Quebec Cancer Coalition

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Policy Brief submitted to the Quebec Ministry of Health & Social Services Consultation on the Management of Quebecers' Health Data

# *Let's not miss this opportunity to create value and improve the health of Quebecers with quality data*

## Introduction

The Quebec Cancer Coalition / Coalition priorité cancer au Québec (CPCQ) was created in 2001 to give a strong voice to people affected by cancer. Wishing to improve the health care and services system for the benefit of people affected by cancer, the Coalition is composed of more than 65 non-profit organizations representing all faces of cancer and coming from all regions of Quebec. On their behalf, the Coalition defends the rights and interests of patients and caregivers. For 20 years, its members have shared the vision of a Quebec that is mobilizing against the scourge of cancer, and that succeeds in improving the health of the population through a care system focused on the needs of patients, survivors and caregivers.

Since 2010, the Coalition has been deploring the lack of health data and the potential impact of this myopia of the system on the effectiveness of the fight against cancer. The Quebec Cancer Registry, which is more than eight years behind schedule, is a flagrant (and embarrassing) illustration of the difficulties we have in documenting the threat posed by cancer, Quebecers' public enemy $^{No.}$ 1. In our country, it is still impossible to have reliable and up-to-date data on the frequency and mortality of the various forms of cancer, as well as any other information necessary for the long-term evaluation of the performance of our public policies in cancer. This information is clearly crucial to better care for patients, better support for caregivers, better allocation of human and financial resources, and better support for research. Quebec is the only place in Canada that does not have up-to-date data on cancer cases.

Recent events have demonstrated the importance of data. If Quebec was able to take control of the COVID-19 pandemic, it was thanks to complete, reliable data and regular updates of statistics. They have informed the decision-making of government officials, guided research with relevance, and informed the public with accuracy.

A recent report published by All.Can International highlights the strategic importance of data in oncology to improve population health, including the opportunities to be seized and the pitfalls to be avoided[1]. In value-based healthcare - where value is determined by improving health at the lowest cost across the care pathway - it is essential to promote a culture of measurement and efficiency. In the absence of quality data, any measure of health system performance is at best an estimate.

Quebec must take the lead in collecting health data while providing a safe framework for their use, as is done elsewhere in Canada and the world. This will also make things easier in terms of research, which is essential for developing new care and service options in oncology. This shift is necessary to improve the health of our population and is essential in our fight against cancer.

The Quebec Cancer Priority Coalition thanks the Ministry of Health and Social Services and the expert table for the consideration given to its comments.

## 1. The data belongs to the patients

The first fundamental principle: **patients' health data belong to the patients.** Patients must be able to access *their own* data in a user-friendly way; to know what use is made of their digital health data (e.g., which health/social services professional has consulted their file, or which research project is using their data); and to be able to simply decide what access they do or do not have to their identifying data.

The current 30-day delay in accessing one's data on the Health Record is often decried and considered unacceptable by patient organizations and their beneficiaries. Elsewhere in Canada, as well as in other countries, these results are accessible to patients at the same time as their doctor. In Quebec, patients have to wait in uncertainty, if not anxiety, for the next appointment with their doctor to obtain their results. Furthermore, if the results were known in advance, Quebec patients could prepare for their meeting with their doctor, by writing down questions for example, and be better informed.

The principle that data belong to patients also implies that **patients have the right** to information, consent, access, mobility and correction and de-identification of their data. They also have the right to benefit from their personal health data and to object to the use of their personal health data not related to the care they receive. They have the right to privacy and security. They have the right to be forgotten

[1] Harnessing data for better cancer care: a policy report. 2021 All.Can International. www./allcan.org/what-we-do/research/datapaper-project/

and they must be able to participate in decision-making about their personal data to ensure that their views, perspectives and values are taken into account[2].

## 2. Mobility of Patient Data

Another key principle is that **the data must follow the patient**. It must therefore be mobile. Relevant information must be accessible both when the person is in hospital and when he or she uses other services in the health and social services network (e.g., in FMGs, physiotherapy or at the pharmacy). In addition, relevant data in other government agencies (e.g., CNESSST, SAAQ, Civil Registry) should also be able to track the patient. It should be noted that several groups, including the Canadian Medical Association, have expressed concerns about how to determine which professional should be able to access the data. [3]

Data mobility implies the adoption of a unique identifier for each citizen. In the meantime, the health insurance card number should be able to meet the needs in most cases. A single patient record for the patient, as well as for all authorized health and social services clinical staff, would allow for better follow-up and coordination of care and services. A single number would reduce the risk of medical errors, which are currently all too common, as well as the financial and quality of life losses that result from them.

Despite the different sources, thanks to cloud platforms, data mobility is now facilitated. They allow interoperability between different systems, while protecting identifying data that would remain in their original database.

The mobility of inter-institutional and inter-professional patient data will open up new opportunities for the Ministry of Health and Social Services and its institutions, such as the INESSS. For example, in oncology, sharing data across the entire care trajectory will facilitate better harmonization of care, treatment, support, and research across Quebec.

All citizens in this country deserve an equal chance of recovery. This is one of the values of our public health system. Yet regional equity is currently compromised by poor data sharing between institutions and regions. For example, many patients seeking care or participating in clinical trials in Ontario are required to share their own clinical history. Interoperability of databases, both between institutions and between provinces, must be considered and planned for in the new bill.

