast Cancer Diagnosis Pathways in Quebec*

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Abstract

Delays in breast cancer diagnosis can worsen the severity of illness and reinforce inequalities. This report analyzes Quebec's capabilities and performance along the diagnosis pathway, gathering information from the scientific literature on cancer care, government reports, and expert interviews. The first section outlines which types of breast cancer data Quebec collects, and how data availability impacts the measurement of performance indicators. The second section discusses how socio-economic factors and unclear guidelines for patients outside Quebec's organized screening program create barriers to diagnosis. We also explore how Quebec's lack of standardized and integrated care and its outdated cancer registry can create further delays and inefficiencies. The final section of the report compares innovations in breast cancer diagnosis in Quebec to those in Alberta and Ontario, where diagnostic delays are shorter. This comparison suggests that Quebec should include high-risk individuals in its screening program, create personalized screening recommendations, update available imaging and genetic testing technologies, and modernize communication methods. Relevant research and initiatives seeking to increase screening adherence among groups with low screening rates are also discussed. Overall, this paper highlights tangible strategies to shorten and streamline the breast cancer diagnosis interval, and points the reader to key resources for further investigation.

Keywords: cancer, health, public health, breast cancer, screening, healthcare performance, diagnosis

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Key takeaways

- Statistical indicators across Canada
 - Quebec is well equipped to measure and improve the performance of the *Programme Québécois de Dépistage du Cancer du Sein* (hereafter PQDCS).
 - Various administrative databases can be combined to calculate diagnosis intervals in Quebec.
 - Stage-related outcomes at diagnosis are impossible for Quebec to calculate because the *Registre Québécois du Cancer* is unavailable.
- Accessing timely breast cancer diagnosis in Quebec
 - Screening adherence is unequal across demographics and regions in Quebec.
 - Patients outside the PQDCS do not know where to seek care.
 - The shortage of family physicians in Quebec is a barrier to diagnosis.
- Pre-diagnosis processes and trajectories in Quebec, Ontario, and Alberta
 - PQDCS's targeting rules are outdated.
 - Targeted ads are effective at enhancing participation in screening.
 - “*Information is power.*” (Robin Morgan). Standardizing care is too.

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Acronyms

BAC Breast Assessment Centre.

CCO Cancer Care Ontario.

CCR Canadian Cancer Registry.

CCS Canadian Cancer Society.

CDD *Centre de Dépistage Désigné*, Designated Screening Center.

CHU *Centre Hospitalier Universitaire*, University Health Centre.

CHUM *Centre Hospitalier de l'Université de Montréal*, University of Montreal Health Centre.

CPAC Canadian Partnership Against Cancer.

CRID *Centre de Référence d'Investigation Désigné*, Designated Reference Center for Investigation.

DAP Diagnostic Assessment Pathway.

EPS Electronic Pathway Solution.

FP Family Physician.

FQC *Fondation Québécoise du Cancer*, Quebec Cancer Foundation.

INESSS *Institut National d'Excellence en Santé et en Services Sociaux*, Institute for Excellence in Health and Social Services.

INSPQ *Institut National de Santé Publique du Québec*, Quebec National Institute of Public Health.

ISQ *Institut de la Statistique du Québec*, Quebec Bureau of Statistics.

MSSS *Ministère de la Santé et des Services Sociaux*, Ministry of Health and Social Services.

MUHC McGill University Health Centre.

PQC *Programme Québécois de Cancérologie*, Quebec Cancer Program.

PQDCS *Programme Québécois de Dépistage du Cancer du Sein*, Quebec Breast Cancer Screening Program.

RAMQ *Régie d'Assurance Maladie du Québec*, Quebec Health Insurance Fund.

RDU Rapid Diagnostic Unit.

RQC *Registre Québécois du Cancer*, Quebec Cancer Registry.

SI-PQDCS *Système d'Information du Programme Québécois de Dépistage du Cancer du Sein*, Quebec Breast Cancer Screening Program Information System.

SPR Synoptic Pathological Reporting.

TMIST Tomosynthesis Mammographic Imaging Screening Trial.

Less than half of patients who had an abnormal mammogram result in Quebec in 2017 were able to obtain an investigative clinical exam within the 17-day deadline set in 1999 by the provincial Ministry of Health and Social Services.¹ Meanwhile, during breast cancer awareness month last year, the newspaper *La Presse* alerted readers to the alarming fact that individuals outside the target ages of 50-69 of the *Programme Québécois de Dépistage du Cancer du Sein* (hereafter PQDCS) are usually unable to access mammograms and clinical exams, worsening stage at diagnosis.² People diagnosed with breast cancer in Canadian jurisdictions which do not provide organized screening for 40–49 year olds were 23% more likely to have stage IV breast cancer compared to those in jurisdictions with a screening program encompassing this age group (Wilkinson et al., 2022). Since Black, Asian and Hispanic people are most likely to develop breast cancer in their 40s (Stapleton et al., 2018), this is also an equity issue.³

This report responds to these concerns by providing context for the delays in breast cancer diagnosis in Quebec and reflections on opportunities to reduce these delays.

1 Access to timely breast cancer diagnosis: a review of performance indicators across Canada

Several established indicators exist to measure outcomes for people moving through the diagnostic phase of their breast cancer journey. They can reveal areas of the breast cancer pathway needing more attention and resources, especially when compared to Quebec’s own targets, outcomes in high-performing provinces, and Canada-wide targets. This section reviews common diagnosis-relevant breast cancer indicators across Canada, the data necessary to compute them, and examines the feasibility of measuring these indicators for Quebec.

1.1 Relevant data

Indicators for the diagnostic phase of the breast cancer care pathway are based on three types of data, which capture information on patients along diagnosis pathways within and outside organized screening programs.

1.1.1 Screening program data

Every province and territory in Canada (except Nunavut) has an organized breast cancer screening program (CPAC, 2021). Eligibility for these programs varies by province/territory, but is usually based on age and whether a woman is “high-risk” (see appendix table A1). Each of these programs collect data on every eligible woman who is screened for breast cancer through the program. This information can include demographic characteristics, risk factors, screening test and results, subsequent referral, diagnostic tests, outcomes, and cancer information (CPAC, 2017). Information on patients who were not eligible to participate in the organized screening program but who access diagnostic services due to the presence of symptoms or high-risk status is not included in these data. Quebec’s breast cancer screening program, the PQDCS, read 365,910 mammograms in 2021.⁴ The *Institut National de Santé Publique du Québec* (INSPQ) gathers data from the program in an information system called the SI-PQDCS. The system stores consultation, screening, investigation, and pathology forms, which are used to evaluate the program. The INSPQ releases annual

¹See PQC (2019). For more detail on the targets set in 1999 by the MSSS, see MSSS (1996).

²See: Slight, Anne. 2022. “Cancer du Sein – Les femmes n’ont pas toute l’information”. *La Presse*. September 29. <https://www.lapresse.ca/debats/opinions/2022-09-29/cancer-du-sein/les-femmes-n-ont-pas-toute-l-information.php>.

³This difference is linked to socio-economic conditions associated with risk factors such as excess weight but also potentially to biology (see Siddharth and Sharma, 2018, for the determinants of breast cancer risk among African American women). For instance, West African ancestry is correlated with predisposition to triple negative breast cancer (Newman, 2017), which is particularly aggressive and affects younger individuals. Monticciolo et al. (2018) identify Black women as higher-risk individuals for breast cancer and recommend them to undergo screening from age 30.

While this report will provide an outlook on the inequities faced by First Nations people in terms of breast cancer screening and diagnosis, they do not seem to be more likely to develop breast cancer earlier, compared to non-Indigenous populations.

⁴See: INSPQ. *Système d’information pour le dépistage du cancer - Volet cancer du sein*. Retrieved online on October 27, 2022. <https://www.inspq.qc.ca/evaluation-du-programme-quebecois-de-depistage-du-cancer-du-sein/systeme-d-information-pour-le-depistage-du-cancer-volet-cancer-du-sein>.

reports describing indicators over time, updated dashboards for indicators⁵ and external researchers also conduct research using these data (see for example Perron et al., 2019). These data contain details about the number of mammograms and breast cancer diagnoses within the screen-eligible population but do not contain information on disease severity, patient demographics, screens without cancer diagnoses, and symptomatic patients outside of the screening program. However, the SI-PQDCS can be linked to administrative data like Quebec’s hospital and physician claims databases to provide supplemental information and increase its potential to provide additional useful information (Perron et al., 2019).

1.1.2 Cancer registry data

Cancer registries comprehensively document incident cases of cancer over time and are designed to be comparable across jurisdictions. In Canada, provincial registries dating from 1992 have been combined into the Canadian Cancer Registry (CCR) by the Canadian Council of Cancer Registries (Statistics Canada, 2022a). The CCR documents patient and cancer characteristics at diagnosis, including age, sex, location of residence, cancer site, cancer stage, and other details. This national registry standardizes this information, so indicators derived from the data are comparable across provinces. Cancer registry data is linkable with administrative health data within provinces (Chan et al., 2020), and even across provinces within Statistics Canada’s Research Data Centres. Accordingly, in 2021, Statistics Canada published a new linkage of the cancer registry to health survey, ambulatory care, inpatient, census, tax and mortality data: the “Canadian Population Health Survey data (CCHS Annual and Focus Content) integrated with mortality (CVSD), hospitalization (DAD, NACRS, OMHRS), historical postal codes (HIST-PC), cancer (CCR), tax data (T1FF) and Census”.

Quebec has collected information on all women in the province with breast cancer since 1984. The *Registre Québécois du Cancer* (RQC), based on data collection in hospitals’ local registries since 2011, has released aggregate statistics on breast cancer incidence by age group, sex, and place of residence up until 2017. As of the November 17, 2022 update of these public statistics, this remains the most recent available data.⁶

Unlike all other Canadian provinces, the data from which these statistics originate are not available for analysis by government agencies, academic researchers, clinicians, or patient advocates. The RQC also has not contributed data to the CCR since 2010, thereby excluding itself from national research (Statistics Canada, 2022a).⁷ In the absence of accessible registry data, some groups of hospitals have moved ahead to conduct analysis with their local registry data, such as the Quebec Metastatic Breast Cancer Registry⁸ and the Rossy Cancer Network Cancer Registry.⁹ While university-affiliated hospitals may have this capacity, rural hospitals without the resources to analyze their own data and their patients will be left unrepresented. Furthermore, the absence of provincial registry data hinders the accurate understanding of provincial breast cancer outcomes and their evolution. This is a longstanding concern raised by researchers and health professionals and criticized in the press.¹⁰

⁵Such as delays. See: INSPQ. *Délai d’obtention des rendez-vous (online)*. Accessed on December 6, 2022. <https://www.inspq.qc.ca/sites/default/files/pqdc-sondages/delais.html>.

