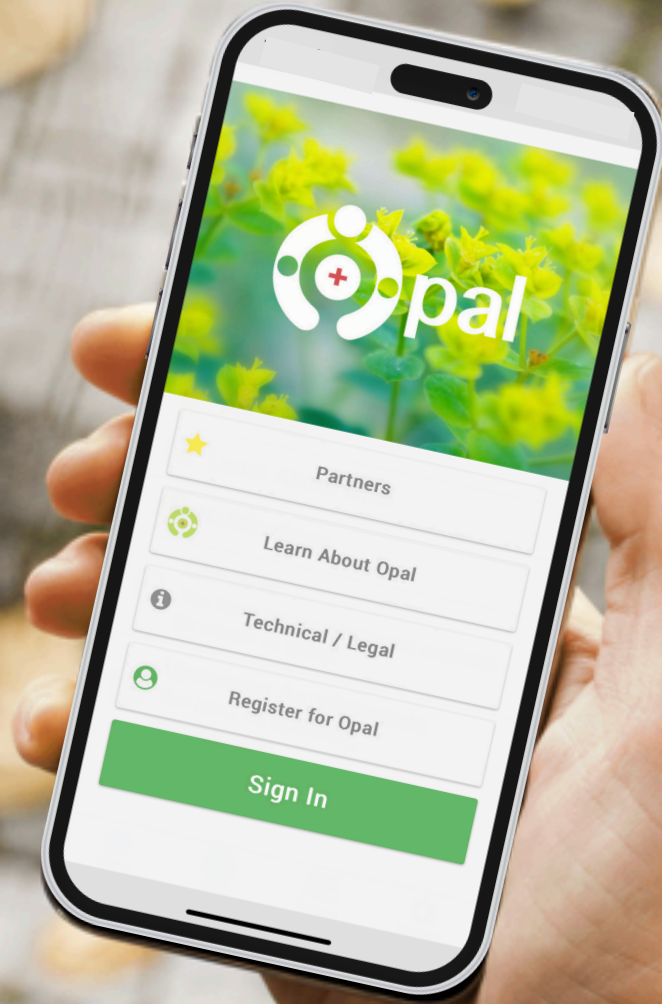# Impact Report

A Decade of Innovation and Impact

Consortium québécois de soins intelligents

Quebec SmartCare Consortium

Centre universitaire de santé McGill
Institut de recherche

McGill University Health Centre Research Institute

Dear Opal team,

I want to share a personal story with you that emphasizes Opal's value and efficiency. On *** ***, 2024, I went to the RVH ER. I had abdominal pain, etc... After a scan, I was diagnosed with diverticulitis and prescribed antibiotics. I was also asked to provide a stool specimen and did that the next day. On the third day, I decided to check my lab results on Opal. I found *C Diff*. Positive.

It was a Friday at 4PM. I knew my GP was away. I then decided to call the ER. I was surprised they had not contacted me. They said it would have taken several days before they would have received the results on paper (yes) and called me. The bug is also contagious. They told me to go back to the ER to pick up a prescription to treat it.

Thanks to Opal, I had the results rapidly and I was able to receive adequate treatment before aggravation.

     Thank you Opal.

– Pierre H.

A made-in-Quebec technology platform that measurably improves the patient experience and increases patient engagement

TABLE OF CONTENTS

EXECUTIVE SUMMARY

Sharing the impact of Opal

The Opal patient-in-the-loop data platform is an award-winning suite of applications that arose in 2014 from a research collaboration between a patient, a clinician, and a researcher. In 2018, it became the first platform to provide patients with real-time access to their health data inside Quebec's hospital network. As of November 2024, Opal is still the only platform offering this service.

At the McGill University Health Centre (MUHC), patients with Opal have secure real-time access to their health data, including appointments, laboratory results, clinical notes, personalized educational explanations, and questionnaires tailored to their diagnoses and treatments. The Opal app allows patients to check-in for appointments from their phones, to wait wherever they like at the hospital (not just in the waiting room), and be alerted via their phones when their doctors are ready to see them. Clinicians have access to a virtual waiting room, tools to collect patient-reported outcomes, and the ability to remotely monitor patients. For researchers, Opal offers secure communication with patients, e-consent forms, research questionnaires, and a data donation framework.

This impact report was prepared at the request of the Research Oversight Committee of the Quebec government's *Fonds d'accélération des collaborations en santé* program, which has funded Opal's development and operations over the last three years via the Quebec SmartCare Consortium. It is an opportunity to mark the ten-year anniversary of the Opal Health Informatics Group (OHIG), the research team that was founded by the initial tripartite collaboration. OHIG continues to design, develop and operate Opal at the Research Institute of the MUHC, and is presently releasing it under an open-source license.

Over the years, OHIG has received feedback from hundreds of grateful patients who have left messages via the Opal app and Opal's support email, or have participated in surveys, focus groups, and interviews. Feedback guides the continuous development of Opal and helps demonstrate its impact. In the spirit of contributing to a learning healthcare system, in which exemplary experience is used to inform future decision making, this impact report summarizes and shares the feedback from more than 1,500 MUHC patients as well as Opal user and usage statistics. To avoid diluting patient feedback, almost 200 statements from Opal users are shared verbatim.

The data presented in this report show clearly how Opal has helped patients and provided savings to the Quebec healthcare system. It demonstrates why patient-in-the-loop data should be the norm in Quebec, as they are elsewhere, and not the exception. As an open-source platform, Opal will soon be available to empower patients, clinicians and researchers with patient-in-the-loop data anywhere in the world.

Opal Health Informatics Group
November 2024

AT A GLANCE

Innovation to impact

This report demonstrates that Opal...

OPAL IN NUMBERS

~7,000
Opal Patient portal users

~399,400
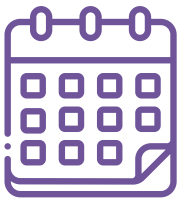Patient portal user logins

~200
Clinicians use ORMS daily

1.3+ million
Appointments managed by ORMS

6.7+ million
Lab test elements shared

62,300+
General announcements sent

15,000+
Questionnaires distributed

38,700+
Number of times educational materials disseminated

17,600+
Clinical notes distributed

OPENING MESSAGES

Opal has been a game changer for both clinicians and patients at the Cedars Cancer Centre. For the past 6 years, patients have been able to view their clinical notes and laboratory results, allowing them to be more active in their care and decreasing their anxiety. The wait room management system has allowed the clinic to function more efficiently.

Tarek Hijal, MD MSc FRCPC
Co-founder of the Opal project
Director, Division of Radiation Oncology, MUHC
Cedars Cancer Centre

Since its inception, the MUHC Patients' Committee has been overwhelmed by enthusiastic feedback and heartfelt appreciation from grateful Opal users. This unique platform is firmly centred around patients and their needs, and it has improved the quality of very challenging journeys as well as numerous health outcomes. It is a marvellous example of the limitless possibilities borne of innovation and collaboration between patients, clinicians and researchers across the MUHC and Research Institute.

Ingrid Kovitch, MD
Deborah Radcliffe-Branch, PhD
Chairs, MUHC Users' (Patients') Committee

The Canada Health Infoway congratulates the Opal Health Informatics Group for 10 years of ground-breaking research into providing patients with their health information in Quebec. The experience of the Opal patient portal, as reported in this document, demonstrates the importance of providing citizens with real-time access to their health data. This is consistent with the vision of the Canada Health Infoway and represents the future of healthcare in Quebec and Canada.

Daniel Gauvreau MSc.
Directeur principal pour le Québec et la coordination nationale des fournisseurs
Senior Director for Quebec and National Vendor Coordination

I am delighted to see Opal flourish since Laurie Hendren's untimely demise over 5 years ago. It is a fruit of the vision that she shared with Tarek Hijal and John Kildea. I know how much patients benefit from having access to their medical data instead of waiting anxious weeks before their doctor's appointment. I have seen the waiting room management system in action and was amazed at how much things like check-in were simplified and how the suspense of waiting for the actual meeting was greatly diminished. I only wish Opal was available far more broadly for all the clinics to use.

I wish to congratulate John Kildea and Tarek Hijal and the rest of the incredible Opal team for the growth and development of Opal and for the impact they are having on the delivery of care.

Prakash Panangaden FRSC
Husband of Opal co-founder, Laurie Hendren
Professor Emeritus
School of Computer Science, McGill University

As executive director and chief-scientific officer of the Research Institute of the MUHC, I applaud and congratulate the Opal Health Informatics Group on 10 years of impactful research. The Opal patient-in-the-loop data platform is a wonderful example of a research project that has truly translated from the bench to the bedside. The manner in which the Opal Health Informatics Group has worked collaboratively at every step to involve patients, clinicians, researchers, healthcare institutions, and industry partners has been key to Opal's successful clinical impact, which this report attests to. I am extremely proud that the Opal project arose from the Research Institute and I wish the Opal Health Informatics Group continued success as they embark on Opal's next phase and exciting open-source projects.

Rhian Touyz, MBBCh, PhD, FRCP, FRSE, FMedSci
Executive Director and Chief Scientific Officer, Research Institute of the MUHC

As a tool for direct and secure communication with our patients, Opal has been instrumental for the patient-partnership subcommittee in Radiation Oncology at the MUHC. We use it to gather patient feedback regarding their experiences in radiation oncology and to identify patients who are willing to get involved in patient partnership initiatives.

Thanks to the feedback collected through Opal, we were able to identify specific areas of improvement and subsequently launch two new initiatives from the patient engagement subcommittee: patient pre-treatment information sessions and departmental tours, as well as patient support groups. These initiatives directly address the needs highlighted by patients, underscoring the importance of incorporating their perspectives in our ongoing efforts to enhance the quality of care.

Opal has also proven invaluable in helping us recruit patient partners, whose insights drive meaningful changes that align with patient needs. Getting patient feedback is vital for quality improvement initiatives, as it ensures that the patient voice is considered at every stage of the process.

We are eager to continue leveraging Opal in our upcoming projects, as its role has proven to be indispensable in fostering effective communication and engagement. Opal is highly valued by both our team and the patients we serve, who appreciate the seamless, secure communication it provides. Its use is essential in helping us implement future projects and initiatives that prioritize patient needs and enhance the quality of care in our department.

Blair Mackasey & Gabriela Stroian
Co-leads of Radiation Oncology
Patient Engagement Subcommittee

The Quebec Cancer Coalition has been a leading advocate for people affected by cancer since its inception in 2001. Our goal is to improve the health care system for a healthier Quebec that is centered on patients, survivors and caregivers. In November of 2022, we published our recommendations on the management of health and social services data in Quebec, our number one recommendation being the importance of "Ensuring that patients have access to their personal data at all levels of the healthcare system." We believe that the data must follow the patient, belong to the patient, and be accessible in real time. Opal has been doing exactly this for the last six years and the benefits to the users, as summarized in this report, are clear and have had an important impact on the patients that use the application.

Opal has been a trailblazer and has set the standard for how patients should have access to their health data in Quebec. On behalf of the Quebec Cancer Coalition, I congratulate the Opal Health Informatics Group for 10 years of exemplary research!

Eva Villalba, M.B.A., MSCHCT
Executive Director of the Quebec Cancer Coalition

While making the closing remarks at the Laurie Hendren Symposium, I had the opportunity to emphasize the users' right to immediate online access to their entire medical file. It is the fastest and most user-friendly way for users to participate in their care. The Opal mobile application is doing remarkable pioneering work in this area. I ask that the MUHC maintain and support Opal in the years to come for the benefit of thousands of users who subscribe to it.

Me Paul G. Brunet
CEO and Chairman of the Board
Conseil pour la protection des malades

During the pilot of the Opal patient portal in pediatric nephrology, it was amazing to see how it benefited patients and families in following their own results and appointments. Opal has set the standard for empowering the parents of pediatric patients with the information they need to advocate for their children and play a fully-informed role in their care.

Bethany Joy Foster, MD, MSCE, FRCPC
Pediatrician-in-Chief,
Montreal Children's Hospital

As a clinician and bioethicist, as well as one of the pioneers and architects in the USA of OpenNotes and The Cures Act, in opening up our clinical notes directly to patients through their own personal devices, I completely support and endorse the transformative work that the Opal Health Informatics Group has been undertaking, and hopefully will be expanding. Extensive research, which is confirmed once again in this report, has shown that providing direct access to one's clinical notes improves patient engagement and trust, significantly improves patient safety and contributes greatly to better treatment adherence.

When patients receive a life-threatening diagnosis, it is hard for anyone to absorb and take in. Having their health record immediately available provides clarification and also saves time when the patient does not then need to call or email their provider with follow-up questions. The Opal group has been doing pioneering work in Canada as part of the movement toward health care transparency which we know improves both the patient and the provider experience. Opal's transformative work needs to be continued and expanded!

Steve O'Neill, LICSW, BCD, JD
Director of Behavioral Health for OpenNotes
Beth Israel Deaconess Medical Center
Faculty, Center for Bioethics
Harvard Medical School

The Opal patient portal has been used at the Inflammatory Bowel Disease program at the Montreal General Hospital for more than two years now. We currently have roughly 2,000 patients using it. During this time, I have personally witnessed Opal's benefits.

I have observed that our patients are empowered by rapid access to their results, which helps them expedite their care, provides them with a sense of ownership of it, and enables them to share in the decision making about it. Patients with Opal who have abnormal results are more apt to start new treatment or continue current treatment than patients without Opal, while patients with normal results are reassured by seeing them in Opal. Our nurses spend less time explaining results, as patients have them and have explanations on Opal. For our physicians, Opal's waiting room management software has worked very well, and the surveys on Opal help us to better assess patients' nutritional status and risk of IBD. Overall, Opal has been a definite plus for our program.