[2] Canadian Health Data Bill of Rights. 2021. The future of health care in Canada redefined by patients. https://sauvetapeau.ca/wp-content/uploads/Declaration-FR-1.pdf

[3] Patient Privacy Principles. 2017, Canadian Medical Association. https://www.cma.ca/sites/default/files/2018-11/PD18-02F.pdf

With better interoperability and sharing, we will finally be able to **use existing clinical data in medical records to collect and analyze it in** *real-world evidence* (*RWE)*, including data on **therapeutic value, side effects, patient health and quality of life outcomes, and the financial cost of treatments across the care pathway.** This information would enable better evidence-based clinical, regulatory and public policy decisions.

## 3. Data for Research

The pandemic has demonstrated how crucial data and collaboration between researchers is for the protection of public health. A key element of success has been the removal of administrative barriers necessitated by the urgency of the situation. What if we stayed focused on the needs of people and maintained this ability to work together for the health of the population?

Our goal must be to use data to improve the health of our citizens while adhering to strict safety rules. By doing so, researchers will be able to focus a greater proportion of their efforts on evaluating promising treatments (and thus achieve results more quickly); policymakers will be able to make evidence-based decisions; our health system will be on a path of continuous improvement that is much more in line with scientific advances. Government will need to communicate strongly and clearly to assure citizens that patient data will not be "sold" for economic gain, and to establish that sharing anonymized data can benefit the health of all.

The current situation hinders scientific progress. Difficulties in assessing patients' clinical records and the lack of digitized research data have led to many clinical trials being stopped in 2020. The lack of data hinders the uptake of new therapies because it makes it difficult to recruit patients for clinical trials. How can potential trial subjects be identified without accurate data? Data lakes that can be queried by search engine features, or artificial intelligence, could greatly facilitate the recruitment of patients according to well-defined criteria. Also, by allowing patients to grant access to their digital health data in real time, they will be able, with the appropriate information, to contribute in a conscious and informed way to the advancement of science and the well-being of their fellow citizens.

It is time to modernize the processes of data collection and access to facilitate research. Countries such as the United Kingdom[4], France, Israel, and even closer to home, the provinces of Ontario and Alberta, have developed systems that facilitate research, whether public or private, and guarantee the protection of information. Some progress has been made, however. In some cases in Quebec, patients are directly involved in the design and implementation of clinical studies, as is the case at the CR-CHUS. Quebec should build on these successes and adopt a similar balanced and responsible approach to advancing knowledge and therapies while protecting the security of confidential data.

[4] Oxford University DataLab https://www.thedatalab.org/opensafely/

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## 4. Dashboards for Health System Management

What types of data would we benefit from collecting and analyzing?

The MSSS currently collects operational management data, such as waiting times for surgery and screening programmes, hospital emergency room capacity, hospital budgets and drug costs. These data are undeniably important for public administration and planning.

Responsibility for the performance of clinical research has generally been left to the Ministry of the Economy and Innovation, which is responsible, as its name suggests, for innovative activities. However, the MSSS cannot absolve itself of its responsibility for health research. In line with the Quebec Life Sciences Strategy and the mission of several organizations working in the field of research, such as Catalis, Oncopole and Q-CROC, the MSSS should commit to better integrating clinical research and to measuring the performance of innovative treatments with appropriate indicators, in the best interest of patients. More specifically, we believe that the participation rate of Quebec patients in clinical trials and their health outcomes should be part of the data collected and analyzed, in addition to serving as references for the development of our public health policies. **Research must be a treatment option for patients.** Yet, outside the major centres, few patients benefit from it. This situation must change with the determined involvement of the MSSS and real teamwork between ministries.

In order to accurately measure the performance and value creation of the health system, it is obviously important to refer to specific population health indicators. **The mission of the MSSS is to provide services, but also to aim for an improvement in the health of the population.** Thus, **in addition to the clinical data currently collected** - such as pathology reports, genetic and genomic data, and imaging results - it would be relevant to **collect what are known as Patient-Reported *Outcomes* (PROMs)**. This is in line with the orientations of the PARS Support Unit in relation to learning health systems.

Detailed demographic and population data will also be of key importance in ensuring that **health equity is** achieved**, considering the implications of the social determinants of health.**

In order to measure the value of public policies and the organization of care and services for patients and the system, the government would be well advised to develop performance indicators to monitor the costs associated with health services and outcomes, as well as the satisfaction of stakeholders (patients, carers, clinicians, researchers), in a cross-sectional manner.

These data could form a scorecard that integrates the notions of performance and value creation of the health system, i.e., the measurement of the real contribution of the system to the improvement of the health of the population.

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## Recommendations

The Quebec Cancer Priority Coalition makes five recommendations.

**Recommendation 1:** Make the Quebec Cancer Registry an urgent priority in order to complete the implementation of health data management, set a precise timetable for updating the data, making it operational, and ensuring that the data are shared effectively with researchers.

**Recommendation 2:** Ensure the mobility of health data based on the principle that the data belongs to the patient, follows the patient, and accelerates data collection initiatives by using the health insurance number as a unique identifier. By using this already existing number, which all Quebecers already have, delays associated with the development of a new digital key would be avoided.

**Recommendation 3:** Use existing clinical data at the level of medical records to collect and analyze *Real-World Evidence (RWE),* including data on therapeutic value, side effects, health and quality of life outcomes for patients and the financial cost of treatments across the care pathway.

**Recommendation 4:** Ensure health data management that supports the needs of clinical research, which would facilitate the recruitment of patient groups meeting specific criteria and needs of current and future clinical trials.

**Recommendation 5:** Collect data needed to truly measure health system performance and value creation, i.e., comprehensive population data and data known as *Patient-Reported Outcomes* (*PROMs*), linking health indicators to costs over the entire care trajectory, not just for interventions.