⁶See: Gouvernement du Québec. *Statistiques Du Registre Québécois Du Cancer (online)*. Accessed on December 6, 2022. <https://www.quebec.ca/sante/systeme-et-services-de-sante/organisation-des-services/donnees-systeme-sante-quebecois-services/donnees-cancer>

⁷The reason for this remains unclear. The Quebec government’s report on the incidence of cancer in 2013 (MSSS, 2021) presents the improvements on the effectiveness and quality of the RQC. In his foreword, the provincial cancer program director, Dr Jean Latreille, praises a registry “aiming to be more exhaustive than other data sources on cancer” as well as “[compliance] with international standards, enhancing the comparability of data with the rest of Canada and North America”. The report used the RQC to generate incidence statistics for Quebec and compared these numbers with the incidence data for the rest of Canada (computed by Statistics Canada using the CCR). Ten years later, in June 2022, clinicians and health system experts interviewed in *La Presse* deplored the lack of a functioning cancer registry in Quebec, despite millions of dollars of investment. See: Lacoursière, Ariane. 2022. “Registre québécois du cancer – Le Québec est ‘dans le noir’.”. *La Presse*. June 14. <https://www.lapresse.ca/actualites/sante/2022-06-14/registre-quebecois-du-cancer/le-quebec-est-dans-le-noir.php>.

⁸See: “The Quebec Metastatic Breast Cancer Registry: Advancing Research and Care.” McGill University Health Centre, 21 Oct. 2021, <https://muhc.ca/news-and-patient-stories/news/quebec-metastatic-breast-cancer-registry-advancing-research-and-care>.

⁹See: “RCN Cancer Registry.” Rossy Cancer Network, 19 Apr. 2022, <https://www.mcgill.ca/rcr-rcn/projects-activities/rcn-cancer-registry>.

¹⁰See: Roy, François. 2022. “Registre Québécois du Cancer – Le Québec est ‘dans le noir’.”. *La Presse*. June 14. <https://www.lapresse.ca/actualites/sante/2022-06-14/registre-quebecois-du-cancer/le-quebec-est-dans-le-noir.php>.

1.1.3 Administrative data

Data that are automatically created in the healthcare system can describe many elements of a breast cancer patient’s experience, including timely diagnosis, high-quality treatment, and appropriate palliative care. Data held by Canadian provincial insurers include physician billing, hospital, emergency department, pharmaceutical, and demographic data. While administrative data provides important information regarding the number and types of health care services used by patients with cancer, many details that are important for cancer research, but irrelevant for billing, are unavailable. For instance, there is often no information about cancer stage at diagnosis or the type of mammogram (screening *versus* diagnostic). These gaps can be addressed by linking cancer registry data to administrative data at the individual patient level.¹¹

Quebec’s provincial insurer, the RAMQ, produces or holds databases that capture insured persons’ demographic (FIPA) and mortality (RED-D) information, and information on patient care provided in hospitals (MED-ECHO), emergency departments (BDCU), and by physicians (SMOD). Information on prescriptions filled in community pharmacies by patients with public coverage for medications is also captured (SMED). All of these databases are anonymized and can be linked at the individual patient level to provide a detailed understanding of cancer diagnostic processes as well as cancer care across the continuum, as has been done in other Canadian provinces. INESSS has privileged access to Quebec’s administrative data. Researchers can access them via the ISQ, from a secure environment and at a financial cost, conditional on their projects having been evaluated and accepted by the ISQ: this process is hence neither cost-less nor fast.¹² Administrative data could also be linked to cancer registry data if those data were accessible, as is commonly done in other Canadian provinces.

1.2 Key performance indicators

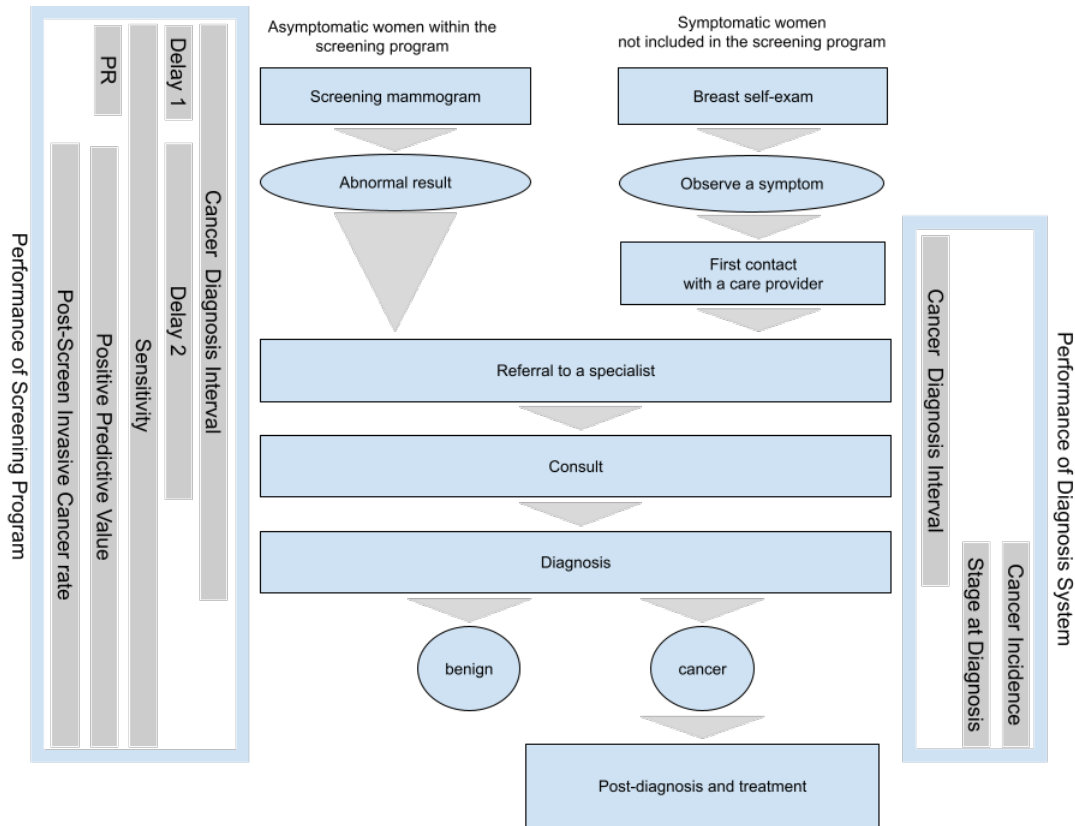
Researchers use registry, screening program, and administrative data to understand care and patient experience across the cancer continuum. Process and outcome indicators based on such data that focus on the breast cancer diagnosis pathway can be used to understand and evaluate access to timely diagnostic services and performance of screening programs. In fact, up-to-date and accurate indicators are a crucial input to inform a learning health system in cancer care and to support continuous quality improvement to lead to better cancer care outcomes for patients and their families.

This report considers the different pathways to breast cancer diagnosis experienced by people within and outside of organized screening programs. An abnormal mammogram result following organized screening participation is handled according to the provincial program guidelines. On the other hand, symptomatic people outside organized screening have to be proactive and seek care by themselves. They may go to a family physician, a rapid specialized clinic, or other provider. After diagnosis, care pathways become more similar in the two groups.

Figure 1 represents the breast cancer diagnosis pathways for both groups and illustrates which stages and intervals of these pathways the indicators apply to. Indicators are divided into two groups based on the type of outcomes that they measure: the performance of the breast cancer diagnosis system or the performance of screening programs. The former group includes overall incidence rates, timeliness of diagnosis, and stage-related outcomes at diagnosis. Each of these indicators are illustrated in tables 1 and 2. These tables show which provinces measure each indicator, the types of data needed to calculate each indicator, and Quebec’s ability to measure each indicator given current data availability.

¹¹Such as the MSSS and RAMQ data collected by the ISQ (see for example ISQ, 2020). This has been done for the other Canadian provinces, as Statistics Canada has produced linkages of the CCR to administrative data, including detailed income data. In particular, their most recent linkage (Statistics Canada, 2021) comprehends data from hospitalization, tax files and others. Previously, researchers had been relying on the 1991 Census-Longitudinal Worker File data (see Jeon and Pohl, 2017, for an example and detail on these data).

¹²See: ISQ. “Research data access services – FAQ”. <https://statistique.quebec.ca/research/#/a-propos/foire-aux-questions>. Retrieved online on August 16, 2023.



Note: the abbreviation ‘PR’ stands for ‘participation rate’.

Figure 1: Breast cancer diagnosis pathways and their related indicators in Canada

1.2.1 Population-level indicators related to breast cancer screening and diagnosis

The breast cancer incidence rate is the number of newly diagnosed patients with breast cancer in the population per year per 100,000 people ([‘Canadian Cancer Statistics 2019’ report](#)). It can be compared over time, across jurisdictions, and across relevant population subgroups to understand progress in addressing risk factors, evaluate the effectiveness of health care system innovations to improve access to screening, and to identify under-served populations (see pp 10-32 of [‘Canadian Cancer Statistics 2021’ report](#)).

Incidence rates are commonly calculated using **cancer registry data**, which is **not accessible or up-to-date in Quebec**. However, other methods are available to produce cancer incidence rates, in particular using administrative data. For instance, to accurately identify and study care and outcomes for patients with incident lung cancer, INESSS worked around the absence of up-to-date registry data by creating an algorithm based on administrative data, specifically the hospitalization, mortality, pharmaceutical, and physician billing databases ([Boily et al., 2021](#)).¹³ They also used administrative data to calculate lung cancer incidence rates in Quebec overall and by age, sex, region, and “vulnerability” status.¹⁴ Although INESSS used validation strategies to develop these methods and corroborate the resulting incidence estimates, their work is currently limited to lung cancer. Assessing breast cancer incidence in Quebec could be done by investing in an analogous project. Yet, investing in RQC data on all cancer sites that is accessible and

¹³Applications of this algorithm to research includes the work of [Qureshi et al. \(2022\)](#), which studies the overall survival of patients receiving EGFR tyrosine kinase inhibitors, used to treat patients with tumors containing EGFR-TKI sensitizing mutations, including resistance mutations. Future work could explore adapting the algorithm for other cancer sites.

¹⁴“Vulnerability” is an area-level measure based on unemployment, income, and education.

up-to-date would be preferable. Beyond the fact that this is a more straightforward solution to measure cancer incidence, cancer diagnoses and diagnosis dates in registries are validated by trained cancer registrars who ensure compliance to North American standards. This not only guarantees the validity of the data but also its comparability across jurisdictions.