Waqqas Afif, MD, M.Sc., FRCPC
MGH Site Director
IBD Clinic Research Director

My research centers on developing and implementing patient-reported outcome measures (PROMs) and self-management programs for cancer patients and their caregivers, enabling them to track physical and psychological symptoms, share results with their healthcare team, and access vital information for symptom management. Through Opal, we launched the e-IMPAQc program (Electronic Implementation of Patient-reported outcomes Across Cancer Centers in Quebec) to over 100 patients at the MUHC. This collaboration with Opal has been symbiotic: Opal provides patients with easy access to our PROMs and self-management resources and gives clinicians real-time access to PROM results. Patients using e-IMPAQc report fewer symptoms than non-users and benefit from personalized self-management information tailored to their PROM results.

Sylvie Lambert, PhD
Canada Research Chair, Associate Professor
Ingram School of Nursing, McGill University
Scientist, St. Mary's Research Centre

An award-winning "patient-in-the-loop data" platform

DIRECTOR'S MESSAGE

The future is _now_

A personal reflection on 10 years of Opal research

When Dr. Tarek Hijal introduced me to breast cancer patient Prof. Laurie Hendren in 2014, I had no idea that our discussion would give rise to something that would become as impactful as Opal has been. Our goal was simple–do research that would improve the experiences and outcomes of MUHC patients. As a patient and a professor of computer science, Laurie could not understand why it was so difficult to "get stuff done" in healthcare. She also couldn't understand why she was kept out of the loop on her own medical data and why she was constantly waiting (for appointments, for results, for phone calls, etc.). Surely the system could be more accessible and efficient...

So, we set out to do research that "got stuff done". Not talking about it, not analyzing what needed to be done in the future but getting it done _now_. Laurie helped me understand that when you are a cancer patient, the future is _now_. Opal is the result of our research.

At a personal level, I am both proud and excited about where we are today, 10 years later.

I am immensely proud that our research has led to a tool that has had such a positive impact on the almost 7,000 people who use it at the MUHC (the almost 200 statements in this report are a testament to that–please take a moment to look at the Appendix, they are powerful). I am super proud of the fantastic team that works on Opal—dedicated professionals who prioritize patients' needs. I am also proud of the awards and grants that Opal has won.

But above all, I am proud that Opal was the first (and is still the only) patient portal in a Quebec hospital—the first to provide Quebec patients with secure real-time access to their lab results and clinical notes, to offer virtual check-in for appointments, and to electronically collect patient-reported outcome and experience measures. All done as a research project!

I am also super excited to announce that we will shortly release the source code of the Opal patient portal under an open-source license! This will make Opal the first patient portal in the world to have its code available for free in the public domain. It will be available for developers in Quebec and around the world, to use, improve, and expand.

As a renowned computer scientist, Laurie was a strong proponent of open-source software. She saw it as a way to improve the world. By releasing Opal open-source, we aim to solidify Laurie's legacy and make Opal's benefits available to patients across the world. Our vision is bold and ambitious but we are up for the challenge!

I am sometimes asked "what has kept Opal going in Quebec given that no other patient portal has broken through?". The answer is simple: Opal is non-commercial and our research team includes patients and caregivers, people like Laurie who use Opal themselves. As Warner Slack, a pioneer in the development of electronic health records, once said, "patients are the largest and least utilized resource in healthcare". This is so true. The Opal Health Informatics Group perseveres because it includes patients who know and understand Opal's impact firsthand.

However, motivation alone does not sustain a project. Funding does. For this, we have been fortunate to have had the fantastic support of our financial partners (hospital foundations, research funding agencies, and industry partners) who share our vision of empowering patients with their data. There are too many to name here but please see pages 57 and 58 for the list of supporters who have sustained Opal over the last 10 years.

As we move into a new and exciting open-source chapter of Opal, funding remains as important as ever. We will continue to apply for research grants to innovate and test new ways of improving patient care using Opal.

As we do so, we will also rely on those who share in our **bold and ambitious open-source vision** to help us keep the lights on. If this is you or your organization, **please consider donating via our website (opalmedapps.com/donate)**. If you are in any doubt about the benefits of Opal or our ability to deliver, please read this report!

I would like to end by thanking everybody who has supported Opal over the last 10 years. Whether it is the patients who have left us motivating feedback, our colleagues who championed the project and helped us make connections, the software development professionals who believed in the project enough to work on it, or the financial partners who have sustained us, THANK YOU!

The future is still _now_ and patients still need access to their data. So, here's to another 10 years of working together to share the benefits of Opal!

– John Kildea, PhD, MCCPM
Director, Opal Health Informatics Group
Scientist, RI-MUHC

❝

"I think this APP is great. Very helpful, useful info. A definite benefit! Thanks."
– Denise

"Opal est génial!!! C'est si simple et pratique. Et très accessible."
– Annabelle

❞

INTRODUCTION

The Opal Story

Patient-driven innovation

Laurie Hendren   **John Kildea**   **Tarek Hijal**

The Opal story began in 2014 when the late Prof. Laurie Hendren, who was a renowned professor of Computer Science at McGill University, was treated for breast cancer at the MUHC. Following a discussion about the computational needs of healthcare, Laurie's radiation oncologist Dr. Tarek Hijal introduced her to Prof. John Kildea, a McGill Medical Physics professor and health informatics researcher. The three started a research project using machine learning to estimate patient waiting times. This ultimately led to the creation of the Opal patient-in-the-loop data platform. Unfortunately, Laurie succumbed to her cancer in 2019 but her legacy of patient leadership persists in Opal.

Over the last 10 years, Opal has innovated in four important ways:

1. It broke new ground by **involving patients** at all levels of the project.
2. It pioneered the **sharing of healthcare data with patients** in Quebec.
3. It **changed the way appointments are managed** at the Cedars Cancer Centre and at the Inflammatory Bowel Disease Clinic at the Montreal General Hospital.
4. Its underlying technology is a **secure data-sharing innovation** as yet unmatched in the Quebec healthcare system.

Overview

Quebec's only patient-in-the-loop data platform

The Opal platform consists of a **patient portal**, a **waiting room management system**, and a **databank framework** for the collection of real-world data with patient e-consent through integration with the LORIS platform at the Montreal Neurological Institute.

Patient Portal	Opal Room Management System (ORMS)	Databank
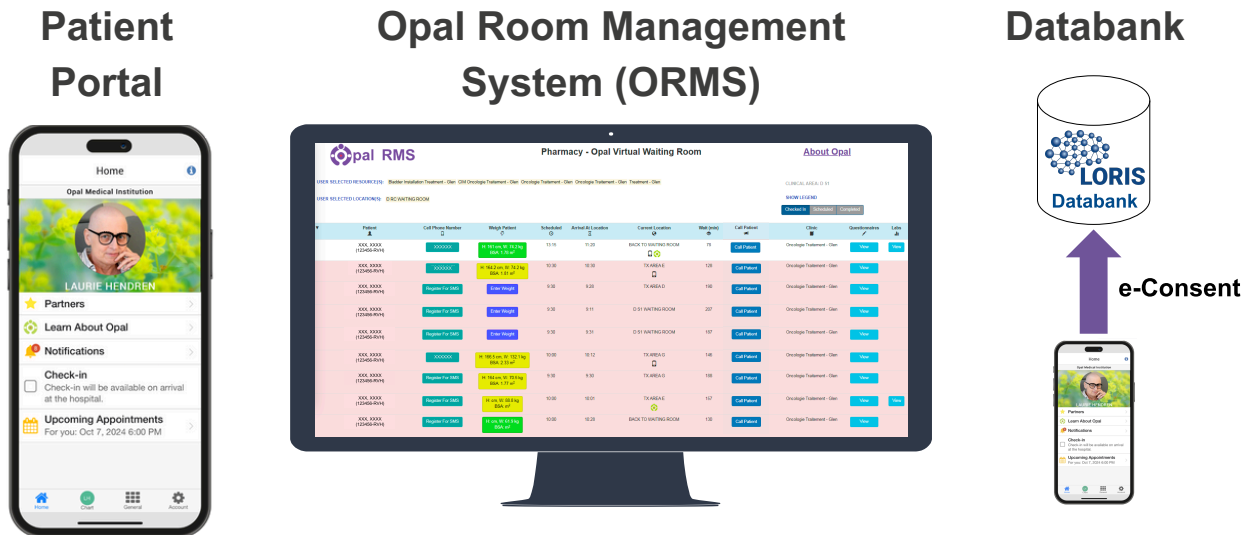
The **Opal patient portal** is currently operated in four clinics at the MUHC where it provides **almost 7,000 patients** with access to their medical data at the hospital.

The **Opal Waiting Room Management System** (ORMS) is in use at the Cedars Cancer Centre, where about 40% of the MUHC's ambulatory patient population are cared for. To date, the Opal Room Management System has managed **roughly 1.3 million patient visits**.

Opal's databank framework for patient-donated data was recently developed as part of the Quebec SmartCare Consortium project in collaboration with McGill's Centre of Genomics and Policy and the Montreal Neurological Institute.

Opal Patient Portal

Empowering patients with information
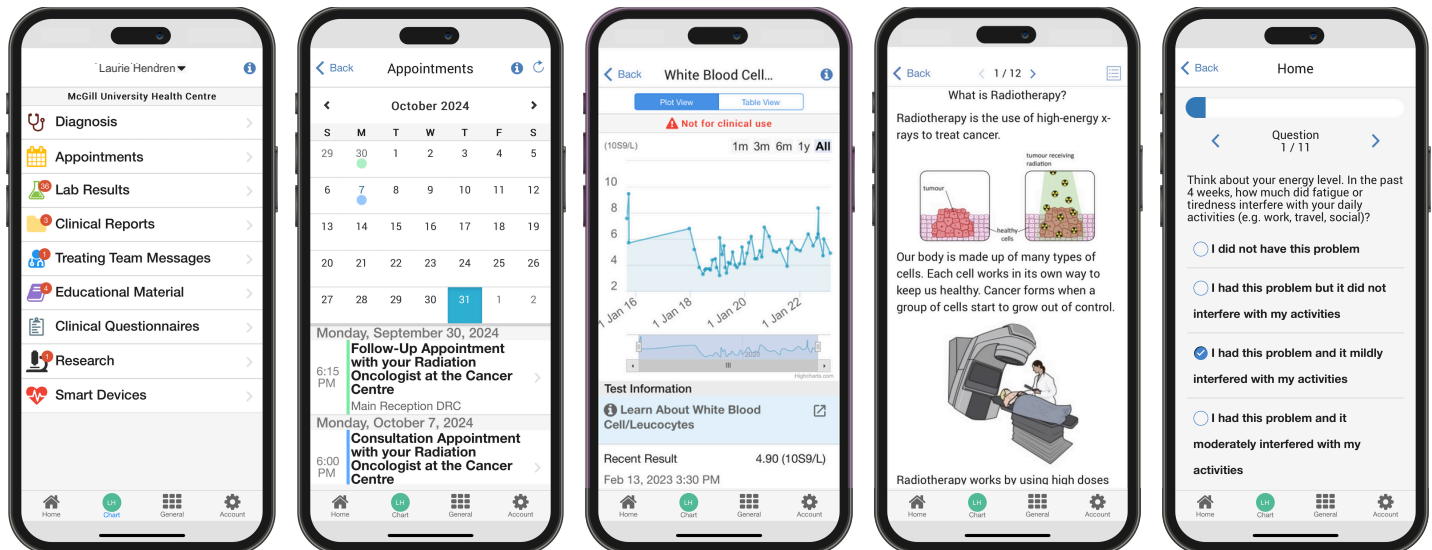
The Opal patient portal provides patients with:

- Diagnosis information,

- Appointment information with maps and "how to prepare" instructions,

- Lab results (in real-time with trends and links to explanatory materials),

- Clinical notes (radiation oncology),

- Treating team messages,

- Questionnaires (PROMs, PREMs, research studies, surveys),

- A library of personalized informational resources (booklets, videos, factsheets), and

- Waiting room management resources (virtual check-in and call-in).

Opal has been in live clinical operation at the MUHC since 2018.

Effective and efficient data collection from patients

Opal User Feedback Survey

Tap "Begin" or swipe to the left to start the questionnaire.

Description:
We hope that you are finding the Opal app useful. We value feedback from users like you that helps us to understand what is working well and what can be improved.

To learn about your experience using Opal and to hear your thoughts regarding its future, we have made a short 20-question questionnaire.

Please take a few moments to provide us with your important feedback by completing this questionnaire.

Question 1 / 20

How has Opal affected your experience as a patient at the MUHC?

◯ **Opal has made my experience better**

◯ **Opal has made my experience worse**

◯ **Opal has not affected my experience one way or another**

Feedback

Your feedback is invaluable to us. Please take a moment to let us know what you think about Opal.

Leave us a message

Send

In the clinic, **Opal's built-in questionnaire system** is used for the collection of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). The system can also be used for quality improvement and research surveys such as the Opal feedback questionnaire that was used to collect data for this impact report.

Within one hour of sending the feedback questionnaire in Opal, 230 patients had responded to it! This is a powerful testament both of Opal's importance to its users and its effectiveness as a communication tool.