Table 1: Population-level indicators related to breast cancer diagnosis

Indicator	Provinces	Data needed	Data available in Quebec
Breast cancer incidence ^a	all, except QC after 2017	Cancer registry	RAMQ linked administrative databases
Breast cancer incidence by age group	all, except QC after 2010	Cancer Registry	RAMQ linked administrative databases
Breast cancer incidence among First Nations people	all, except QC	Cancer registry, Registered Persons Database and Indian Registration System, Cancer Screening Database	
Cancer diagnostic interval inside organized screening programs ^b	all	Cancer Screening Database	SI-PQDCS, RAMQ linked administrative databases
Cancer diagnostic interval outside organized screening programs ^b	all (except NB, QC, SK)	Cancer registry, physician claims, ambulatory care reporting	RAMQ linked administrative databases
Stage of breast cancer at diagnosis ^c	all (except NT, QC)	Cancer registry or tumor registry	

Notes:


^a See [Canadian Cancer Statistics Advisory Committee \(2019\)](#); [Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada \(2021\)](#); [Boily et al. \(2021\)](#); [Qureshi et al. \(2022\)](#)

^b See [Webber et al. \(2021\)](#); [Jiang et al. \(2018b\)](#); [Weller et al. \(2012\)](#)

^c See [Cancer Quality Council of Ontario \(2021\)](#); [CPAC \(2017\)](#)

Legend:

 Quebec measures this indicator.

 Quebec does not measure this indicator but could do so using data it currently collects.

 Quebec does not measure this indicator and would need to collect additional data to do so.

1.2.2 Access to and performance of organized breast cancer screening program indicators

The screening program participation rate ¹⁵ quantifies adherence to the screening program among the eligible population. This is measured as the percentage of screen-eligible women who completed at least 1 mammogram in the last 30 months (see pp 12 [CPAC, 2017](#)). A high rate across demographic groups means the program is accessible and the eligible population is educated on its purpose.

The positive predictive value evaluates the accuracy of abnormal screens. It is measured as the percentage of all screen-eligible women with an abnormal screening mammogram result who are then diagnosed

¹⁵Denoted by "PR" in figure 1.

with breast cancer. A high positive predictive value means the program minimizes unnecessary follow-up procedures and undue stress (see pp 26 [CPAC, 2017](#)).

The sensitivity of the screening mammography program evaluates the effectiveness of a screening test in detecting cancer in people who truly have cancer ([Ontario Health, 2021](#)). This is measured as the percentage of all breast cancer cases in screen-eligible women¹⁶ that were screen-detected (see pp 27 [CPAC, 2017](#)). A high rate means the screening program can identify breast cancer early if adherence is high.

Similarly, the post-screen invasive cancer rate evaluates the ineffectiveness of a screening test in detecting cancer in people who truly have cancer. This is measured as the percentage of all breast cancer cases in screen-eligible women that are found during the interval after a normal/benign screening mammogram and before the next screen is due, including new cancers that developed between screens and cancers that were missed during the earlier screening test. A high rate may indicate that mortality reductions due to the screening program will be less than expected (see pp 27 [CPAC, 2017](#)).

Quebec has the necessary data to calculate all of these indicators. As discussed in section 1.1.1, the INSPQ collects information on consultations for screen eligible women with breast cancer, which constitutes the SI-PQDCS. Thanks to this information system, **Quebec is well equipped to measure the PQDCS's efficacy and track screen-eligible women** along the diagnosis pathway.

Table 2: Key indicators assessing the performance of the screening program

Indicator	Provinces	Data needed	Quebec
Mammography and examination delays ^a	all	Cancer Screening Database, survey of screening and referral centres	SI-PQDCS
Cancer diagnostic interval	all	Cancer Screening Database	SI-PQDCS
Screening program participation rate (PR) ^b	all	Cancer Screening Database, mammogram claims	SI-PQDCS, SMOD
Sensitivity of the screening mammography program ^c	all (except PEI)	Cancer Screening Database	SI-PQDCS
Breast Cancer Screening (Mammogram) Positive Predictive Value (PPV) ^b	all	Cancer Screening Database, mammogram claims	SI-PQDCS, SMOD
Post-screen invasive cancer rate ^b	all	Cancer Screening Database	SI-PQDCS

Notes:


^a See [MSSS \(2022\)](#)

^b See [CPAC \(2017\)](#)

^c See [Ontario Health \(2021\)](#); [CPAC \(2017\)](#)

Legend:

 Quebec measures this indicator.

 Quebec does not measure this indicator but could do so using data it currently collects.

 Quebec does not measure this indicator and would need to collect additional data to do so.

¹⁶This includes the screen-detected cancers, as well as the non-screen cancers detected within 12 months of the last screen.

1.2.3 Timely diagnosis indicators, in and outside of organized breast cancer screening programs

Mammography and examination delays evaluate the time taken for screen-eligible women to obtain an appointment for a screening mammogram, a complementary mammogram, and an ultrasound, by centre for each financial period. The Ministry of Health and Social Services (MSSS) regularly surveys designated screening centres (*Centre de Dépistage Désigné*, hereafter CDD) and designated referral centres for investigation (*Centre de Référence d'Investigation Désigné*, hereafter CRID), which provide the dates of the next three appointments available on their schedule, and the second date is used to calculate wait time (MSSS, 2022).

The diagnostic interval measures the time from a patient's first presentation to the healthcare system to the final cancer diagnosis (Webber et al., 2021).¹⁷ The patient's first presentation to the healthcare system could be a mammogram within a provincial screening program, or a visit to a family physician after experiencing a symptom. In the former case, defining the diagnostic interval is relatively straightforward (it is the delay between the screening exam and the diagnosis). Provided data on screening and follow-up is collected, estimating the diagnostic interval is also feasible. In Quebec, the diagnostic interval for women screened in the PQDCS can be estimated from the SI-PQDCS data.

For patients outside organized screening programs, computing the diagnostic interval is more challenging as it requires identifying the first contact with the healthcare system that is related to a cancer symptom.¹⁸ In this case, the diagnostic interval can be estimated using registry data linked to administrative data. This is done in other jurisdictions (see Jiang et al., 2018b, for an example with Ontario) but not in Quebec. Yet, since claims data contain the dates of mammograms, diagnoses, and other relevant encounters with healthcare providers, with some adaptations to existing methods **linked administrative data could be used to identify cancer patients and to calculate the diagnostic interval in Quebec.**

1.2.4 Stage-related outcomes at diagnosis indicators

Stage at diagnosis reflects, in part, access to diagnostic services for breast cancer and the delays in diagnosis experienced by patients. This indicator is measured as the percentage of all patients diagnosed with breast cancer who are at each stage (1, 2, 3, and 4) upon diagnosis (Cancer Quality Council of Ontario, 2021). Staging of invasive cancers is based on tumour size, lymph node involvement, and presence of distant metastasis, which can also serve as their own indicators. A high percentage of patients diagnosed at stage 1 or 2 may indicate more effective screening and diagnostic pathways. It also permits treatments to occur earlier when they are more effective, and leads to lower breast cancer mortality rates (see pp 4-5 CPAC, 2017).

This indicators is impossible for Quebec to calculate because reliable stage data is only available in cancer registry data. The aggregated statistics currently available from the RQC do not include the distribution of incident cases by stage.¹⁹ This means these cancer patients cannot be connected to external demographic data (besides sex, age, and region) to compare indicators across groups, as is commonly done in research using the SI-PQDCS.

1.3 Consequences of not measuring indicators

When indicators are measured, strengths, weaknesses, and disparities in the breast cancer screening and diagnostic processes can be observed, compared, and tracked over time. For example, Quebec researchers used the SI-PQDCS to calculate screening performance indicators, concluding that Montreal has a poor screening participation rate (66%) compared to the rest of the province (73%) (PQC, 2019). **When indicators are**

¹⁷The diagnostic interval encompasses many other steps in the diagnostic process, such as referral to a specialist, first diagnostic screen, and notification of screen results that can be used to measure even more precise sub-intervals.

¹⁸In light of this complexity and the lack of a clear consensus to address it, Weller et al. (2012) provide a series of recommendations for definitions and methodological approaches to stimulate and guide forthcoming research on reporting early-cancer diagnosis.

¹⁹See: Gouvernement du Québec. *Tableau de bord – Statistiques du Registre Québécois du Cancer*. Accessed on December 6, 2022. <https://app.powerbi.com/view?r=eyJrIjo1Njc2ZTAxNmMtMWF1Mi00NDIwLTg0MzYtOTY2OTIzMD1iYjA2IiwidCI6IjA2ZTFmZTI4LTVmOGItNDA3NS1iZjZjLWFlMjRiZTFhNzk5MjIj9>.

not measured, identifying poorly performing areas of the diagnosis pathway and improving them is impossible. Although the 2022 breast cancer incidence is not available from the RQC, the Quebec Cancer Foundation (*Fondation Québécoise du Cancer*, hereafter FQC) estimated that last year in Quebec 6,700 women would be diagnosed with breast cancer and 1,400 would die from it.²⁰ These estimates show room for improvement in the breast cancer care system, but in order to lower these numbers we must measure them in real time.

Refusal to share data is another obstacle preventing Quebec from improving the breast cancer diagnosis pathway. Since Quebec has not contributed data to the CCR since 2010, they are excluded from Canadian-wide analyses like the Cancer System Performance Report, and cannot be compared to other provinces. When jurisdictions have different strengths and weaknesses, there is an opportunity to learn from each other’s successful innovations. Since Quebec does not share complete registry data, they also do not benefit from the many registry-linkage possibilities. They are absent from the Canadian Partnership Against Cancer Linkage Project, where Statistics Canada merged the CCR with discharge, ambulatory, demographic, and other databases.²¹ Quebec misses out on insight from the many Canadian cancer studies using linked CCR (Essue et al., 2022). Within-province research using linked registry data is also extremely valuable. Ontario linked its cancer registry with demographic data to measure cancer incidence, mortality, survival and prevalence among indigenous people.²² The reports created from this data (*‘Cancer in First Nations People in Ontario 2017’ report*) spurred the Ontario government into action, informing initiatives like the First Nations, Inuit, Métis and Urban Indigenous Cancer Strategy (Cancer Care Ontario, 2021a).

2 Accessing timely breast cancer diagnosis in Quebec

This section reviews the barriers to accessing a swift breast cancer diagnosis in Quebec. We discuss barriers hindering and delaying breast cancer diagnosis at two stages of the pre-diagnosis process: the first breast imaging and its investigative follow-up exam. We identify the obstacles affecting individuals along the diagnosis pathway, both within and outside the PQDCS.

2.1 Barriers to breast imaging

2.1.1 Socio-economic barriers within the screening program

Women aged 50 to 69 are eligible to undergo a screening mammogram every other year in a CDD within the PQDCS, at no financial cost to them. At age 50, they receive a letter from the government, informing them of the provincial organized screening program and inviting them to make an appointment at a CDD. In the event of an abnormal mammogram result, CDDs refer patients to a CRID, which is in charge of further breast exams and diagnosis.

In 2018, 73% of eligible women received a screening mammogram through the PQDCS. However, this participation rate varies across the province. Montreal displays only 66% participation, while the Mauricie and centre Quebec region reach above 78%. All regions except Montreal and the Outaouais showed rates above 70% (PQC, 2019).

This heterogeneity is consistent with the fact that people with lower socio-economic status, who are immigrants,²³ or who are Indigenous are generally less likely to be screened for cancer. Even in universal healthcare systems, lower socio-economic status individuals show lower participation in screening programs (see for example Kumachev et al., 2016). Raynault et al. (2020) provide evidence that lower literacy and lack of knowledge about breast cancer inhibit access to screening for women within the PQDCS. Further, even in

²⁰FQC. *Facts and Statistics about Cancer*. Accessed on October 30, 2022. <https://fqc.qc.ca/en/information/the-cancer/statistics>.

²¹These databases include the Discharge Abstract Database, the National Ambulatory Care Reporting System, the Canadian Vital Statistics Death Database, the Longitudinal Immigration Database, the T1 Family File, and the Census. See <https://crdcn.ca/data/canadian-partnership-against-cancer-linkage-project/>.

²²CCO. *Measuring Cancer in First Nations, Inuit & Métis Populations*. Accessed on December 6, 2022. <https://www.cancercareontario.ca/en/first-nations-inuit-metis/understanding-cancer-statistics>

²³See Vahabi et al. (2015) for evidence on breast cancer screening disparities among immigrant populations in Ontario.

universal healthcare systems where screening within organized programs is free, lower socio-economic status is associated with lower participation in organized screening (Shields and Wilkins, 2009). One explanation is that lower SES is linked with psycho-social factors such as higher levels of stress and numerous work and family obligations that do not easily accommodate time-consuming screening visits.

This is particularly true for immigrant (Lofters et al., 2019; Ferdous et al., 2020) and Indigenous populations who might face language barriers, and for whom stigma or beliefs may limit participation in screening. These groups of people comprise a large proportion of Montreal’s population. For instance, 34% of people living in Montreal are immigrants (compared to 13% province-wide) and 16% experienced material deprivation in 2020 (compared to 10% province-wide).²⁴

2.1.2 Outside the screening program

The screening and pre-diagnosis guidelines for asymptomatic individuals within the organized screening program are clear. Yet, this is not the case for symptomatic women outside the targeted age group. The lack of clarity is particularly worrying since women self-selecting for screening mammograms outside of publicly organized screening programs are more likely to have cancer (Einav et al., 2020).

The first point of contact for individuals outside the PQDCS is their family physician. *Santé Montréal* indicates that diagnostic mammography exams in a CDD require a medical prescription.²⁵ Yet because they present a lower risk of contracting cancer, physicians are less likely to suspect that younger patients have breast cancer, which delays their diagnosis (Webber et al., 2021). Sahay (2022, p.45) reports that “[t]he early phase of diagnosis for many is characterized by multiple and repeat visits to primary care providers, unnecessary strain and costs to the health care system, delays in appropriate testing (possibly leading to poorer health outcomes) and personal worry about advancing illness.” The high density of younger patients’ breasts, combined with generally atypical symptoms, complicate clinical and imaging exams, worsening delays in diagnosis.

2.1.3 The importance of access to primary care

Family physicians play an important role at every stage of breast cancer diagnosis. They educate, accompany and advise patients from the first contact before they undergo a mammogram to the post-diagnosis and recovery stages. This role is all the more important and expansive in a context where cancer prevention and early diagnosis are at the heart of health policy focus (Rubin et al., 2015). Yet, 1 out of 4 adults across the province of Quebec did not have a family physician in 2022 (MSSS, 2023). Again, regional variation is important, ranging from 30 to 40%²⁶ in Montreal Island to below 10% in Saguenay-Lac Saint-Jean.

For asymptomatic, screen-eligible women in the early stages of pre-diagnosis, poor access to primary healthcare translates into less education about breast cancer and its prevention, and hence lower participation to organized screening. On the other hand, people experiencing breast symptoms who are not screen-eligible and do not have access to a family physician or a gynecologist may search online for guidelines or a consult. This search may direct them to private clinics with high costs for breast imaging. In the absence of any other alternative, some patients may directly present at the emergency room.²⁷

2.2 Sub-optimal practices and diagnosis delays

The lack of standardized patient-centred care is reflected in patients’ apparent confusion about diagnosis delays and pathways. Interviewed earlier this year, Laurent Proulx, President and CEO of PROCURE²⁸

²⁴For the province-wide and Montreal immigration statistics, see: [Gouvernement du Québec, Ministère de l’Immigration, de la Francisation et de l’Intégration \(2021\)](#).

For the province-wide deprivation statistics, see: [Statistics Canada \(2022b\)](#).

For the Montreal deprivation statistics, see: Ville de Montréal. *Montréal en Statistiques*. “Portrait de l’immigration de la région de Montréal”. Retrieved online on October 30, 2022. https://ville.montreal.qc.ca/portal/page?_pageid=6897,67885721&_dad=portal&_schema=PORTAL.

²⁵See: Santé Montréal. *Mammographie de dépistage (online)*. Accessed on October 31, 2022. <https://santemontreal.qc.ca/population/services/mammographie-de-depistage/>.

²⁶Depending on the area.

²⁷As reported by Dr Sarkis Meterissian, director of the Breast Centre of the MUHC, in October 2022.

²⁸PROCURE is a nonprofit organization dedicated to fighting against prostate cancer.

Although the guidelines regarding the target screening population are defined federally, there are some differences from one province to the next (CPAC, 2021). Examples include the age at which individuals are allowed to self-select into screening and the definition of at-risk populations. The guidelines regarding screening itself also differ, particularly which at-risk individuals should be included in the organized screening program and how frequently the target population should undergo screening.

In this section, we analyze the main differences in screening policies and pre-diagnosis pathways in Quebec and compare them to Ontario and Alberta, as these provinces have the shortest waiting times for breast cancer diagnosis in Canada for women aged 50-59.³⁶ Quebec’s performance on these indicators is second to last (CPAC, 2018).³⁷ We also review innovative programs proposed and implemented by these provinces to facilitate breast cancer diagnosis for individuals within and outside screening programs. We distinguish three channels through which these initiatives have contributed to this objective. Enhancing access to care and patient support is simply the first step towards diagnosis. One example of this objective is optimizing targeting and imaging within the screening program, as well as ensuring the participation of eligible groups. Further, we provide insight on diagnosis trajectories following abnormal mammogram results or breast cancer symptoms. We present Quebec’s recent initiative to implement dedicated access points (*guichets d’investigation*) for patients needing cancer diagnosis based on the evidence from Ontario, where standardized and integrated care pathways accelerated the diagnostic process (Brouwers et al., 2009). Finally, we review examples of data networks that enable the sharing of clinical and pathology data for diagnosis and research purposes.

More detail on the similarities and differences between the screening programs in place in Quebec, Ontario and Alberta is provided in appendix table A1. Tables A2 to A4 summarize recent innovations in the three provinces and the channels through which they may contribute to improving breast cancer pre-diagnosis processes and trajectories.

3.1 Strategies to optimize targeting and imaging in organized screening programs

Screening strategies targeting women aged 50-69 are not necessarily optimal anymore – and may be out of date. The decision of U.S. Preventive Task Force to extend the recommended screening age to 40-74 this spring was praised by several Canadian oncologists.³⁸ The European Commission recommends screening from as early as 45 and up to 74 years old. Which population to target in organized screening is subject to policy and scientific debate (see for example Marmot et al., 2013, for a review). While extending screening notably enhances breast cancer survival rates, it also entails significant social costs, chiefly through over-diagnosis and its adverse impacts on health and well-being. Notwithstanding, guidelines should be regularly revised and evolve with scientific knowledge as well as demographic changes. Quebec has not reviewed the target age of the provincial organized screening program since it was created 25 years ago.

While the PQDCS is restricted to women aged 50-69, **over a third of new breast cancer cases are among women aged over 70** (‘Canadian Cancer Statistics 2021’ report). The breast cancer incidence rate in Canada reaches its peak between ages 70 and 74 (Wilkinson et al., 2022). Further, the life expectancy of Canadian women has increased from 80 in 1988, when British Columbia introduced Canada’s first organized screening program, to 84 years old in 2020.³⁹ Hence, the Canadian Task Force on Preventive Health Care (2011) recommends for women aged 70-74 to undergo screening every two to three years and Ontario and Alberta have included women aged 70-74 in their screening programs’ target population since 2013. However, to our knowledge, these policy changes still remain unevaluated; which is why the Task Force advertises this recommendation as ‘weak’. A decade’s worth of subsequent cancer registry data and new linkages gathered by

³⁶In Alberta for 90% of patients, time to diagnosis with a biopsy is at most 7.6 weeks; without a biopsy, it is at most 3.4 weeks. In Ontario, these figures are respectively 9.9 and 4 weeks.

³⁷For 90% of patients in Quebec, time to diagnosis is up to 16.7 weeks when a biopsy is required and 9.0 weeks otherwise.

³⁸See: Lindsay, Bethany. 2023. “Canada should follow U.S. call to screen for breast cancer at 40, doctors and patients say”. *CBC News*. May 9. <https://www.cbc.ca/news/health/breast-cancer-screening-guidelines-1.6837907>

³⁹See: World Bank, World Development Indicators. “Life expectancy at birth”. Retrieved online on October 18, 2022. <https://data.worldbank.org/indicator/SP.DYN.LE00.FE.IN?end=2020&locations=CA&start=1960>.

Statistics Canada (see section 1.1) now provide the means to carefully analyze their costs and their benefits. Note that screening mammography has not been proven effective at reducing breast cancer mortality among all older women. In particular Braithwaite et al. (2016) highlight that women over 74, since they present large heterogeneity in life expectancy and comorbidity, on average do not benefit from organized screening.

As for women younger than 50, they represent 20% of the projected new breast cancer cases in 2021 in Canada – and nearly two-thirds of these cases are among women between 40-49 (‘Canadian Cancer Statistics 2021’ report). While its associated harms makes systematically screening younger women questionable (Klarenbach et al., 2018), **one can hardly ignore that a notable portion of new breast cancer cases affect younger individuals.** In addition, these cases tend to be associated with adverse pathological factors, compared to these occurring among women over 50 (Assi et al., 2013). Consequently, Alberta’s 2022 breast cancer screening guidelines include women from age 45 for the first time.⁴⁰

In particular, genetic factors influence the chance of women being diagnosed, not only over their lifetime but also at a younger age. The odds of developing breast cancer in their lifetime can reach 85% for Canadian women presenting mutations of the BRCA1 or BRCA2 genes.⁴¹ Meanwhile the probability of developing cancer is only 12.5% among the whole population of Canadian women.⁴² Further, breast cancer incidence rises early in adulthood until ages 30 to 40 years for BRCA1 and until ages 40 to 50 years for BRCA2 carriers. It then remains constant until age 80 (Kuchenbaecker et al., 2017).