Opal Room Management System (ORMS)

Improving the waiting room experience
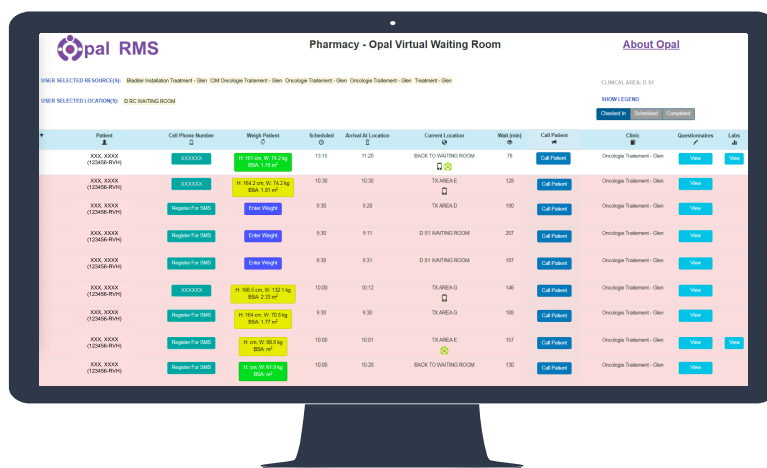
ORMS provides:

- Virtual check-in for patients via:
  - Check-in kiosks
  - Opal patient portal app
  - SMS service
  - Reception desk check-in webpage
- Appointment reminders via SMS

- A Virtual Waiting Room for clinicians
- Access to Patient-Reported Outcome Measures (PROMs) from Opal
- Appointment call-in for patients via:
  - Opal patient portal app
  - SMS service
  - Waiting room TV screens

ORMS has been supporting clinical operations at the MUHC since 2015.

EFFICIENCES AND SAVINGS

How Opal can help Quebec's overstretched healthcare system

Emergency Rooms

Quebec's ERs are frequently overcrowded. Opal's patient portal can keep patients out of the ER by empowering them to take care of themselves and access care before complications.

Evidence:
- Pierre's story on page 2 shows how patients can react faster than the health network.
- An independent study by Attieh et al. (2024) [1] has shown that using Opal for remote monitoring of COVID patients saved an average of **$253 per patient due to reduced ER visits**. See page 23.

Appointment check-in

All patients must register on arrival at a hospital clinic. Typically, this is done by a clerk at a reception. With Opal, the clerk is not needed. Patients can check-in on their phones or at Opal-powered kiosks, saving personnel in the short-staffed healthcare system.

Evidence:
- Before Opal's Room Management System (ORMS) was implemented, 3-4 clerks checked in patients at the Cedars Cancer Centre. Post-implementation, only 1 clerk is required, **a saving of 2-3 full-time equivalent staff (FTEs) per year over the last six years (31 FTE over the last 10 years)**. See page 48.

Medical Record Requests

The MUHC spends more than $50,000 per year on postage stamps to mail medical records. Patients report that the process is cumbersome (see page 36). Only 20% of respondents to Opal's Radiation Oncology Clinical Notes survey indicated that they had requested other clinical notes via Medical Records, whereas 90% indicated that they wished they could receive all their notes in Opal. By making clinical notes accessible, Opal not only saves costs but improves patients' understanding of their care and trust in their doctors (page 39).

Evidence:
- Since 2018, **Opal has delivered more than 17,600 clinical notes** to radiation oncology patients and shared **6.7 million, and counting, test results with almost 7,000 patients**. See pages 7 and 44. Applying the methods of Kim et al (2017) [2], we estimate that Opal can save the MUHC at least $40/patient/year through reduced inquires related to accessing and understanding records, in addition to saving on postage stamps.

How Opal can help Quebec's overstretched healthcare system

Sharing data with family doctors

Access by family doctors to patient data helps in the transition of cancer patients from hospital to community care. However, most clinical notes are currently sent by fax, which is unreliable and outdated. Opal enables patients to share their data with their family doctors.

Evidence:
- In the Radiation Oncology Clinical Notes survey, **almost 30% of respondents reported sharing notes with family doctors using Opal** (page 40). In the Feedback Survey, **98%** said they would like to use Opal to share data with their family doctors (page 37).

PROMs and PREMs – measuring what matters

Collecting and acting on patient-reported outcome measures (PROMs) from cancer patients has been shown to improve survival and reduce ER visits [3]. Likewise, patient-reported experience measures (PREMs) can be used to improve the quality of care. Opal is uniquely able to support PROMs and PREMs in Quebec and deposit results in electronic medical records without cloud storage. Furthermore, unlike other systems, Opal can personalize questionnaires according to diagnosis, phase of treatment, etc.

Evidence:
- During the pandemic, Opal users completed more than **8,000 symptom screening questionnaires**. Opal was able to provide this service at the outset of the pandemic.
- To date, Opal has facilitated the creation of **72 unique questionnaires**, which have been **distributed more than 15,000 times** to Opal users.
- Opal supports the e-IMPAQc project at the MUHC that has provided distress screening for cancer patients since 2020.

Appointment no-shows

Appointment no-shows are a vexing and expensive problem in healthcare. The no-show rate in Quebec is typically 10%. Opal's appointment reminders and appointment preparation instructions, including clinic maps and transport information, can help reduce no-shows.

Evidence:
- A health economics analysis by the team of Prof. Alton Russell at McGill (Li et al, 2023) [4] has provided preliminary evidence indicating an almost 10% reduced no-show rate for Opal users compared to non-users.

ALIGNMENT

With Quebec government orientations

The Plan santé

The Quebec government's *Plan pour mettre en oeuvre les changements nécessaires en santé* [5] was published in March 2022. It promises results by 2025 and lays out Minister Dubé's strategy to **improve patients' experiences and Quebec healthcare's performance**. An analysis of the plan and the data in this report shows that Opal is already delivering in four of the eight key action areas discussed in the report.

Access to data
The plan provides a guarantee that all citizens will have direct access to their own health information. **For six years already, Opal has been doing exactly this**. The plan also calls for improvements in access to data for research, something Opal supports with its **e-consent module and databanking framework.**

Innovation
Opal was **developed with patients inside the Quebec healthcare system**, at the Research Institute of the MUHC. The fact that it was the first and is still the only platform of its type to provide Quebec patients with real-time access to their hospital data, is a testament to its innovative nature, something the Plan santé embraces.

Information technology
The plan recognizes that the use of fax is outdated and must be replaced. Implementation of the *Dossier santé numérique* is now underway but will take some time. In the meantime, Opal users can use Opal to share their records with their family doctors (see page <u>40</u>).

Caregivers and old and vulnerable people
The vital role played by informal caregivers is recognized in the plan and highlighted in the context of the ageing population. After patients themselves, their caregivers are the best advocates for their care. But caregivers too need access to their patients' data to play a fully-informed role. As presented in this report (page <u>40</u>), **almost 40% of Opal users already share their data in Opal with informal caregivers**, enabling this vital role.

In summary, <u>Opal is already in action</u> and can demonstrate improvements in the experiences of Quebec patients, in alignment with the Plan santé.

Plan d'action 2024-2026 du Programme québécois de cancérologie

Opal aligns perfectly with four out of the eight axes of the *Plan d'action 2024-2026* [6] recently published by the **Programme québécois de cancérologie**.

Axis 1: Active participation of the population and people touched by cancer
Opal fits this axis exactly. This report shows how Opal can **involve patients in decisions about their care** (by sharing with them their test results, clinical notes, personalized educational materials, etc.) and by providing a secure mechanism for **self-reporting of symptoms (PROMs and PREMs) and facilitating remote care**.

Axis 4: Rapid pertinence-based investigation
Opal can reduce delays for follow-up testing appointments, by allowing patients to manage their appointments, receive notifications, and access their test results in real-time. This is aligned with the axis' focus on **improving rapid access to tests and results**.

Axis 5: Effective treatments, pertinent and innovative
This axis focuses on ensuring that patients have access to optimal treatments and innovative treatments with minimum delay. It prioritizes the goal of measuring the real-world benefits and value of treatments. Opal's system for PROMs and PREMs, and its e-consenting and databanking frameworks were built for this purpose.

Axis 6: Provision of care and support services throughout the trajectory
Opal can **support cancer patients throughout their care journeys**, including after treatment. It can provide **personalized information** depending on patients' conditions and phases of treatment, which can ease the transition between the difference phases. Patients can share their records with family doctors, easing transition to community-based care.

Many cancer centres struggle to communicate securely with patients. Many patients are confused and feel excluded from their care. As the data and the statements in this report attest, Opal helps patients play an informed and active role in their care, and it can collect PROMs and PREMs. **Crucially, Opal is not a plan for the future–it is already delivering for cancer patients at the MUHC, today.**

PANDEMIC EXPERIENCE

Opal during COVID

Uniquely ready for the challenge

During the pandemic, Opal was leveraged to provide:

- **A parking lot waiting room:** Radiation Oncology patients were able to check-in using Opal from their cars in the MUHC parking lot and get called in via Opal without being exposed to other patients in the waiting room.

- **Symptom screening questionnaires:** Patients with Opal completed more than **8,000** screening questionnaires from home before coming for their appointments at the MUHC.

- **COVID results to patients:** Opal securely shared COVID test results with patients as soon as they were ready. Using Opal, the MUHC was the only institution in the province able to communicate test results electronically with patients at the start of the pandemic.

- **Remote monitoring of COVID patients:** A study led by Dr. Bertrand Lebouché in the Chronic Viral Illness Service at the MUHC used Opal to remotely monitor 50 COVID+ patients from home. **The study showed that using Opal for remote monitoring avoided ER visits and saved an average of CAD $253 per patient.** (Attieh et al, Journal of Primary Care & Community Health. 2024) [1].

Use **Opal** to monitor COVID-19 symptoms

As part of the Opal-COVID study at the MUHC, people who have contracted COVID-19 may self-monitor and report their symptoms from home using Opal.

Download Now: App Store + Google Play

Contact Us: Research team of Dr. Bertrand Lebouché
(+1) 438 822-2004
opalcovid.study@gmail.com

The Gazette

News / Local News

MUHC has taken measures to treat cancer patients safely during pandemic

Intended to limit unnecessary interactions, measures range from a dedicated parking lot and entrance to registration via text message.

Susan Schwartz • Montreal Gazette
Published Apr 22, 2020 • 5 minute read

After several months of chemotherapy, I was expected to start several weeks of radiation therapy at the Cedars Cancer Centre. This was in March 2020, at the start of COVID. Chemo left me immune suppressed, so I was extremely concerned with being exposed to COVID in the waiting room. This anxiety resulted in my initial refusal of the treatment, despite it being a crucial treatment for my Triple Negative Breast Cancer diagnosis.

At my refusal of treatment, I was informed of the Opal application and how I could use it to check in and leverage the safety of my car as a virtual waiting room for my daily radiation therapy. This was a first, for this kind of application, in my experience at many hospitals.

Receiving questionnaires, and explanations of the various appointments and how to prepare for them, also made me feel prepared and closer to my treating team.

Thank you Opal.
– *Susie*

METHODS

Measuring impact

Sources of data

The first Opal focus group, in 2016.

Multiple sources of information have been used to attest to Opal's impact.

These include:

1. **User and usage** data,
2. **Feedback in Opal** directly from its users:
   a. Feedback questionnaire (646 respondents, 2023 and 2024),
   b. Radiation Oncology clinical notes questionnaire (118 respondents, 2024),
   c. Messages via the Opal feedback form and support email (124 messages, since 2018),
3. **Waiting room survey** at the Cedars Cancer Centre (524 respondents, 2023),
4. Semi-structured **interviews** (16 participants, in 2019 and 2022),
5. **Focus groups** with Opal users (3 groups, 15 participants, in 2018 and 2021).

PATIENT VOICES

Salient themes

In total, almost 1,500 patients answered surveys, participated in interviews and focus groups, or provided unsolicited feedback. The data collected from all of these sources were combined and analyzed to find common themes. Five themes emerged:

1. Patients love Opal

Patients overwhelmingly praise Opal, feel that it has improved their experience of healthcare at the MUHC, would highly recommend it to other patients, and want it to continue.

2. Real-time test results are essential

Real-time access to test results reduces patient anxiety and brings tangible value to both patients and the healthcare system.

3. Patients want all their data in Opal

Patients love that they can easily access some of their data in Opal and are keen to access more.

4. Opal can engage patients further

Patients are willing to report symptoms and engage more using Opal if given the opportunity.

5. Reading clinical notes is empowering

Patients who read their clinical notes in Opal report improved understanding, increased trust in their clinicians, and more involvement in their care.

Each theme is presented in the pages that follow along with supporting survey data and supporting written feedback from patients. Additional patient statements are in the Appendix.

THEME 1

Patients love Opal

Overview

Patients overwhelmingly praise Opal, report that it has improved their experience of healthcare at the MUHC, would recommend it to other patients, and want it to continue. Of the almost 200 statements quoted in this report, 21 use the word "love" when talking about Opal. Six examples are reproduced here:

> "I **love** your app because I know what is going on in my medical life, which currently is pretty much all that is going on." – *Kathleen*

> "I **love** this app it helps me control and take care of blood counts with food." – *Janice*

> "J'**adore** l'application Opal, elle nous permet une certaine indépendance. Tout est clair et précis." – *Répondant CS161*

> "**Love, love, love** Opal. Please let's keep it. Thank you."
> – *Respondent FD01*

> "I **love** Opal! I see my medical appointments for Radiologist and Oncology here. Keeps me organized!"
> – *Respondent* **CO138**

> "**Love love love** having quick and direct access to my blood results." – *Respondent CB40*

Patients love Opal

Supporting data

Would you recommend Opal to another patient? [646 respondents]

**How has Opal affected your experience as a patient at the MUHC? [646 respondents]**
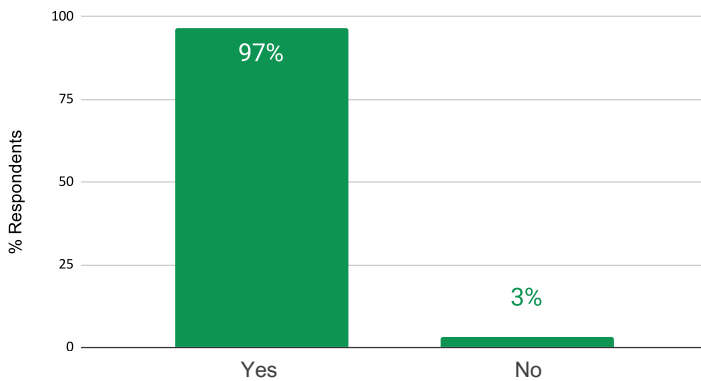
The vast majority of respondents to the Opal feedback survey (97%) would recommend Opal to other patients and report that it has improved their experience at the MUHC (82.3%). 89% would use it in another hospital if it was offered there.