Combined with the fact that diagnosis is expectedly quicker for women within the screening program (Habbous et al., 2022), genetic susceptibility explains Ontario and Alberta’s efforts to define higher-risk categories and to **provide specific screening guidelines for high-risk individuals, which include eligibility for screening, screening frequency, and imaging methods.** Ontario systematically includes high-risk individuals aged 30+ in a specific division of the screening program. Alberta welcomes them to get screened from age 25. In both provinces, these participants are invited to undergo yearly screening – instead of biennial.⁴³ In addition to a mammogram, they are also screened through MRI and/or ultrasound. This is in line with evidence that these imaging techniques are more effective on patients with higher breast density (who are younger) or reconstructed breasts, as well as individuals displaying certain genetic predispositions to breast cancer (Heller and Moy, 2019). **Quebec, on the other hand, does not designate higher-risk individuals, ignoring the specific needs of these people.**

Overcoming the trade-off involved in expanding screening requires refining target populations and using more accurate imaging technologies. The British Columbia Gynecologic Cancer Initiative advocates for **genetic testing to enhance gynecologic cancer prevention** (Tindale et al., 2022). In Quebec, the PERSPECTIVE research project⁴⁴ led in the National Capital and Lanaudière regions implements this recommendation and provides women aged 40-69 with tailored breast cancer screening recommendations, based on their genetic profile (Brooks et al., 2021). As a rising leader in artificial intelligence research,⁴⁵ Montreal could provide opportunities to invest in refining screening strategies, so long as appropriate data on the Quebec population is gathered.⁴⁶

The benefits of genetic testing extend further down the breast cancer care pathway as it informs clinical decisions. For instance, clinical advances have revealed PARP-inhibitors as promising monotherapy and

⁴⁰Alberta Health Services, Screening for Life. 2021. *Get Screened (online)*. Accessed on October 20, 2022. https://screeningforlife.ca/breast/get-screened/#who_should_get_screened.

⁴¹See: CCS. *Risks for breast cancer*. Accessed on November 17, 2022. https://cancer.ca/en/cancer-information/cancer-types/breast/risks#ci_brca_gene_mutations_10_185_04.

⁴²CCS. *Breast cancer statistics*, Accessed on November 17, 2022. <https://cancer.ca/en/cancer-information/cancer-types/breast/statistics>

⁴³In Ontario, the recommendation of yearly mammograms extends to women with high breast density.

⁴⁴See: PERSPECTIVE. 2022. *PERSPECTIVE – Faites partie de la solution*. Accessed on December 13, 2022. <https://etudeperspective.ca/>.

⁴⁵Investissement Quebec International. *Information and communication technologies*. “Montréal’s Artificial Intelligence Hub”. Retrieved online on October 20, 2022. <https://www.investquebec.com/international/fr/secteurs-activite-economique/technologies-information-communications/Montreal-centre-mondial-de-l-intelligence-artificielle.html>

⁴⁶Other local initiatives to exploit biological data at a relatively large scale to advance health research include the CARTAGENE platform, set up by Sainte-Justine university hospital centre (CHU) in Montreal. This public research platform consists of a linkage between biological samples and health and lifestyle data on 43,000 Quebecers ages 40-69 at recruitment. See: CARTAGENE. 2022. *CARTAGENE: a new era of research*. Accessed on December 13, 2022. <https://www.cartagene.qc.ca/en/index.html>.

combination therapy for carriers of BRCA1 and BRCA2 mutations.⁴⁷ Hence, by making the information on certain genetic markers in patients available at the time of an eventual positive diagnosis, preemptive genetic testing allows for prompt, targeted treatments (as patients need not wait for molecular testing results).⁴⁸

On imaging, the evidence on the combined use of tomosynthesis and 2D radiography to enhance cancer detection and reduce false-positive results is mixed. Additionally, this imaging technique exposes individuals to at least as much radiation as mammography. For these reasons, INESSS does not recommend the systematic use of tomosynthesis for screening until clear evidence in favour of it emerges (INESSS, 2019). It is, however, useful in some specific contexts, in particular for patients who are young, high-risk or have dense breasts. Meanwhile, over a hundred clinics across the US, Canada and Argentina are engaged in the Tomosynthesis Mammographic Imaging Screening Trial (TMIST) since 2017, to assess the accuracy of 3D imaging in screening.⁴⁹ The use of tomosynthesis for screening purposes is relatively widespread in Alberta and on trial in Ontario, while in Quebec its use remains reserved for diagnosis only. Quebec should therefore monitor the results from the TMIST: should the use of both 2- and 3-dimensional imaging at screening improve efficiency, it could also yield shorter diagnosis delays.

Key points

- Ontario and Alberta have included women aged 70-74 in the breast cancer screening program since 2013;
 - based on the recommendation from the [Canadian Task Force on Preventive Health Care \(2011\)](#).
 - based on epidemiological observations.
 - These policy changes should be evaluated using currently available data.
- Although epidemiological observations suggest the benefits of tailoring prevention for younger higher breast cancer-risk individuals, Quebec does not designate higher-risk individuals.
 - Ontario and Alberta propose guidelines for younger higher-risk individuals. Quebec does not.
 - These guidelines are subject to debate and need evaluation.
- Advances in data science and personalized medicine create opportunities to tailor breast cancer prevention and design optimal screening recommendations.
 - In this regard, initiatives such as the PERSPECTIVE project should be closely monitored.
 - These personalized screening recommendations are not limited to age targets and screening frequency, but also involve adapting imaging techniques (for instance, complementing a mammogram with an MRI or a TMIST).

⁴⁷This type of therapy is especially appropriate for these patients. Mutations of the BRCA1 and BRCA2 genes cause the malfunction of the BRCA1 and BRCA2 proteins, which are involved in cells' DNA repair. This malfunction causes cells to rely on other repair mechanisms, including PARP enzymes. By hindering the repair mechanism related to PARP, PARP-inhibitors let gaps in the DNA accumulate. Since those cannot be repaired by the BRCA proteins, PARP-inhibitors thereby induce the death of cancer cells. See for example: [Lee et al. \(2014\)](#); [Rose et al. \(2020\)](#).

⁴⁸We thank Samia Qureshi, PhD(c) at the Department of Epidemiology, Biostatistics and Occupational Health, McGill University, for this comment.

⁴⁹Trial participants are recruited in 6 centres in Vancouver, London, Toronto, Ottawa, Quebec City and Montreal (CPAC, 2021). For more detail, see: National Institute of Health, National Cancer Institute. "TMIST: Study Comparing Digital Mammograms (2-D) with Tomosynthesis Mammograms (3-D)". Accessed on October 30, 2022. <https://www.cancer.gov/about-cancer/treatment/clinical-trials/nci-supported/tmist>.

3.2 Participation in screening: pilot studies and interventions in the spotlight

Since Canadian breast cancer screening programs have proven their effectiveness at reducing breast cancer mortality for thirty years (Fletcher et al., 1993), breast screening has become an integral part of women’s health care. Yet, **around 1 in 4 women within the screening target population in Quebec, Ontario and Alberta does not undergo regular screening.**⁵⁰

In light of this situation, the 2018 Breast Cancer Facebook Study was implemented in Ontario (CPAC, 2021). This pilot study consisted of circulating six ads on Facebook during a month, from January 25, 2018. These ads were targeted to female Facebook users aged 50-59 and living in Sudbury, Hamilton and Ottawa. The study involved unpersonalized and personalized ads. **Results indicate that personalized ads generated more user engagement than unpersonalized ads, revealing themselves as a relatively cheap option to potentially enhance participation in organized breast screening programs.** Targeting aggressively certain population groups with advertising should be more cost-effective at reaching participation objectives than untargeted advertising. However, while targeted ads are shown to generate more user engagement, the impacts of these ads on health behaviour remain unknown (CPAC, 2021). To what extent does exposure to targeted ads actually induce higher participation in screening programs, and which population groups are most affected?

This is particularly applicable since the lack of participation in screening programs is most prominent among well identified groups (i.e. from lower socio-economic status and from visible minority groups). Further, participation to breast cancer screening is subject to selection that is associated with breast cancer risk. Einav et al. (2020) show that women who follow screening recommendations are at lower breast cancer risk than those who do not participate in screening. This advantageous selection is also linked to other positive behaviour in terms of preventive care. On the other hand, individuals who choose to get screened whether recommended or not, tend to be at higher risk (adverse selection).

Another example, the 2019-2020 study “Assessing Cancer Screening and Outcomes among First Nations People in Alberta”, measured cancer screening participation, follow-up and outcomes for First Nations people in Alberta.⁵¹ **Studies like these which examine the behaviour of diverse population groups and identify opportunities for policy intervention, are indispensable.** In this instance, the study relies on linkages between the First Nations registry and several data sources. This strategy addresses the issue that most health administrative databases and provincial cancer registries do not include information on race or ethnicity (Ahmed et al., 2015) and highlights the **need to gather and use comprehensive data on the health of Canadians, including socio-demographic indicators.**

All Canadian provinces and territories, except Quebec, Yukon and Nunavut, have implemented communication campaigns to encourage participation among groups with low screening rates (CPAC, 2021). These groups include First Nations, Inuit and Metis peoples, immigrants, non-English or -French speakers, low-income populations, and visible minorities.

The history of coercion and abuse inflicted by the healthcare system towards Indigenous communities has broken their trust in this institution (Vogel, 2015). Enhancing breast cancer prevention is therefore dependent on repairing this trust. Distrust in the healthcare system is aggravated by the fact that Indigenous populations are at higher risk of victimization than non-Indigenous populations (Boyce, 2016; Maranzan et al., 2018): it feeds a general feeling of distrust and discourages them from participating in screening.⁵² **Reaching out to First Nations, Inuit and Metis peoples requires consequently adapting strategies by involving community leaders in the communication development process, including**

⁵⁰See: PQC (2019); Ontario Health (2021); CPAC (2018)

⁵¹As of October 24, 2022, the results of this study have not yet been published. For an update, see: Alberta Health Services, Cancer Epidemiology and Prevention Research. Assessing cancer screening participation and uptake among First Nations people of Alberta. <https://www.cepr.ca/multimedia-archive/assessing-cancer-screening-participation-and-uptake-among-first-nations-people-of-alberta/>

⁵²Testimonies gathered in British-Columbia by Maranzan et al. (2018) report victimization as one of the factors explaining the reluctance of Indigenous women to participate in screening for HPV and cervical cancer. It is reasonable to expect similar effects for breast cancer screening, as trauma has been observed to reduce participation in breast cancer screening in other populations (Farley et al., 2001).

individuals from different generations (Boyd et al., 2021). In this vein, Alberta and Ontario have held health workshops and fairs in Indigenous communities, in collaboration with key stakeholders (CPAC, 2021).⁵³ This type of intervention is also in line with the importance of oral storytelling in the Indigenous culture (Friedman and Hoffman-Goetz, 2007).

Further, effective communication should respect and understand the Indigenous belief systems and cultures. The qualitative study led by Hoffman-Goetz and Friedman (2007) in Ontario highlights that incorporating cultural diversity in communication enhances its credibility. It is all the more important since Indigenous beliefs on some issues are very different from the Western belief system⁵⁴ and may vary from one Native culture to the other (Boyd et al., 2021). Other initiatives led by the two provinces include organizing seminars for FPs. These seminars equip FPs with an understanding of screening behaviours among Indigenous peoples, as well as applied knowledge aimed at encouraging participation in provincial programs. Alberta has also shared resources with health professionals to help them discuss screening with their patients. At a more granular level, Ontario has coordinated individual training for FPs (CPAC, 2021). Ontario has also implemented targeted communication through social media and advertisements in smaller media adapted to Indigenous cultures. Friedman and Hoffman-Goetz (2007) provide evidence that Aboriginal women understand the material adapted to their culture better than the material designed for the general public. Yet, this work remains descriptive and relies on a small sample size. Although we recognize the challenges of conducting larger studies or trials on Indigenous populations, such studies would help assess the impact of personalized communication on screening participation.

More generally, both culturally and linguistically adapting communication to visible minorities has the potential to increase screening mammography, as demonstrated by the qualitative study led in New York City by Fung et al. (2021). In this line, Ontario’s communication cancer awareness campaigns in October made sure to represent visible minorities. Further, mobile screening units reached out to populations in rural, remote or under-served areas. Other measures include translating information pamphlets and making them understandable to non-English speakers. More comprehensively, Alberta has proposed to analyze the socio-demographic barriers to cancer screening through the ongoing project Creating Health Equity in Cancer Screening (CHECS). It is organized in three stages. After identifying target communities characterized by low participation in screening, local stakeholders were consulted to better understand the factors hindering or easing screening. The next phase will consist of implementing and evaluating policies built in collaboration with local decision makers.

Key points

Various strategies have been implemented outside Quebec to enhance participation in organized screening.

- The Breast Cancer Facebook Study in Ontario shows that targeted ads on social media generate more user engagement than general ads. But the report does not mention whether or not exposure to these ads increases participation to organized screening.
- Socially marginalized groups tend to participate less in organized screening. Understanding their behaviour and beliefs towards cancer prevention is important to design policies enhancing their engagement.
 - Indigenous populations are sensitive to how information on breast cancer prevention is conveyed.
 - Yet, to our knowledge there is no evidence on how effective culturally adapted communications methods are in terms of increasing participation in screening.

⁵³To our knowledge, Quebec has not implemented any analogous strategy yet.

⁵⁴For instance, in the US, Sanderson et al. (2010) underline that in the Navajo culture, one would avoid conversing about negative health topics in the first person, as it may bring illness upon oneself.

- Ontario and Alberta have adapted their communication campaigns to reach out to other populations. The effects have not been evaluated yet.

3.3 Access to diagnosis: efficient and integrated pathways

Further along the diagnostic pathway, **Quebec’s processes following an abnormal mammogram result unnecessarily burden patients and delay diagnosis.** Alberta and Ontario communicate such results by phone to the patient and/or their FP.⁵⁵ **Quebec communicates by mail, despite evidence of mail communication hindering timely follow-up.** Schapira et al. (2018) gather 4 years of patient data in 28 breast imaging facilities in the US and analyze how communication practices influence the timely follow-up after an abnormal mammogram. They show that patients contacted by mail were half as likely to have a timely follow-up on their result, compared to patients contacted directly by phone or through their FP.⁵⁶ Mail communication also leaves women on their own, with no possibility of conferring with health care professionals while receiving this news. This is why verbal communication of abnormal results – whether in person or by phone – is preferred by patients (Marcus et al., 2012) and why it is associated with higher likelihood of follow-up (Poon et al., 2004).

Once (abnormal) results are communicated, participants in Quebec are invited to communicate with their FP or the diagnostic centre where they were screened to organize a follow-up appointment. While patients have a responsibility to be proactive about their health, the anxiety of receiving a cancer diagnosis may discourage them from booking quickly. **Ontario and Alberta implement more proactive practices.** In Ontario, the follow-up appointment is coordinated either by the screening centre or the FP. In Alberta, the clinic or the FP communicates with the participant to organize the follow-up. Some centres directly organize follow-ups. These practices avoid delays caused by patient anxiety-related procrastination. They also result in more coordinated communication and service, enhancing continuity of care and thereby helping to empower patients (CPAC, 2020).

The difficulty for Quebecers to access family medicine also makes taking such steps difficult.⁵⁷ For this reason, efforts to ease and clarify the access to breast cancer investigation to patients in Quebec have included assigning screening participants who do not have a FP and receive an abnormal result to a volunteer doctor from the PQDCS program.⁵⁸ This measure is expected to favour access to care and patient support. However, the extent to which it is efficient at doing so is unclear, since it does not seem to have been evaluated (Sahay, 2022).

Other solutions to alleviate part of the burden caused by the gap in primary care include implementing a distributive care model. This model enables clinical practitioners and allied health professionals to adopt some of the family physicians’ responsibilities preceding cancer diagnosis.⁵⁹ Specialists can focus on tasks specific to their training while other providers communicate with patients and fulfill more general tasks surrounding diagnosis. In British Columbia, nurse practitioners receive special training in cancer care delivery, enabling them to order diagnostic tests, diagnose cancer, and screen for cancer recurrence with oncologists available for consults.⁶⁰ Similar efforts have also seen success in Alberta and Ontario.

⁵⁵In addition to mailing the results to the patient.

⁵⁶One should note, however, that two aspects of the study design in Schapira et al. (2018) threaten the external validity of their results. Out of the 31 facilities invited to participate the survey, only 28 actually did. While these represent 90%, we might be concerned with sample selection, as better performing units might be more inclined to complete the survey. More importantly, the facilities included in the survey are located on the East Coast, in areas relatively affluent economically and close to urban centres – if not in major urban centres. In addition to having more resources than rural areas, urban and suburban centres might generally serve a population that has better access to quality public services, including postal services. Hence, the results of Schapira et al. (2018) could underestimate the inefficiencies of mail communication in rural and under-served areas.

⁵⁷A 2022 survey of the professional order of Quebec physicians revealed that 94% of them think it is difficult for patients to obtain a medical appointment on evenings or weekends. See: Archambault, Héloïse. 2022. “L’accès aux soins de santé critiqué par les médecins du Québec”. *Le Journal de Montréal*. May 2. <https://www.journaldemontreal.com/2022/05/02/laces-a-ux-soins-critique-par-les-medecins>.

⁵⁸PQDCS- Région de la Capitale-Nationale. *Volunteer doctors and IPS*. Accessed on October 30, 2022. <http://www.depistagesein.ca/medecins-et-ips-volontaires-intervenants/#.Y2LUMHaZ05d>.

⁵⁹CPAC. “Models of Care Toolkit”. Retrieved online on December 13, 2022. <https://www.partnershipagainstcancer.ca/to-pics/models-of-care/optimizing-scope-practice/distributed-care/>

⁶⁰BC Cancer. “Primary Care Nurse Practitioners”. Provincial Health Services Authority. Retrieved online on December 13, 2022. <http://www.bccancer.bc.ca/our-services/services/primary-care>

For patients both within and outside the PQDCS, Montreal has set up health service dispatch centres (*Centres de Répartition des Demandes de Service*, hereafter CRDS), which provide patients with appointments for specialist consults following the recommendation of a FP. Patients without a FP may book an appointment with a FP to obtain such a recommendation.⁶¹ **Such centres are intended to help patients navigate the healthcare system.**⁶² This purpose is shared by units specializing in breast cancer diagnosis, such as Marion C. Soloway Breast Rapid Diagnostic Unit (RDU) at Sunnybrook Health Sciences Centre, Ontario.⁶³ Racz et al. (2016), using before and after comparison, show that the average wait time between consultation and diagnosis decreased from 16.7 to 2.2 days after this RDU was implemented.⁶⁴ In Ontario, the Hotel Dieu Hospital and the Kingston General Hospital set up the Breast Assessment Program (BAP).⁶⁵ This extension of a breast RDU acts as one single point of access to diagnostic imaging and to a comprehensive list of related services, and shortens diagnosis delays (Jiang et al., 2018a). Across the province, Breast Assessment Centres (BACs) set up by the Ontario Breast Screening Program follow the same principle. Chiarelli et al. (2017) show that patients assessed through a BAC were twice more likely to obtain a diagnosis within 7 weeks than patients assessed through usual care. Quan et al. (2012) indicate that in addition to timely diagnosis, other BACs performed better than usual care on other quality indicators (e.g. appropriateness of follow-up and biopsy indicators). **By integrating care, this initiative favours timely breast cancer diagnosis.**⁶⁶

Practice standardization is another innovation that often accompanies integrated care initiatives. At a larger scale, Ontario (Cancer Care Ontario, 2021b) and Alberta (Bond et al., 2019) have set screening and diagnosis pathway maps, which rely on scientific consensus to standardize prevention and care practices, and provide a clear framework to support clinical decisions. In addition, Alberta has implemented a specific pathway for patients presenting BI-RADS 5 lesions.⁶⁷ Before-after evaluation of this program demonstrated it has substantially decreased time to diagnosis for the patients it targeted (Laws et al., 2019).

In continuity with these measures, Quebec’s Ministry of Health and Social Services announced on June 3, 2022 the launch of a 11.2 million-dollar project coordinating investigative pathways in cancer care.⁶⁸ This project extends existing efforts by the provincial government to improve access to cancer care, regularly monitor diagnosis delays in imaging centres (MSSS, 2010, 2022), standardize practices, and build data-sharing networks through information systems (INSPQ, 2022). Dedicated access points (“*guichets d’investigation*”) will be created in each of the 28 government-affiliated cancer care centres. From referral to diagnosis, clinical algorithms will assist health professionals in monitoring and organizing care. Teams in access points should ensure that investigative processes are properly coordinated and patients adequately supported. **The goal of this initiative is to provide participants with an integrated and standardized pathway to diagnosis, in line with the established consensus that such practices can enhance diagnostic efficiency.**⁶⁹ The government and stakeholders expect this innovation to reduce delays in diagnosis, enhance

⁶¹Gouvernement du Québec, Santé Montréal. “Médecin spécialiste : Centre de répartition des demandes de services (CRDS)”. <https://santemontreal.qc.ca/population/services/medecin-specialiste-centre-de-repartition-des-demandes-de-services-crds/> Retrieved online on October 27, 2022.

⁶²See: FQC. 2022. “New access windows for cancer to optimize access to screening: a step forward for patients”. June 3. <https://fqc.qc.ca/en/news/guichets-pour-optimiser-l-acces-a-l-investigation-du-cancer-une-avancee-pour-les-patients>.

⁶³Sunnybrook Health Sciences Centre, Breast Cancer. *Marion C. Soloway Breast Rapid Diagnostic Unit (RDU)*. Retrieved online on October 27, 2022. <https://sunnybrook.ca/content/?page=occ-breast-rapid-diagnostic-unit-rdu>.

⁶⁴Although this analysis does not account for other potential variation that might decrease wait times and has limited external validity, it provides an example of a successful RDU implementation.

⁶⁵Kingston Health Sciences Centre. “Breast Assessment Program”. Retrieved online on October 27, 2022. <https://kingstonhsc.ca/cancer-care/types-care/breast-assessment-program>.

⁶⁶The effects of integrated care extend to treatment. Blackmore et al. (2019) highlight that patients assessed through BAC experienced shorter times to treatment after diagnosis.