Among the few survey respondents who reported that they would not recommend Opal or that it had made their experience at the MUHC worse, the data show that the biggest issue is the incomplete nature of the clinical data provided by Opal. Patients want access to all their data in Opal (see theme 3).

If Opal was available at another hospital/clinic, would you sign up for it there? [646 respondents]
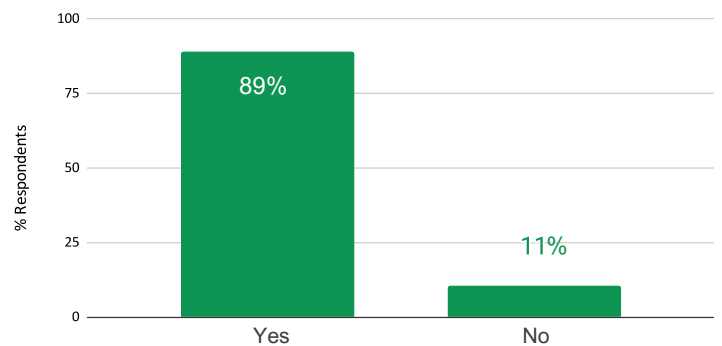
As can be seen in the statements below and in the Appendix, the high degree of appreciation for Opal shines through in the feedback left by patients about it.

Patients love Opal

Supporting statements (additional statements in the <u>Appendix</u>)

"

"This Opal application is a precious tool and makes me feel in control of what's going on in my life with all my chemo/radiotherapy, consultations etc. A wonderful application!" – *Valerie*

"J'ai été traité au CUSM pendant 3 mois et continue de voir des médecins et j'ai utilisé Opal comme système d'enregistrement de rendez-vous et d'informations et j'ai été très satisfaite et de système très élaboré et j'en ai parlé à des personnes. J'espère de tout cœur que tous les hôpitaux du Québec utilisent un système comme Opal comme centre de rendez-vous et de renseignements qui mettra leurs patients en confiance suite aux informations générales et soins de leurs maladie." – *Diane*

"Merci d'avoir développé une app si aidante, ou toutes nos données sont regroupées au même endroit."
– *Anne-Marie*

"Service très utile et surtout rassurant."
– *Répondant CO7*

"C'est un outil formidable, dommage que les informations soient partielles. il devrait inclure au minimum toutes les informations du CUSM, et dans l'idéal des autres hôpitaux et prestataires de santé, résultats et rapports d'analyse, autre RV, clic santé et Carnet santé Québec." – *Françoise*

"This is a terrific app for a cancer patient. Gives you everything you want at your fingertips, without the need for input from the patient." – *Glenn*

"I think Opal is an outstandingly good piece of software. I use it for keeping track of my blood test results (which are numerous because I am an ESKD patient in dialysis). I find It extremely well suited to this purpose, particularly because of the intuitive ease of finding a time series (graphic or tabular) for a specific blood test." – *Joseph*

"Excellent well beyond what I thought could be available" – *Gerald*

"

THEME 2

Real-time test results are essential

Overview

Consistent with findings in the literature (e.g., Steitz et al., JAMA Netw Open, 2023) [7], the majority of respondents to the Opal feedback survey (58%) reported that real-time access to their test results reduces their anxiety, 40% reported that it does not affect their anxiety one way or another, and only 2% reported that it increased their anxiety.

In your experience, how has receiving your blood test results in real time using Opal affected your anxiety [480 respondents]
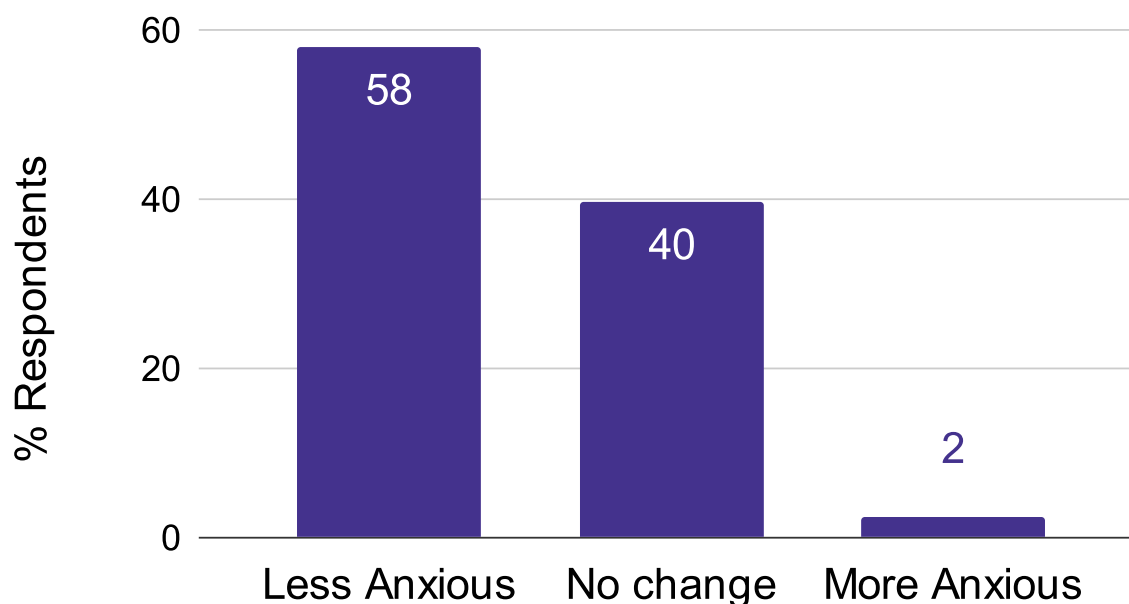
Out of a total of 480 respondents who reported accessing results, 325 took the time to provide a written answer to the question "Please leave any comments or concerns you may have regarding seeing your blood test results in Opal". This high level of feedback indicates the importance that patients put on access to their lab results in Opal.

The comments received (some of which are included below and in the Appendix) indicate that seeing test results before meeting with their doctors allows patients to be better prepared for their appointments and get more value out of them. It also reduces their anxiety and helps them feel in control during what is otherwise a very vulnerable period of their lives.
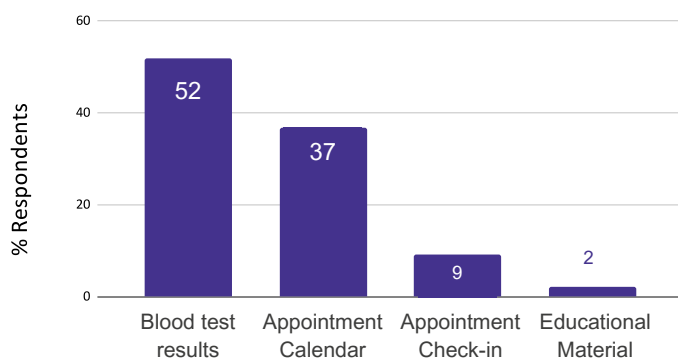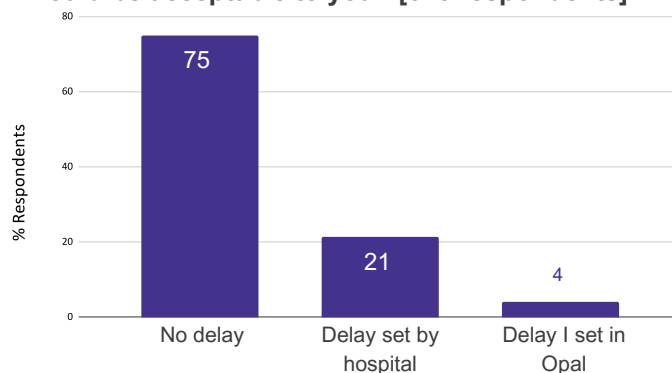
Real-time test results are essential

Supporting data

Which of the following features in Opal is the most important to you as a patient? [646 respondents]

Currently your blood test results are available in Opal without a delay. If a delay was added, what type of delay would be acceptable to you? [646 respondents]


The majority of respondents (52%) indicated that blood test results are the most important feature to them in Opal. This finding is also borne out in the written feedback.

Several healthcare systems delay the delivery of test results to patients, ostensibly to allow the doctor to share the news with the patient and explain them. Opal has no delay. When asked what delay they would find acceptable if test results were to be delayed, the majority (75%) of patients indicated that they would not accept any delay, 21% said they would be ok with a delay set by the hospital, and 4% indicated that they would rather set any delay themselves inside Opal.

The Carnet Santé Québec is Quebec's centralized system for patients to access their data in the Dossier Santé Québec. It imposes a 30-day delay on results. Almost half the feedback survey respondents reported that they have either never used it (19%) or don't know what it is (29%).

Written feedback overwhelmingly indicates that the Carnet Santé is of little use to patients due to its 30-day delay on test results.

Do you use the Québec Health Booklet (Carnet Santé Québec)? [646 respondents]
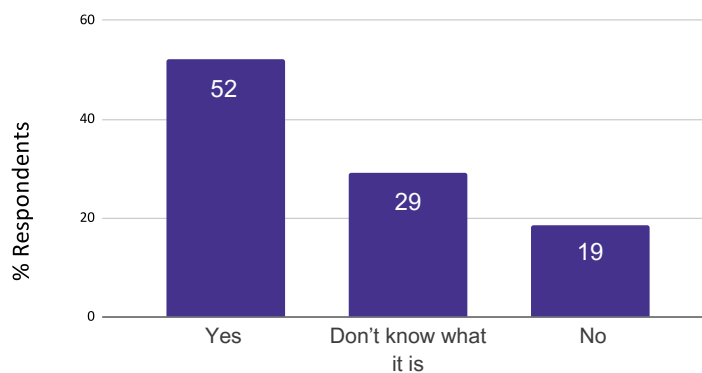
"I love the idea of Opal and how it shares info with patients. I am a huge proponent of blood test results that are readily available to the patient within the hour after doing bloods. I can't stand the government's present Carnet Santé's lack of accessibility of any results for at least a month after patient takes blood tests, X-rays, etc."
– *Brenda*

"Très utile et rassurant pour notre paix d'esprit."
– *Ghislaine*

"I love having access to my blood work- it eliminates me bothering doctors for information." – *Brigid*

"I love having quick access to my results, reduces stress and worry if waiting." – *Respondent CB317*

"By far the most important feature. Please don't change it!"
– *Respondent CB200*

Real-time test results are essential

They improve care and save the healthcare system

An analysis of the written feedback received shows that real-time access to test results in Opal is not just about reducing stress and providing patients an opportunity to prepare questions for their next appointment. Rather, it is also about **improving healthcare and producing savings for the healthcare system generally**.

Two powerful testimonials attest to this. The first, from patient Pierre H., is on page <u>2</u> of this report. By having access to his test results in Opal, Pierre was able to get timely treatment for *Clostridium difficile* that he would otherwise have had to wait several days for. **His timely treatment not only saved him from potentially aggravating symptoms, it saved the healthcare system from having to deal with those symptoms and it minimized the time Pierre spent potentially spreading the infection unwittingly to others in the community.** The second testimonial along the same lines is below.

> "Seeing the blood test results in real time is good. My last blood test results, the hospital forgot to include one of the blood test markers creatinine. I went back to the hospital with a copy of my requisition and had the test again as it was missed on the first visit." – *Respondent CB50*

Patients are the best advocates for their own care. Like the patient quoted above, when patients are empowered with direct access to their records, they can help spot errors, act on them and have them corrected. This not only ensures better care for individual patients but it saves the healthcare system in the long run.

Real-time test results are essential

Supporting statements (additional statements in the <u>Appendix</u>)

"

"Really like the app. Great to see test results before seeing my doctor - allows me to ask more informed and specific questions." – *Robert*

"I do find Opal very helpful. In particular, having the blood test results before a recent telephone consultation enabled me to ask intelligent questions and receive helpful replies." – *Michael*

"I must admit that when I see some irregularities it's always concerning. I believe it is a normal reaction. That being said, it gives me key information about my health. Sometimes (for example kidney functions), it shows me that I need to drink way more water to help my system." – *Respondent CB139*

"It is excellent. This morning I checked in using the app and then read my blood results prior to my visit with my doctor. I had a couple of questions regarding results and used the reference section which I found very useful. I of course ask my doctor my questions also. The information on the app helps me prepare my questions. THANK YOU."
– *Catherine*

"Vraiment très bien pensé. Bravo. Belle application, très conviviale, facile d'utilisation. Grandement aidant pour se rappeler des rendez-vous et recevoir ses résultats de laboratoire." – *Jeanne*

"Receiving the Opal push notification alerting me of new lab test results is one of my favourite app features. For me, "test result" anxiety is debilitating. Waiting for my doctor to share results that have the potential to change my entire life is something I have grown tired of. I don't want to wait to see if my clock is running out. I want to know now, not later. Not when my doctor has an opening in their schedule. It's my life, my results, my choice —no delays, empowered by Opal."
– *Respondent CB1*

"Great app.. I love having my blood results so I can review them immediately. And the reminders are great also."
– *David*

"En m'inscrivant à OPAL je n'ai demandé que le minimum d'info. J'étais dans mes traitements et ma tête était occupée ailleurs. Maintenant tout voir et tout savoir." – *Répondant CB137*
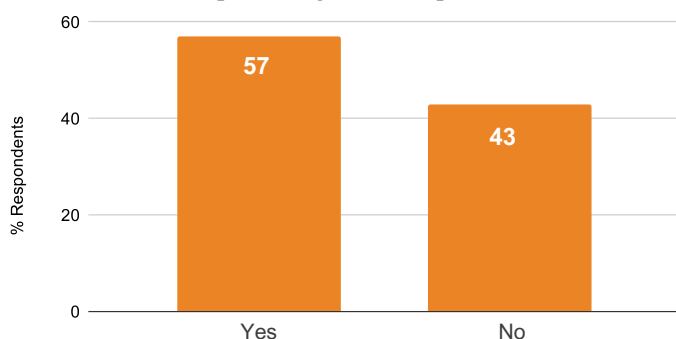
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THEME 3

Patients want all their data in Opal

Overview

Patients are confused as to why they cannot access all of their healthcare data in Opal and **the most frequent request is to access more data.**
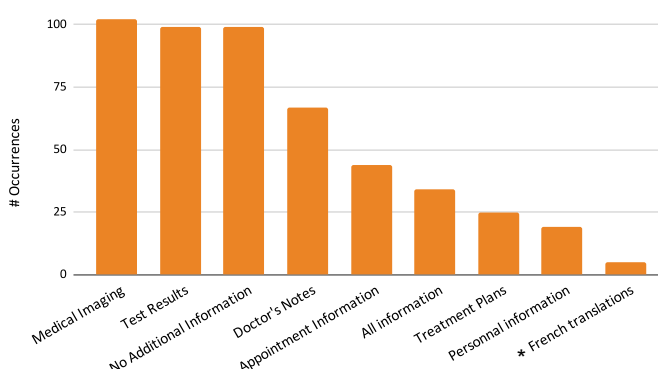
When asked if Opal displays enough information from their medical chart, 57% of respondents to the Opal feedback survey reported that it does. However, all 646 respondents also provided an answer to the question "*What other information in your medical chart do you think that Opal should provide you with access to?*". The answers were grouped into nine categories as shown on the right below.

Does Opal display enough information from your medical chart? [646 respondents]

What other information in your medical chart do you think that Opal should provide you with access to? [646 respondents]

* Opal provides data as they are found in the hospital's information systems.

In responding to questions about their preferences for specific additional information such as radiology reports, pathology reports, radiotherapy treatment plans, medical images, and pharmacy information, patients overwhelmingly indicated that they would like to have access to each of these additional data types. In their written feedback, patients were not shy about sharing how they feel Opal needs to be connected to more data and made more widely available within and beyond the MUHC.

If Opal was to provide you with access to the following information, how important would this feature be to you?

Legend: Very Important, Moderately Important, Important, Slightly Important, Not Important
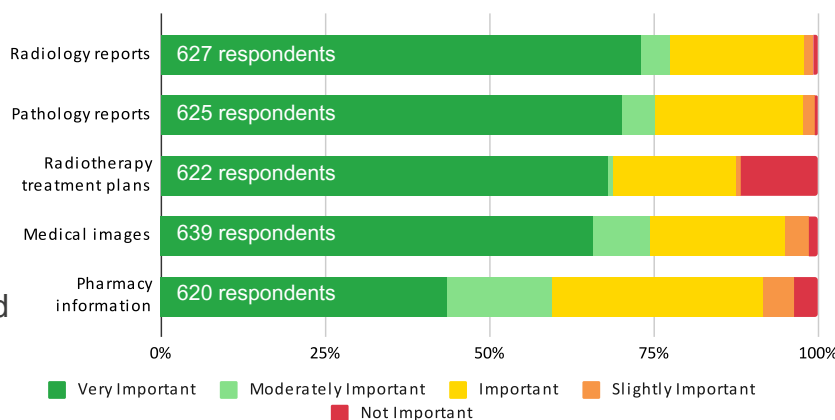
Patients want all their data in Opal

Supporting statements (additional statements in the <u>Appendix</u>)

"

"J'aimerais voir les résultats de test de sang fait au CLSC sur l'application Opal, même si une semaine après."
– *Répondant CB120*

"Il serait bien que ceux hors CUSM soient disponibles." – *Répondant CB138*

"Centralization is the key for all results, every department should have the obligation to use the platform."
– *Respondent CO122*

"Plateforme qui regrouperait tous les services de santé du Québec."
– *Répondant CO185*

"I would like to see my neurologist reports from the Neuro in Opal - currently I receive paper forms by mail."
– *Respondent CO279*

"Include other results Imaging pathology etc." – *Respondent CO197*

"It will be better if connected with other clinics." – *Respondent CO273*

"All appointments and scans available for the patient to see." – *Respondent CO170*

"It is perfect. Thank you. Just please add other test results too." - *Respondent CB159*

"Beside my blood work I would like to see my bone scans results." – *Respondent CB153*

"Aside from clinical notes, I would be disappointed if I lost any access to any of the data Opal provides today. In fact, I want more. **I would go to medical records to receive all my data**, but I hear from other patients it can be challenging."
– *Respondent RO19*

"Devrait être disponible dans tout les hôpitaux et accessible à tous."
– *Répondant CO168*

"I love the Opal app, I wish it was synched with all appointments within the MUHC. For example, I had a PET scan today and didn't get any confirmations or reminders like I did for my chemotherapy sessions/radiation and oncologist appointments."
– *Respondent CO111*

"I have never seen a tool like Opal in any other Quebec hospital, so I would just say the availability of Opal at other clinics and hospitals should be improved."
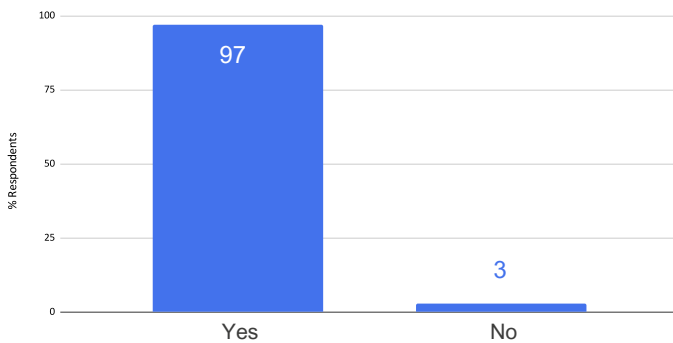– *Respondent CO62*

"

THEME 4

Opal can engage patients further

Overview

In the Opal Feedback Survey, several questions inquired about patients' interest in using Opal for activities that have the potential to provide them additional value and bring savings to the healthcare system. These include symptom reporting from home and sharing data with family doctors and informal caregivers. The survey results, and the written suggestions that were provided, show that patients are overwhelmingly ready and willing to engage more with Opal, and by extension the healthcare system, and eager to get more value out of it.

If it were possible for you to report your symptoms from home using Opal and have a medical professional monitor them and follow-up with you in case of problems, would you use the service? [646 respondents]


If it were possible for you to securely share your medical chart at the MUHC with your family doctor using Opal, would you make use of this service? [646 respondents]
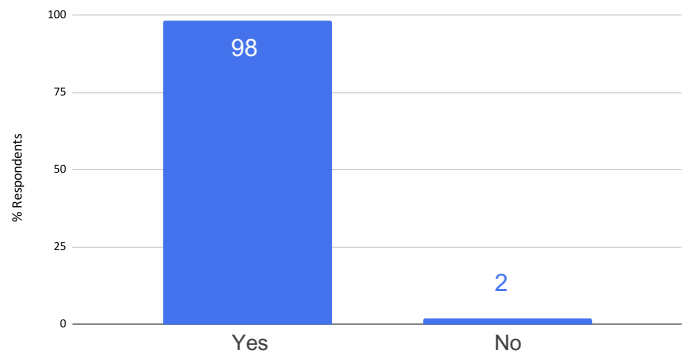
As the population ages and the burden of care increases on the healthcare system, the role of informal caregivers (family members, friends) is becoming more and more important. The need for access to data extends to informal caregivers, whether parents of pediatric patients or adult children of older parents. Opal's feedback survey results show that 82% of patients are willing to share their health data with their caregivers, and of these, 18% would like to be able to chose what data to share.

If your informal caregiver(s) had their own Opal account, which of the following would you choose? [365 respondents]
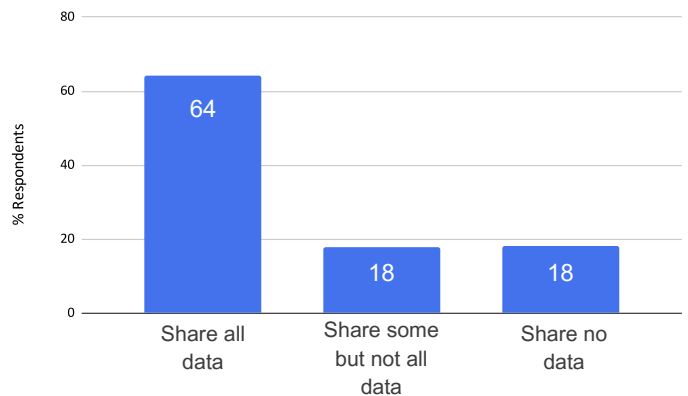
Opal can engage patients further

Supporting statements

"

"It would be nice to have a contact for a nurse or doctor when I have a flare up and treatment is not working. It would be nice if we could communicate with a person, rather than waiting 2 months until my next visit to report the treatment is not working or my condition is worsening."
– *Respondent CO47*

"Rendre le système accessible à toutes les équipes médicales, aux patients pour l'ensemble de leur suivi. Nous pourrions prendre nos rendez-vous pour nos examens selon nos disponibilités et celles des équipes médicales. Dans mon cas, je n'ai pas de problème d'heure et de jour et de disponibilité. Je pourrais ainsi remplacer rapidement une personne qui annule son RDV. Nous recevons déjà des notifications pour mon modifier par exemple nos RDV, Opal pourrait nous notifier une disponibilité dû à une annulation."
– *Répondant CO2*

"I want to write some messages or answer my doctor's questions from the app. So the medical team can get updates about my situation conveniently." – *Respondent CO51*

"Be able to cancel or change appointment." – *Respondent CO193*

"Please add an appointment confirmation feature so that presence to upcoming appointments can be given."
– *Respondent CO202*

"I like a lot the app, like the questionnaire because ask about how much affect my personal life to my health and treatment and medication or give an idea why I can get better faster or improve more."
– *Respondent CO177*

"It would be interesting to have a front and a behind of a human body to be able to mark all the places we are in pain. , because when we meet with the doctors they are very busy and I realize certain pain can be critical informations."
– *Respondent RO27*

"

THEME 5

Reading clinical notes is empowering

Overview

To assess patients' attitudes to reading their radiation oncology clinical notes in Opal, the Opal Health Informatics Group conducted a survey of patients who had read their notes in the summer of 2024. Questions were adapted from a similar study conducted at UCLA in 2019 (Shaverdian et al., 2019 [8]). The findings are presented here.