⁶⁷BI-RADS 5 lesions are defined according to the Breast Imaging Atlas and present the typical imaging features of breast malignancy (see for example d’Orsi et al., 2018).

⁶⁸Gouvernement du Québec, Cabinet du Ministre de la Santé et des Services Sociaux. “Cancérologie - Des guichets mis en place partout au Québec pour optimiser l’accès à l’investigation”. Accessed on October 30, 2022. <https://www.newswire.ca/fr/news-releases/cancerologie-des-guichets-mis-en-place-partout-au-quebec-pour-optimiser-l-acces-a-l-investigation-874817260.html>.

⁶⁹See Brouwers et al. (2009) or a review of randomized controlled trials, case-control studies, and prospective or retrospective cohort studies supporting this claim.

the accuracy of prescribed tests, favour continuity of care, and improve access to cancer screening exams and subsequent follow-up. While access points related to lung cancer have come to light in summer 2023, access points to enhance breast cancer diagnosis are expected in fall 2023.⁷⁰ Evaluations will be necessary to measure whether those expected results are achieved.

While this initiative does not focus on breast cancer in particular – it includes all types of cancer – **one could naturally anticipate beneficial effects on breast cancer diagnosis pathways.** Jiang et al. (2018a) show that Ontario’s Diagnostic Assessment Units (DAU) are linked to shorter times to diagnosis among patients with symptomatic breast cancer. Webber et al. (2020) find similar results among asymptomatic patients within the provincial organized screening program. Both of these evaluations rely on linkages between administrative and patient-level data. Jiang et al. (2018a) further complement these data with Ontario’s Registered Persons Database, which contains individual demographic information.

In addition to providing evidence on the efficiency of standardized and integrated pathways, Webber et al. (2020) also illustrates that **combining health and program assessment data with geographic and socio-demographic data is indispensable to properly evaluate initiatives.** Indeed, symptomatic patients assessed at a breast assessment site tend to originate from wealthier areas, compared to patients receiving usual care. This selection – of populations from better socio-economic backgrounds into expectedly more efficient care – hinders the proper policy evaluation of breast assessment sites. Evaluating the effect of DAUs on wait times would ideally require an experimental setting where some health centres would be randomly assigned with DAUs, which is not feasible. Since outcomes and patterns in usual care are also better for higher SES individuals (see for example Kumachev et al., 2016), **the effects of programs such as diagnostic assessment units are likely to be overestimated.** To limit this bias, one should account for patients’ geographic and socio-demographic characteristics.

Key points

- Communicating results directly to the patient by phone encourages timely follow-up upon abnormal mammogram results.
- Including FPs in breast cancer prevention and follow-up provides patients with a direct interlocutor who can coordinate with specialist services.
 - Such practices are implemented in Ontario and Alberta.
 - Because a large portion of Quebecers do not have a FP, the PQDCS has implemented a volunteer doctor program.
 - This program has not yet been evaluated.
- Initiatives standardizing and integrating care, such as DAUs and RDUs favour timely diagnosis.
 - Supporting evidence (e.g. Jiang et al., 2018a) is however subject to selection bias and might overestimate the effects of such programs.
 - Evidence on RDUs is weak, yet encouraging.
 - Quebec’s ongoing implementation of access points dedicated to cancer diagnosis should be noted as a step in the right direction and should be empirically evaluated later.

⁷⁰See: Centre intégré universitaire de santé et de services sociaux de la Mauricie-et-du-Centre-du-Québec. 2023. “Guichet d’investigation en cancérologie (GIC)”. <https://ciusssmq.ca/soins-et-services/soins-et-services-offerts/passer-un-examen-recevoir-un-traitement-etre-suivi/guichet-d-investigation-en-cancerologie-gic/>. Retrieved online on August 14, 2023.

3.4 Learning from data: towards better and more equal care

As underlined in section 2.2, gathering and analyzing detailed data is essential to evaluate pilot projects and policies. Yet, **information technology can and should be further used to inform clinicians’ decisions** through networks and information systems, and to facilitate research. In particular, telepathology networks enable the remote sharing of pathological data among pathologists and medical professionals for consultation and diagnosis, improving access to expertise and expediting patient care. Telepathology networks involve digitizing specimens, transmitting images over a secure network, and allowing remote experts to collaboratively analyze and diagnose cases. They are particularly suitable in Quebec, and Canada in general, whose geography is characterized by many low population density areas. **Telepathology networks have connected remote communities to pathologists located hundreds of kilometres away in the main metropolitan areas, improving the quality of care and reducing diagnosis delays** (see Têtu et al., 2012, for a qualitative analysis of the Eastern Quebec pathology network).

In Quebec, the OPTILAB initiative gathers 12 laboratory and service clusters which have combined their resources and organization to optimize medical biological services.⁷¹ This 2017 pan-Quebec initiative actually results from the merger and restructuring of the telepathology networks previously set by four of the main universities⁷² across the province.⁷³ OPTILAB has created a telepathology network able to inform the clinical decisions of its members but also to support those of “several healthcare establishments, ranging from large academic health centres to smaller rural ones”, according to Dr. Andre Dascal, chief of clinical laboratory medicine at the McGill University Health Centre (MUHC) and medical director of OPTILAB Montreal-MUHC.⁷⁴

The Multi-Jurisdictional Telepathology Solution is a pan-Canadian version of the networks described above (Canada Health Infoway, 2020). It was first implemented in Manitoba, Newfoundland and Labrador, and Ontario. In the long run, it aims to scale and extend this solution to the other Canadian provinces.

Integrated pathways, because they involve different kinds of professionals and standardize care, are particularly suitable to implement data networks. In this context, Ontario’s Diagnostic Assessment Program has included an Electronic Pathway Solution (DAP-EPS). This initiative takes the form of an online portal for patients and their care providers, through which the data related to the patient’s case is stored. This online portal provides patients with tailored information and clinicians with patient care and workflow management decision support tools, which are based on validated clinical diagnostic pathways. The DAP-EPS also collects data, which is used to monitor and evaluate DAP processes. The electronic initiative seems to have completed its objective to optimize patient experience and support the work of DAP staff and providers. According to the related evaluation report from Canada Infoway: *“[t]he combined results paint a picture of a new application that holds tremendous value for its users and offers significant benefit to patients within the DAP and the individuals who manage their care.”* (Cancer Care Ontario, 2014) .

Further, standardized care also calls for **standardized reporting** of pathology cases, which is the aim of synoptic reporting. Synoptic Pathological Reporting (SPR)⁷⁵ consists in reporting specific pathology data elements in a determined and standardized format in surgical pathology reports. This replaces reports in free text, which tend to be narrative, omit necessary data and lack consistency in their format. **SPR ensures reports do not omit important data and can be used and scaled for pathologists to exchange information, as well as for research** (Renshaw et al., 2018). This is the purpose of Cancer Care Ontario’s Electronic SPR.

⁷¹MSSS. “OPTILAB”. Retrieved online on October 27, 2022. <https://www.msss.gouv.qc.ca/professionnels/soins-et-services/optilab/presentation-de-la-demarche-optilab/>.

⁷²Université de Montréal, McGill University, Université Laval and Université Sherbrooke.

⁷³These initiatives are similar to the University Health Network in Toronto (UHN). The UHN consists of a collaboration between the Toronto General and Toronto Western hospitals, the Princess Margaret Cancer Centre, Toronto Rehabilitation Institute, and The Michener Institute of Education at UHN. The network “uses telepathology to provide diagnostic services (predominantly primary frozen section interpretation) within their sites in Toronto as well as to colleagues in Kingston and communities in Northern Ontario” (Bernard et al., 2014).

⁷⁴MUHC. 2020. “MUHC OPTILAB receives prestigious triple ISO certification — A first in Quebec”. September 8. *MUHC News (online)*. <https://muhc.ca/news-and-patient-stories/news/muhc-optilab-receives-prestigious-triple-iso-certification-first>.

⁷⁵For a definition and examples, see: American College of Pathologists (2018).

Finally, the systematic collection and processing of clinical data has the ability to **help forecast hospitals’ budgets and to inform policy makers on the costs related to the healthcare system**. In this regard, Université de Montréal’s hospital centre (CHUM) has invested in automating clinical data collection and, more importantly, its processing. Creating a database in which information on patient care is clustered into treatment episodes enables such information to be directly exploited for research and analysis purposes. Otherwise, these data are too granular to be tractable.⁷⁶ Ultimately, this initiative will serve to evaluate and forecast the costs of multiple healthcare pathways. While university hospitals have the resources to lead such projects, this is not the case for smaller health providers in remote areas. Yet, generalizing this type of initiative province-wide would benefit patients seen by these smaller providers all the more since they might be subject to tighter budgets.

Key points

- Telepathology networks enable physicians in remote areas to have access to clinical expertise available in urban hospitals.
 - In this line, OPTILAB builds on the Quebec Eastern pathology network.
 - Although encouraging, the scientific evidence evaluating Quebec’s OPTILAB is qualitative and scarce.
 - Similarly, the pan-Canadian Multi-Jurisdictional Telepathology Solution remains to be quantitatively evaluated.
- Telepathology networks are particularly suitable in standardized care programs, as they involve clinical data being uniformly reported.
- The benefits of systematic data collection extend to other purposes such as forecasting health care costs.

4 Discussion

Quebec performs well along several segments of the breast cancer diagnosis pathway. For instance, it has the ability to continuously evaluate the performance of its breast cancer screening program using in-depth data from the SI-PQDCS. This data is put to practical use in annual INSPQ reports (such as [PQDCS, 2022, 2021](#)), updated dashboards,⁷⁷ as well as studies led by independent researchers (such as [Perron et al., 2019](#)). Additionally, Quebec makes efforts to reform its breast cancer diagnosis pathway by supporting innovative programs such as OPTILAB, CRDs, and the Primary Care Provider Support program.

This report attempts to provide a broad understanding of Quebec’s pre-breast cancer diagnosis performance. However, the absence of an available and updated cancer registry hinders anyone’s ability to paint a full portrait of the situation. Although administrative and screening program data may be combined to paint a partial picture, the absence of key information such as stage at diagnosis limits the research and evaluations that are necessary to evaluate and improve current and upcoming policies (see pp 53 [CPAC, 2017](#)). Additionally, since it is the only province that has not contributed to the CCR since 2010, Quebec’s breast cancer data is not standardized ([Statistics Canada, 2022a](#)). This means it cannot be reliably compared to the rest of Canada and is excluded from nation-wide analysis ([‘Canadian Cancer Statistics 2021’ report](#)).

Notwithstanding, comparing Quebec to the two Canadian provinces with the shortest delays, Alberta and Ontario, reveals various areas for improvement along Quebec’s breast cancer diagnosis pathway. For instance, Quebec does not designate higher-risk individuals. It is also the only province without programs to encourage screening program participation among populations with low screening rates ([CPAC, 2021](#)). Since

⁷⁶We thank Michèle Bally for this comment.