On reading my Radiation Oncology clinical note(s)... [118 respondents]

Legend: ■ Strongly Agree ■ Agree ■ Disagree ■ Strongly Disagree
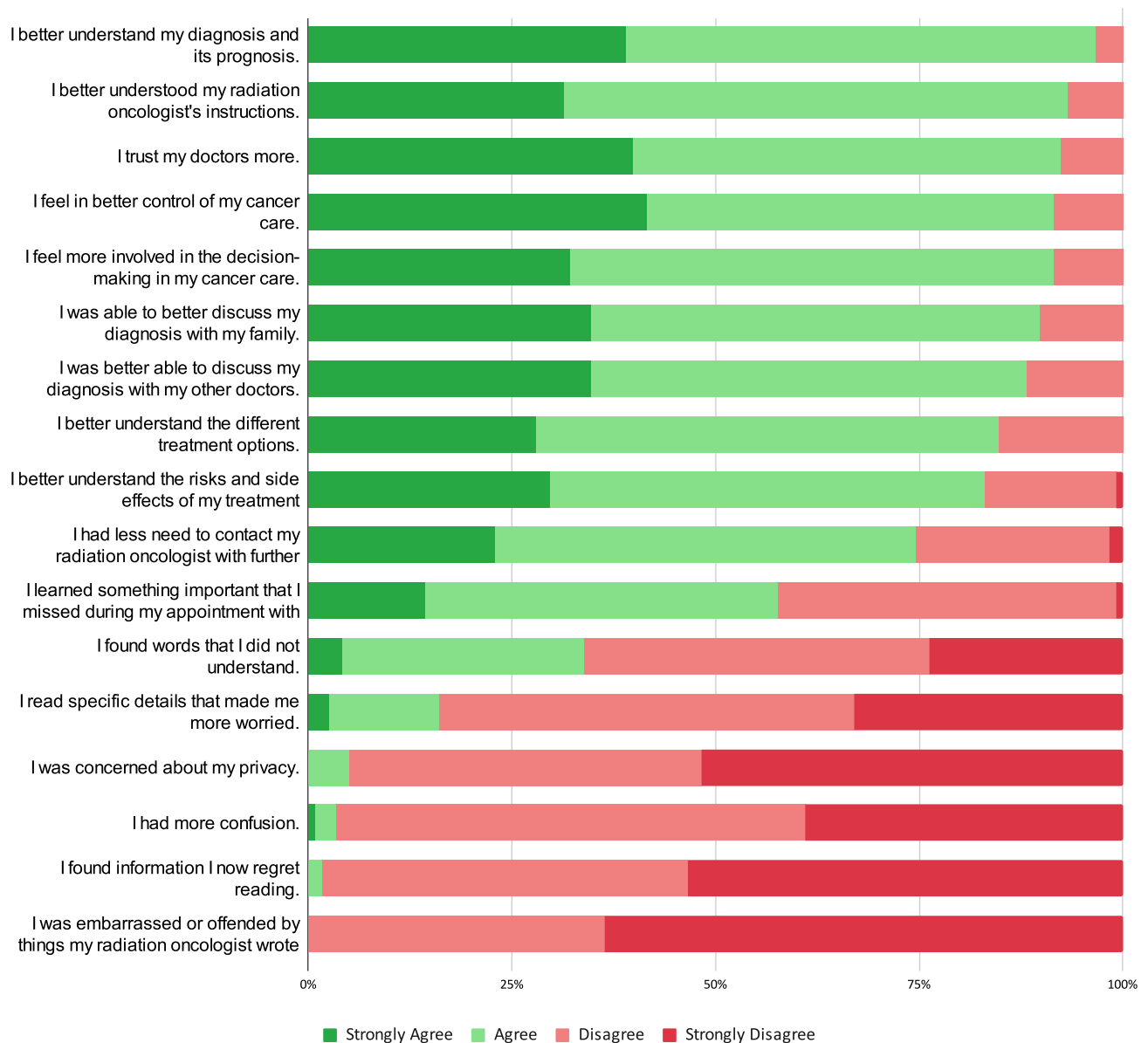
Reading clinical notes is empowering

Survey findings

It is clear from the survey data that access to clinical notes in Opal provides important benefits for the vast majority of patients. It helps them understand and discuss their diagnoses, increases their trust in their doctors, helps them feel more involved in the decision-making process, and feel more in control of their cancer care.

Crucially, on reading their notes, the majority of patients had less need to contact their radiation oncologists with further questions and they felt they learned something important that they had missed during their appointments. A very small minority of patients read things that they did not understand or experienced confusion.

The survey data also showed that 30 respondents (25%) reported finding errors in their clinical notes. Of these, 70% (21 respondents) reported that the error was not at all serious, 27% (8 respondents) reported that it was somewhat serious, and one respondent reported finding a very serious error. Only four respondents tried to have the error corrected.

Patients also shared their notes with other people in their care team, **with almost half of the respondents sharing notes with their family doctors and/or other doctors.**

Who have you shared your Radiation Oncology clinical notes with? [118 respondents]
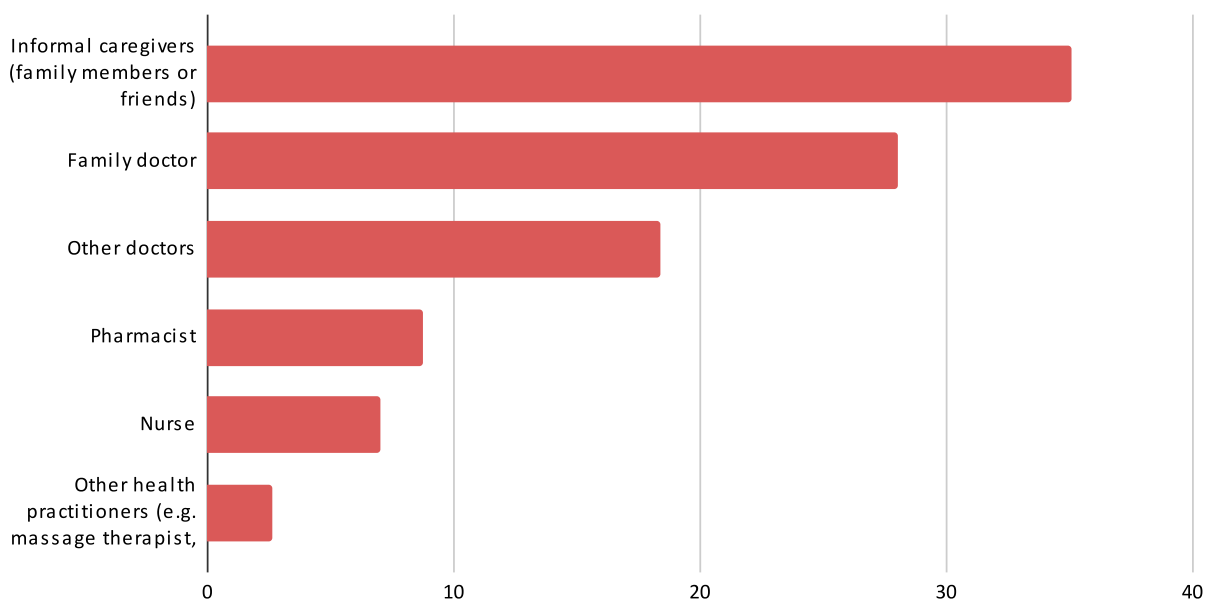
Reading clinical notes is empowering

Supporting statements

❝

"Opal has been a fantastic tool during my cancer journey. I cannot express how important it is for patients like me to access easily and in real time their lab results and Clinical notes. I just wished all physicians' notes were accessible. Not being in the medical field, my knowledge of anything related to cancer prior to my diagnosis was very limited. Having those notes helped me better understand my diagnosis and better navigate my treatment plan and that is extremely valuable!!! :-) I'm a fan."
– *Respondent RO34*

"Opal is so very needed, it's really helpful. The more information available the better, but I already found it incredibly useful for my brief treatment period. Seeing notes from my doctor is great too, I'm not aware if I could access that any other way."
– *Respondent CO85*

"I enjoy having access to the Opal app Essentially before my appointment Once I see my lab results I'm ready to ask the doctor questions regarding my health I would like if the opal app can give me more access to other test results done and doctors clinical notes regarding my health." – *Respondent RO45*

"Merci pour l'acces aux notes cliniques qui nous permettent de connaitre mon état de santé" – *Répondant RO3*

"It has helped me to understand, accept and share my prognostic with my friends and family." – *Respondent RO2*

"I really enjoy the app, have told many people about it, and wish all doctors would submit notes. No other cancer centre I heard off has such an app. I'm surprised it is not better advertised, another patient told me about it when waiting for chemo. Otherwise I would not have known. Also really appreciated the check in option for radiation during Covid!" – *Respondent RO38*

"I love Opal ! I think all the departments at the MUHC should use this app. As a cancer patient I wish my oncologist would make his notes available. I often feel excluded from my care. I think OPAL empowers patients to be an active partner in their own healthcare."
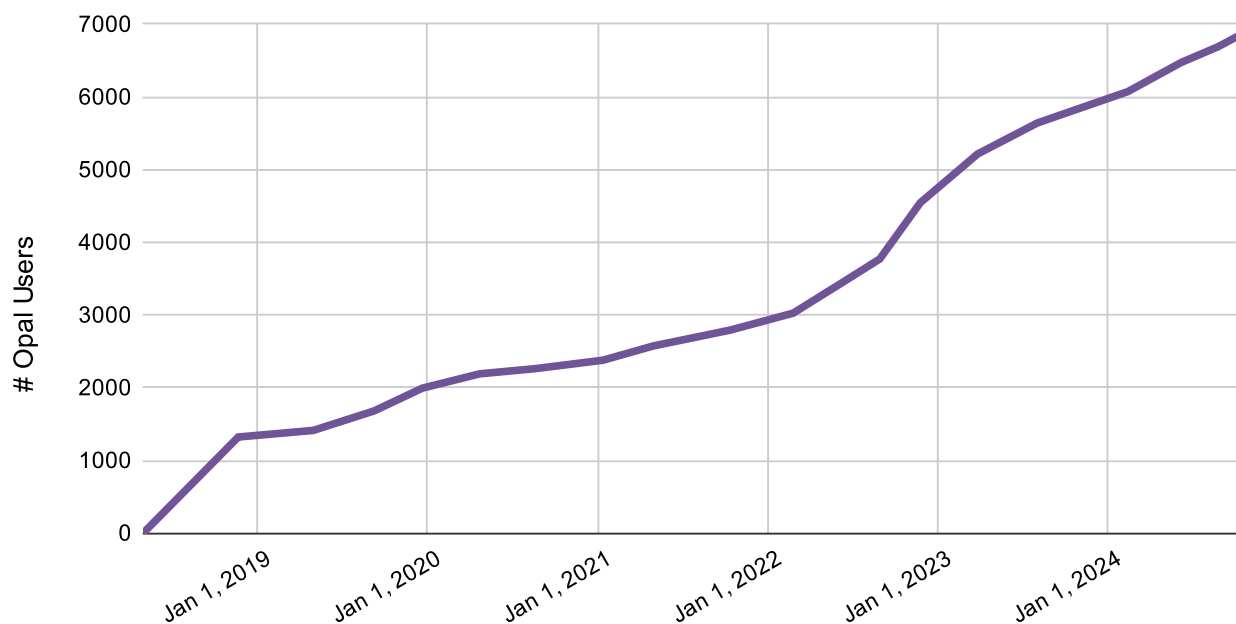– *Respondent RO6*

❞

USER AND USAGE STATISTICS

Opal Patient Portal

User growth

Count of patients registering for Opal

The number of patients registered for Opal has climbed steadily over time. Currently, **almost 7,000 patients** use it, mainly at the Cedars Cancer Centre and the Inflammatory Bowel Disease Clinic at the Montreal General Hospital, with a handful of users in the Nephrology Division at the Montreal Children's Hospital and at the Chronic Viral Illness HIV Clinic at the Royal Victoria Hospital.

Note: As Opal is not an officially-supported MUHC application, it is not actively advertised at the hospital. However, no patient who wants to register is refused. This means that patients mainly hear about Opal from each other and from some clinicians who promote it to their patients. We observed spikes in registration for Opal after we conducted waiting room surveys. As such, we believe that if Opal was advertised to all patients, the number of registered users would be much higher than it actually is.
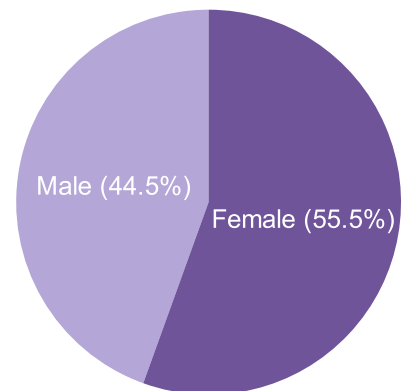
Opal Patient Portal

User Demographics

**Age distribution of Opal users**
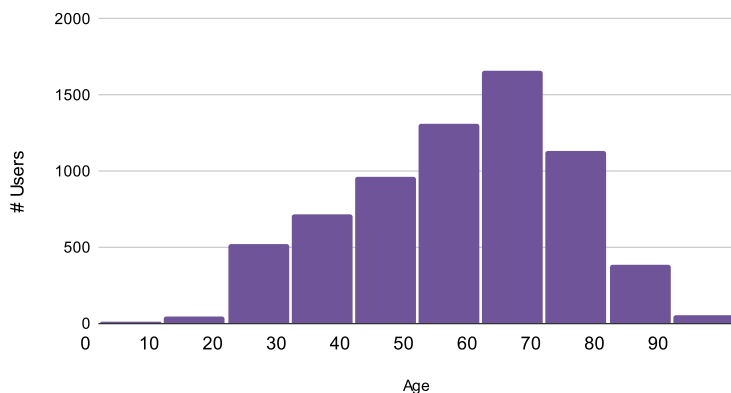
Opal users

Patients of all ages use Opal, with the median age being 58 years old. Currently, most patients are female, as Opal was initially rolled out for breast cancer patients. For pediatric patients (less than 14 years old) seen at the Nephrology Division of the Montreal Children's Hospital, parents are provided access via a request approved by Medical Records.

Almost half of Opal users have informal caregivers, and almost half of these users share their Opal account with them. In particular, older parents tend to provide their adult children with access to their Opal accounts.

Do you have an informal caregiver (for example, a family member or a friend) who helps you with your care? [646 respondents]
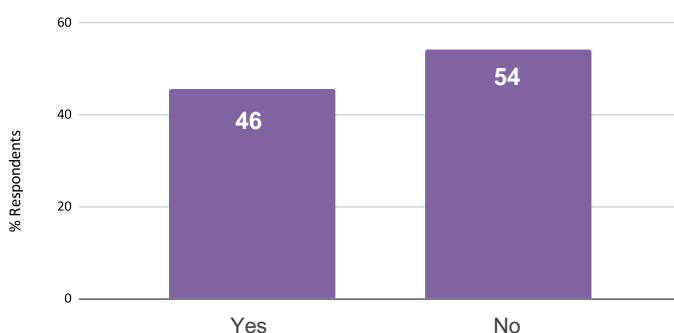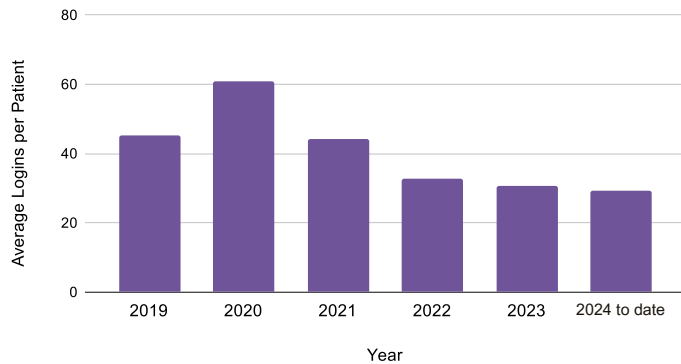

If you have one or more informal caregivers, do you share your Opal account with them? [332 respondents]
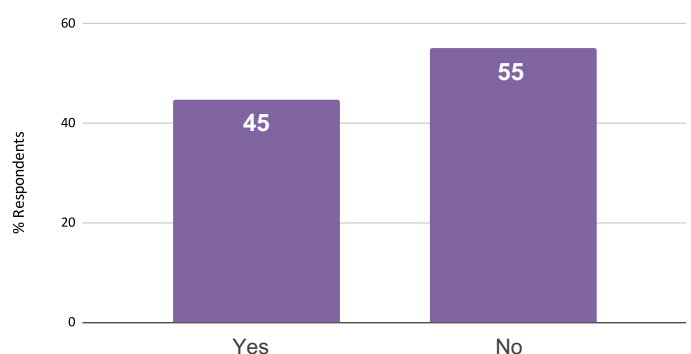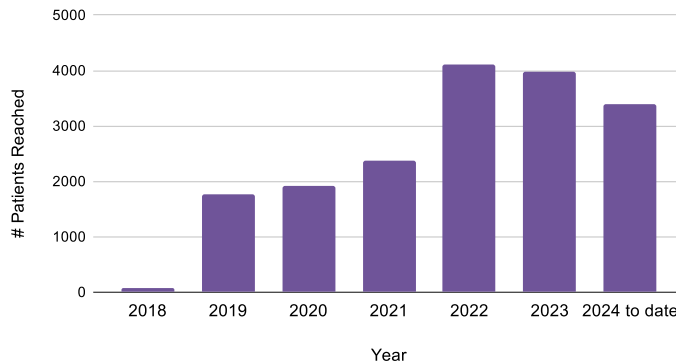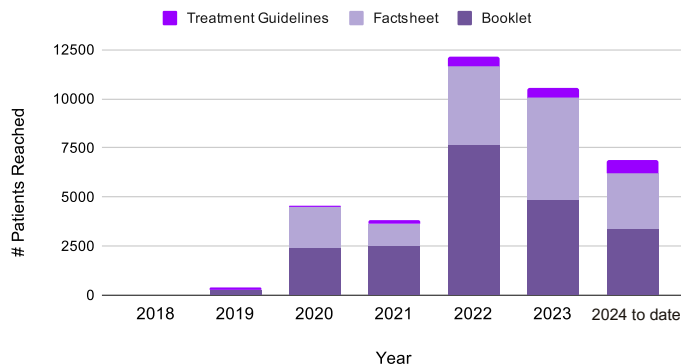
Opal Patient Portal
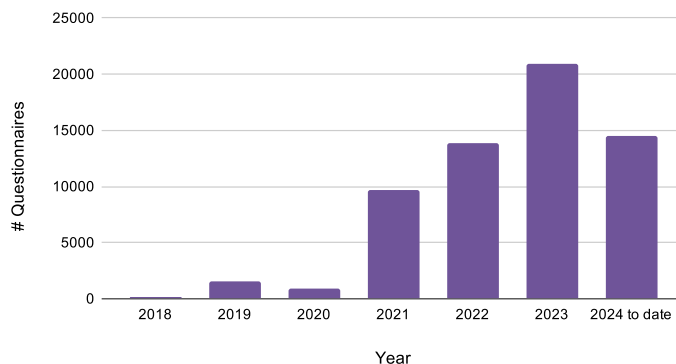
Usage statistics

Average Opal logins per user per year

Clinical notes sent by Opal

Education materials distributed using Opal

Questionnaires distributed by Opal

By sharing clinical data, education materials to explain the data, and questionnaires to patients, Opal meets its goal of being a patient-in-the-loop data platform. Each day hundreds of patients at the MUHC are empowered with the information they need to play an informed role in their own care, and the healthcare system benefits from the efficiencies Opal provides.

Interestingly, the average number of Opal logins per user per year was highest in 2020, likely due to patients accessing COVID test results and information.

Despite its seemingly impressive usage statistics, Opal is underused and underexploited and it is barely scratching the surface of its potential at the MUHC.

Opal Room Management System

The backbone of operations at the Cedars Cancer Centre

ORMS has been used in Radiation Oncology since the Cedars Cancer Centre opened in May 2015. As can be seen in the check-in statistics below, ORMS was initially confined to Radiation Oncology and there was no waiting room management system elsewhere in the cancer centre.

Check-ins using the Opal Room Management System
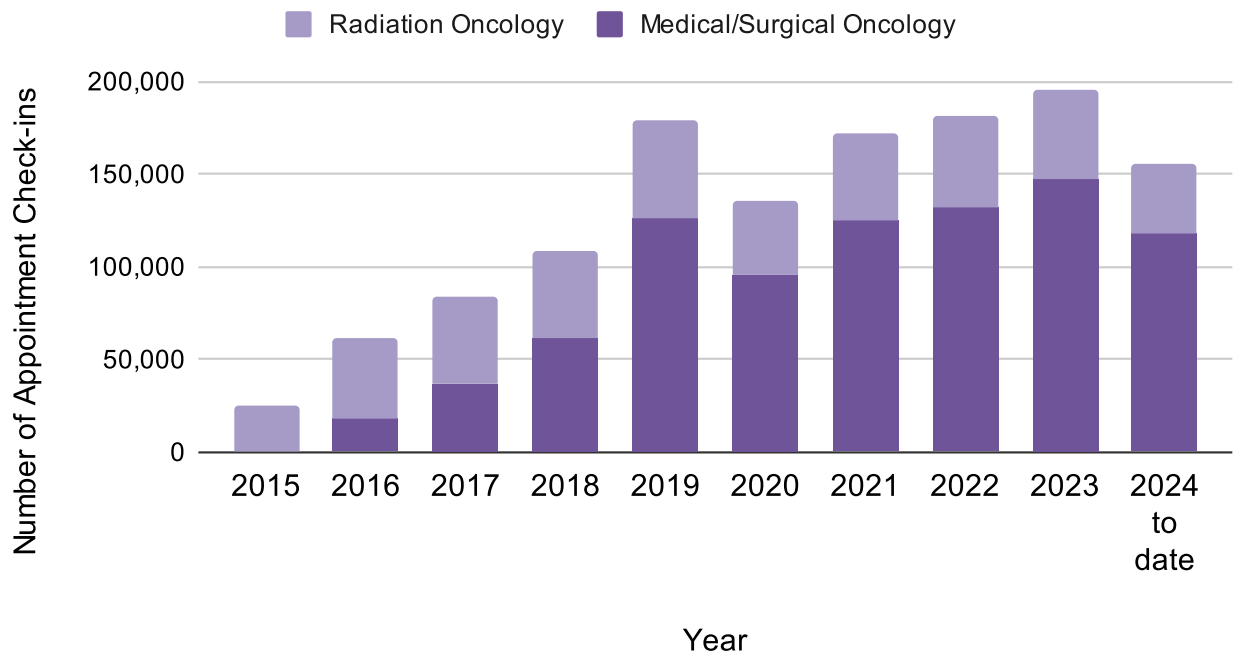
Prior to ORMS, patients at the RC level of the Cedars Cancer Centre were required to stand in line to check in for each of their appointments individually at the reception. This gave rise to long lines of sick people standing waiting, and it required significant clerical resources to check in each patient. Complaints were frequent, and some patients fainted while waiting.

At the same time, patients were called into their appointments via the overhead public announcement system. Given that several hundred patients are seen per day at the cancer centre, with many patients having several appointments, the overhead announcements were incessant, and the jarring noise was painful for both patients and staff.

Opal Room Management System

Designed to address a challenging patient experience problem

> ## Feedback before ORMS
>
> "The loud rings before each announcement are jarring and irritating." – *Pre-ORMS Survey respondent*
>
> "Quand il y a une grande file d'attente, des fois c'est dur de rester debout pour les personnes qui sont en traitement." – *Pre-ORMS Survey respondent*
>
> "(Desk check-in) long, slow line up very inconvenient + tiring (especially when not feeling well)."
> – *Pre-ORMS Survey respondent*

When it was expanded throughout the Cedars Cancer Centre, ORMS offered a seamless waiting room management experience to patients and staff, eliminated the check-in lines at the reception, saved significant clerical resources, and provided for a much calmer and more pleasant waiting room.
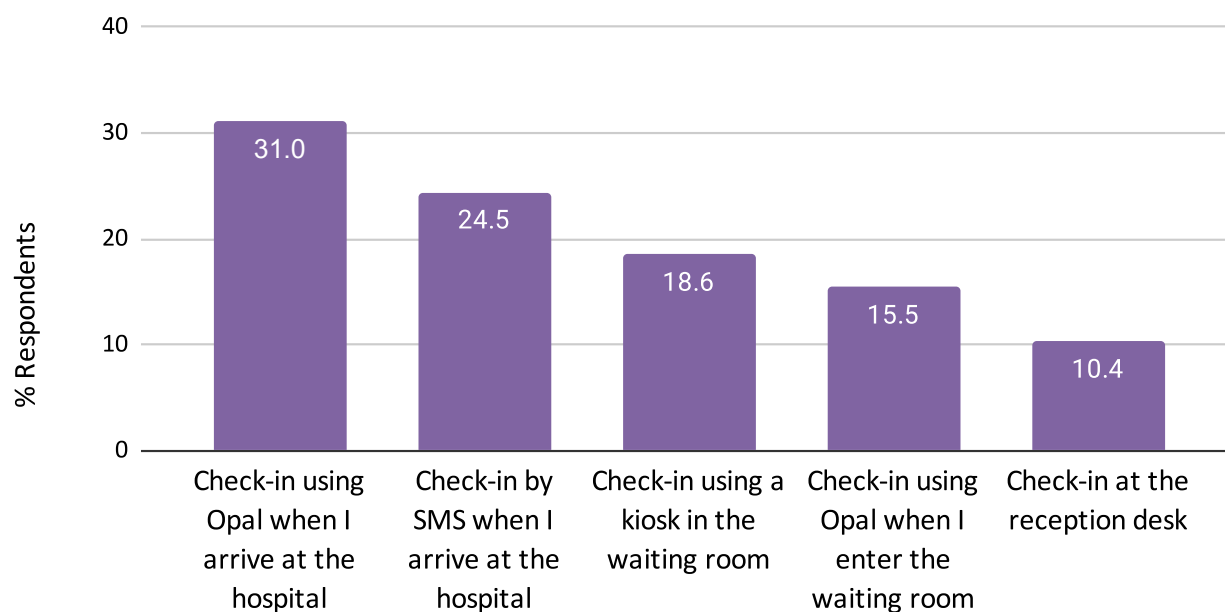
Today, ORMS offers patients a choice of check-in via the Opal patient portal, kiosks, SMS messages, and the reception.

Opal Room Management System

Post-implementation feedback: A major improvement

Which of the following appointment check-in systems do you prefer? [646 respondents]

As the survey results above clearly show, the self-check-in services offered by Opal are by far the preferred methods that patients use to check-in. The reception desk, which initially was the only option, is the least preferred.

Today, ORMS is used by approximately 200 clinicians per day, mainly at the Cedars Cancer Centre where it is used to coordinate the appointments of all patients, representing about 40% of the ambulatory patient population at the MUHC.

Since it was first rolled out at the Glen Site in 2015, ORMS has been used to manage roughly **1.3 million patient visits**. Today, it is the operational backbone of the Cedars Cancer Centre.

Opal Room Management System

An operational savings to the healthcare system
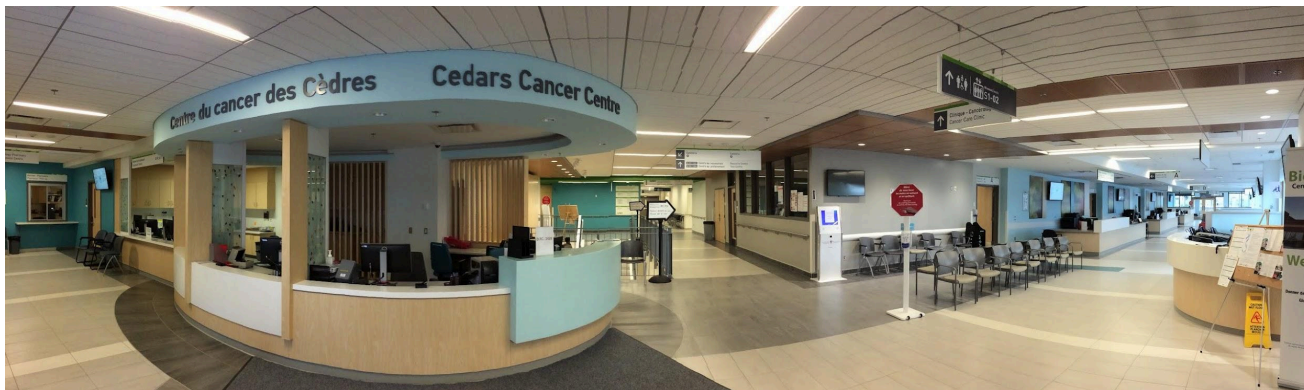
Prior to the implementation of ORMS, 3-4 clerical staff were dedicated to appointment check-in at the RC level of the Cedars Cancer Centre. Today, just one receptionist is required and the job is relatively calm. This represents a savings of 2-3 full-time equivalent (FTE) clerical staff per year. Combined with an estimated saving of 1 FTE at the S1 level, where ORMS has been operational from day one, ORMS has saved the cancer centre an estimated 31 FTE staff over 10 years (accounting for partial savings during 2016-2019).