⁷⁷See for example: INSPQ. *Délai d’obtention des rendez-vous (online)*. Accessed on December 6, 2022. <https://www.inspq.qc.ca/sites/default/files/pqdc-sondages/delais.html>.

screening adherence is unequal across demographics and regions in Quebec, the PQDCS should reevaluate its practices in this respect. Patients outside of the PQDCS face even more obstacles before diagnosis and often do not know where to turn upon experiencing breast cancer symptoms.

Access to timely care is further worsened by the difficulty many Quebecers face in accessing a FP, which creates gaps in care. While one should acknowledge that the lack of FP is not easily solved, Quebec can rectify some of the confusion and delays along symptomatic patients' journey to diagnosis by employing a distributive care model. This would allow more health care providers to participate in integrated care. Helping patients understand the diagnosis pathways is an essential element of quality care that physicians often do not have time for.⁷⁸ Although over a third of patients with an abnormal mammogram result did not receive the follow-up care they needed, patients are more likely to receive the appropriate care after an abnormal screen when a follow-up plan was documented by the physician in the patient's medical record (Poon et al., 2004). The importance of clear communication can also be seen in a behavioural intervention for those at high risk of lung cancer called the 'CHEST Australia Trial' (see Emery et al., 2019, for an evaluation). This intervention included a self-help manual and monthly reminders to monitor symptoms through each patient's desired medium (including texts, phone calls, and fridge magnets). Receiving the CHEST trial was associated with significantly more consultations about respiratory symptoms. Evidently, patients will seek out the care they need if are guided along their journey.

The efficiency of the distributive care model also permits nurses and other providers to triage patients based on clinical characteristics. An example of this is the *Alerta Rose* program in Mexico, which divided women who sought breast cancer screening into three groups and prioritized women with suspicious symptoms. This program was found to accurately predict a patient's likelihood of receiving a cancer diagnosis and decreased the diagnosis interval for the most susceptible patients (Tamez-Salazar et al., 2020). Triageing could reduce delays and stage at diagnosis in Quebec by providing the fastest care to the patients most likely to have breast cancer.

While triaging is an efficient way to distribute care among symptomatic patients outside the PQDCS, patients within organized programs consistently receive faster diagnosis (Habbous et al., 2022). Therefore, the PQDCS should aim to include those most likely to have breast cancer so that diagnosis and treatment happen as quickly as possible, ideally even prior to developing symptoms. Defining a screen-eligible population involves setting a capacity for the screening program, which depends on the volume of the population screened. This maintains swift access to care in the program and a cancer care system that is not overwhelmed. Even in the theoretical event of unlimited resources, increasing the screening program capacity can lead to an increased number of false positives. The subsequent unnecessary follow-up testing can cause harmful physical and psychological consequences (CPAC, 2020). Even three years after confirming they do not have cancer, women who received a false positive mammogram result had worse psycho-social experiences than women who received a normal result. Some of these negative effects include anxiety, worry about breast cancer, as well as negative impacts on their sleep, sexuality, and social network (Brodersen and Siersma, 2013).

To cover those most likely to have breast cancer in the PQDCS without over-screening, it is essential to target high risk individuals using objective criteria. Population-based testing for genetic risk of developing breast cancer is one potentially cost-effective and equitable way to achieve this. Since the infrastructure to accomplish this will take time to develop, groups proven to be at higher risk, like people of Ashkenazi Jewish heritage and relatives of people with breast cancer, could be tested for hereditary cancer syndrome in the meantime (Tindale et al., 2022). Further efficiency and accuracy of the program would be gained from tailoring the frequency of screening and the imaging method used for high-risk patients, based on their genetic and demographic profile. In this line, the results from the PERSPECTIVE research project, which builds personalized breast cancer screening recommendations, should be closely monitored.⁷⁹

Beyond establishing high-risk inclusion criteria and personalized screening recommendations, optimizing the breast cancer diagnosis pathway requires improving participation in the PQDCS. This is an especially

⁷⁸This type of model appears all the more important in the context of labor shortage in healthcare, as it provides an opportunity to optimize the roles held by the different health practitioners.

⁷⁹Bartha Maria Knoppers and Jacques Simard. "Personalized risk stratification for the prevention and early detection of breast cancer". Genome Québec Inc. Retrieved online on December 13, 2022.<https://www.genomequebec.com/158-en/project/personalized-risk-stratification-for-the-prevention-and-early-detection-of-breast-cancer/>

important goal since adherence is lower among marginalized groups (Kumachev et al., 2016), and patients who do not participate in the screening programs are more likely to have breast cancer than those who do (Einav et al., 2020). The method and tone of communication between patients and health care providers during the diagnosis pathway can impact screening rates. For instance, Bertoni et al. (2020) set up a trial in Italy whose results show that breast cancer screening program invitation letters focusing on the potential negative consequences of not getting screened were associated with increased participation.

Wrapping up, to improve breast cancer diagnosis and care, Quebec has the ability to implement innovative policies at every stage of the diagnosis pathway: from the optimal recruitment of screening program participants to improving access to diagnostic services. While other jurisdictions such as Ontario and Alberta have led several innovations in breast cancer screening and diagnosis in the past decade, pilot projects in Quebec such as OPTILAB and PERSPECTIVE demonstrate the dynamism of the health scientific community in the province and its ability to be innovative. To properly evaluate these policies and monitor the health of its population, the province must systematically collect data on patients and care in a uniform way. This includes a functioning cancer registry and scaling up practices already set up locally, including by university hospitals such as the MUHC and the CHUM.

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Appendix

Table A1: Provincial organized screening program: a comparison between Quebec, Ontario and Alberta

	QUEBEC	ONTARIO	ALBERTA
Target population	Women aged 50-69, every other year	Women aged 50-74, every other year	Women aged 45-74, every other year
Access to screening for off-target population	<ul style="list-style-type: none"> from age 35 upon medical recommendation no specified frequency 	<ul style="list-style-type: none"> from age 30 upon medical recommendation or higher risk yearly 	<ul style="list-style-type: none"> from age 40 upon medical recommendation yearly
Screening infrastructures	<ul style="list-style-type: none"> private clinic community clinic screening clinic hospital mobile unit 	<ul style="list-style-type: none"> independent health clinic hospital mobile bus 	<ul style="list-style-type: none"> community clinic (private) hospital mobile unit
Types of digital mammograms	digital and assisted by computer	digital only	digital only
Use of tomosynthesis	for diagnosis only	on trial: in addition to 2D screening, on a voluntary basis	widespread use: systematic in some centres, otherwise in case of high-density breast
Use of MRI	no	high-risk individuals	high-risk individuals
Use of ultrasound	no	high-risk individuals for whom MRI is not appropriate	some centres use ultrasound as a further exam, in case of high-density breast or if the individual cannot undergo an MRI
Procedure after a normal mammogram result	<ul style="list-style-type: none"> normal result is mailed to the participant reminder for next screening test is mailed too 		
PROCEDURE AFTER AN ABNORMAL MAMMOGRAM RESULT			
Communication	by mail to the participant	depending on the centre: either by mail or phone to the participant, or through their family physician FP	mostly by phone to the participant and/or their FP, by mail in addition

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Table A1 – *Continued from previous page*

	QUEBEC	ONTARIO	ALBERTA
Follow-up	<ul style="list-style-type: none"> • participants invited to communicate with their centre or FP for a follow-up appointment or • some centres communicate proactively with the participant 	appointment coordinated either by the screening centre or the FP	<ul style="list-style-type: none"> • clinic or FP communicates with participant to organize follow-up or • some centres directly organize follow-ups
Designation of a FP for follow-up	a voluntary doctor from the program is in charge of the follow-up for participants who do not have a FP	FP designated by the centre if the participant does not have a FP	<ul style="list-style-type: none"> • normally already done at the first mammogram • otherwise centres help the participant to find a FP when organizing follow-up
Infrastructure for diagnostic mammogram	designated investigation centres	diagnostic imaging centres within or outside of the program	<ul style="list-style-type: none"> • same as screening centre if habilitated • community clinic • hospital
HIGHER RISK INDIVIDUALS			
Definition of breast cancer increased risk	N/A	<ul style="list-style-type: none"> • family history: <ul style="list-style-type: none"> → first degree male parent → two first degree family members → one first degree family member aged below 50 at diagnosis • breast density at least 75% • recommendation from the radiologist • personal or first degree family history of ovary cancer • documented pathology of high-risk lesion 	<ul style="list-style-type: none"> • first degree family history • breast density at least 75% • history of high-risk benign breast illnesses • recommendation from the radiologist
Prevention and care	N/A	yearly mammogram age 50-74 <i>within the organized screening program</i>	FP

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Table A1 – *Continued from previous page*

	QUEBEC	ONTARIO	ALBERTA
Breast density guideline	<ul style="list-style-type: none"> • measured • communicated to FP 	<ul style="list-style-type: none"> • measured • participants informed • participants invited to yearly screening 	<ul style="list-style-type: none"> • measured • participants can obtain information through FP • guideline in development
Definition of breast cancer high risk	N/A	<ul style="list-style-type: none"> • carrier of deleterious genetic mutation • or first degree related to a carrier • estimated 25% lifetime breast cancer risk • radiotherapy at age 8-30 • age 30-74 • no acute breast symptom 	<ul style="list-style-type: none"> • carrier of deleterious genetic mutation • or first degree related to a carrier • estimated 25% lifetime breast cancer risk • radiotherapy at age 8-30 • Ashkenazi ascend • breast hyperplasia (ADH, ALH) • lobular carcinoma <i>in situ</i>
Prevention and care	N/A	<ul style="list-style-type: none"> • high-risk section <i>within the organized screening program</i> • yearly mammogram + MRI from age 30 	<ul style="list-style-type: none"> • FP or specialized clinic • yearly mammogram + MRI from age 25 to age 40

Table A2: Recent innovations in Quebec

	Access to care and patient support within the organized screening program	outside the organized screening program	Standardized and integrated care pathways	Data sharing networks	Evaluation
Primary Care Provider Support program	✓				No
OPTILAB Montreal-CUSM telepathology network			✓		Limited and qualitative
Centre de répartition des demandes de service (CRDS) montréalais		✓	✓		No (recent initiative)

Table A3: Recent innovations in Ontario

	Access to care and patient support		Standardized and integrated care pathways	Data sharing networks	Evaluation
	within the organized screening program	outside the organized screening program			
University Health Network in Toronto				✓	Limited and qualitative
DAP-EPS			✓	✓	Qualitative
Electronic Synoptic Pathology Reporting			✓	✓	Qualitative
Kingston Cancer Centre Breast Assessment Program	✓	✓	✓		Quantitative, subject to selection bias
Rapid Diagnostic Units at Sunnybrook Health Sciences Centre in Toronto		✓			Quantitative, subject to selection bias
Breast Assessment Centers	✓	✓	✓		Quantitative, subject to selection bias

Table A4: Recent innovations in Alberta

	Access to care and patient support within the organized screening program	outside the organized screening program	Standardized and integrated care pathways	Data sharing networks	Evaluation
BI-RADS 5 Pathway			✓	✓	Quantitative, before-after (not causal)