Considering that ORMS provides both an improved experience for patients and staff and significant cost savings to the hospital, it is indisputably a cost-effective system.

To date, the cost of operating ORMS has not appeared on the operational budget of the MUHC. It has been covered by research grants provided to OHIG from hospital foundations (Montreal General Hospital Foundation, Cedars Cancer Foundation, and MUHC Foundation) and research grants, including the Quebec SmartCare Consortium project.

COLLABORATION

Quebec SmartCare Consortium

Leveraging Opal's secure data-sharing technology

With a goal of making Opal sustainable, in 2021 John Kildea convened a group of public and private partners to enhance and leverage Opal's secure data-sharing technology to unite patients, clinicians, researchers, healthcare institutions, and the Quebec digital health industry. The collaboration is known as the Quebec SmartCare Consortium (QSCC, quebecsmartcare.com).

The QSCC has included nine private partners (Roche, Novartis, Gray Oncology Solutions, Injoy, CyVault, VitalTracer, iMD Research, MIMs, and Imagia), two universities (McGill and Université de Montreal), two hospitals (MUHC and CHU Ste-Justine), and two hospital foundations (MUHC Foundation and Cedars Cancer Foundation). At McGill University, both the Centre of Genomics and Policy and the Neuro are involved.
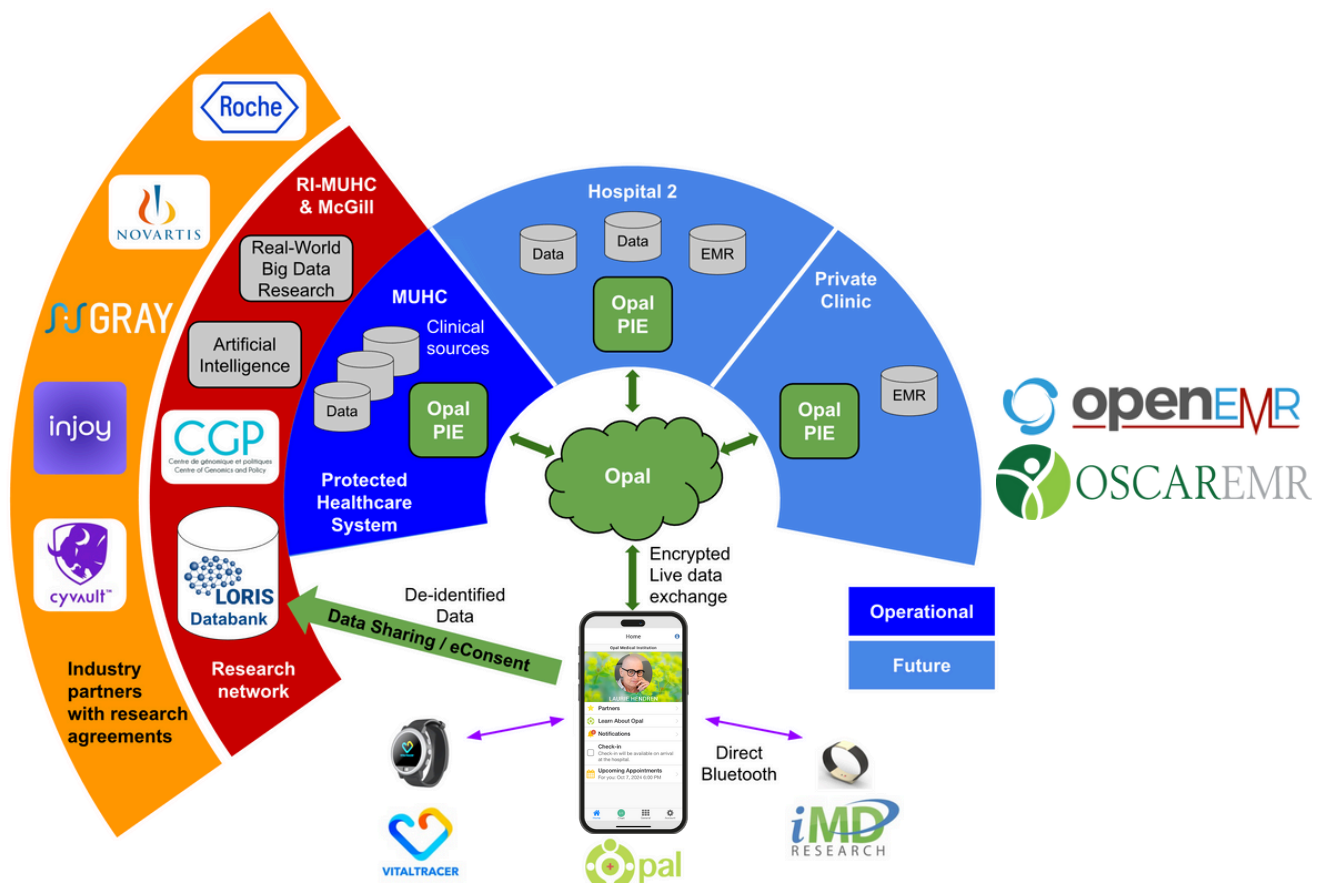
Leveraging Opal's secure data-sharing technology

The QSCC is using the technology of Opal to facilitate multi-institutional patient-in-the-loop data for patients, clinicians, researchers, and industry partners simultaneously.

Over the last three years, via the *Fonds d'accélération des collaborations en santé* program of Quebec's Ministry of Economy, Innovation and Energy, the QSCC has provided the funding ($10.18M) to support Opal's continued development and operation. **All the partners play a role in making the solution scalable and ready to be deployed beyond the MUHC. Funding for the QSCC will finish at the end of 2024.**

Accueil ‹ Nouvelles ‹

Fonds d'accélération des collaborations en santé - APPUI DE 4,8 M$ À L'INSTITUT DE RECHERCHE DU CENTRE UNIVERSITAIRE DE SANTÉ MCGILL ET SES PARTENAIRES POUR UN PROJET DE CONSORTIUM DE SOINS INTELLIGENTS

Fonds d'accélération des collaborations en santé - APPUI DE 4,8 M$ À L'INSTITUT DE RECHERCHE DU CENTRE UNIVERSITAIRE DE SANTÉ MCGILL ET SES PARTENAIRES POUR UN PROJET DE CONSORTIUM DE SOINS INTELLIGENTS

13 décembre 2021, 09 h 00
Publié par : Cabinet de la ministre de l'Économie, de l'Innovation et de l'Énergie et ministre responsable du Développement économique régional
En collaboration avec : Économie, Innovation et Énergie

Participatory stakeholder co-design

Working together to address patient needs

Participatory stakeholder co-design is a design approach that involves **all stakeholders**, including patients, clinicians, researchers, allied healthcare professionals, and students (future stakeholders) as full participants in the design of a product or service. It is the modus operandi of the Opal Health Informatics Group and was vital in the development and roll-out of Opal at the MUHC. As shown, the patient is not considered as the centre of the effort–it is not "patient-centered" as such. Rather, the team, which **included patients as equal stakeholders**, endeavours to put the diverse needs of patients, as people with lives beyond their diagnosis and treatment, at the centre of the effort.

For more details on Opal's design approach, see Kildea et al, (2019) [9].

LOOKING FORWARD

Patient-in-the-loop data

### Rethinking health data with patients and for patients

Patient-in-the-loop data are healthcare data that are shared in real-time with the patient (or their informal caregivers) just as they are with the professional members of the patient's care team. **They promote patient empowerment, transparency, and shared decision making.**

As the population ages and the demands on the healthcare system increase, there is growing recognition of the value of empowering patients to play a more informed and active role in their care. But, the vast majority of patients, particularly in Quebec, do not have direct or real-time access to their healthcare data.

Patient

Physician   Patient in-the-loop data   Nurse

Allied health

As such, most patients are second-class members of their own care teams and unable to play a fully-informed and active role in their care.

Patient-in-the-loop data are designed to ensure that patients are always in the loop about their own health and healthcare and are empowered to make informed decisions.

Opal was designed as a patient-in-the-loop data platform.
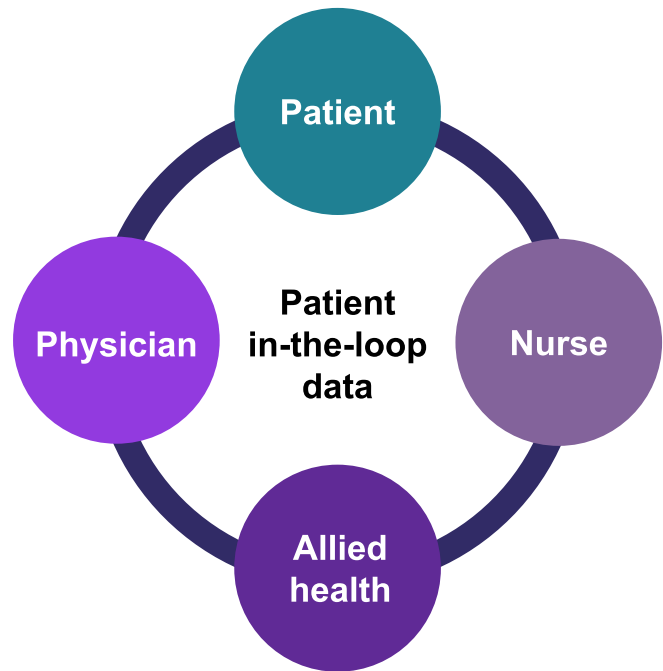
Laurie Hendren Symposium

Starting the discussion in Quebec

Keynote speakers Prof. Maria Hägglund from Uppsala University and Dr. Steve O'Neill from Beth Israel Deaconess Medical Center and Harvard Medical School at the Laurie Hendren Symposium on Patient-in-the-loop data.

The Opal Health Informatics Group hosted the first symposium on Patient-in-the-loop data at the RI-MUHC in August 2024.

20 international and local invited speakers and panelists and more than 200 attendees helped kickstart the conversation on implementing patient-in-the-loop data in Quebec. More details and recordings from the event can be found at lhsymposium.com.

Opal's open-source vision

Sharing Opal's patient-in-the-loop data technology

Over the past year, OHIG has been preparing the source code of Opal for open-source licensing. When released in December 2024, Opal will become the first open-source patient portal that is not bound to a particular electronic medical record system. In fact, Opal is vendor agnostic and can support multiple institutions simultaneously. It can work with any electronic medical record system, including that of Epic Medical Systems, which is presently being installed in Quebec. By going open-source, the source code of Opal will be available for developers and IT specialists in Quebec and around the world, to use, improve, and expand.

OHIG intends to continue to lead Opal's official development at the RI-MUHC and build a robust open-source community to help make patient-in-the-loop data the standard of care everywhere.

OHIG is soliciting like-minded developers, donors, industry partners, and healthcare organizations to join in this exciting open-source effort. If you feel that you can contribute or if you think Opal's open-source technology can help you or your organization, please contact John Kildea at john.kildea @ mcgill.ca. If you would like to donate to the cause, please visit opalmedapps.com/donate.

Patient voices on Opal's future

"

"Cette application mérite d'être déployée. Très utile Je serais déçu si elle prenait fin. Merci aux programmeurs."
– *Répondant RO36*

"Je considère que d'avoir accès à un système comme Opal est un PLUS-PLUS parce que je peux suivre le développement de mon état de santé. Je suis de ceux qui vante le grand mérite d'un tel système. J'en parle ouvertement avec qui ce montre intéressé d'en entendre parler. Cela m'a permis de rassurer des personnes face à ce genre de diagnostic. J'aimerais même avoir accès à plus d'informations comme celles du chirurgien, de l'oncologue, etc. La suggestion que je vous fais dans la mesure où c'est réalisable : demander à chacun des patients s'il consent à voir tous ses résultats (prise de sang, commentaires des spécialiste, scan, etc) sur Opal. Plusieurs personnes à qui j'ai parlé lors de mes attentes dans mes traitements de radio-oncologie ne voulaient pas savoir et ainsi, évitaient de consulter Opal. Par contre, d'autres comme moi consultaient régulièrement Opal parce que nous voulons savoir ce que les spécialistes ont découvert, les traitements, la réussite ou pas de ceux-ci, etc. Quel excellent instrument d'information. SVP garder OPAL."
– *Répondant RO26*

"I hope Opal continues and is expanded."
– *Respondent RO30*

"I love the app and it can be improved by being given to all patients. It should be a part of the start of care and everyone should be told to use it. It can be improved by getting funding and not stopping its service at the end of 2024."
– *Respondent CO285*

"My radiation oncology patient experience was much enhanced once on Opal — Promote its use earlier. Overall impressed by the efficiency of radiotherapy technicians and defined work flows — kudos!" – *Respondent FD02*

"More publicity that it exists. Why aren't there posters around the waiting areas of the cancer care areas?"
– *Respondent CO48*

"Please do not change the way we are currently able to access our blood test results through OPAL. It's amazing and perfect that we're notified as soon as the results are available. If there were a delay, it would cause a lot of stress and anxiety!"
– *Respondent CB135*

"None of the doctors share the Opal account with their patients. I have spoken to several other patients and I'm the 1st person to let them know there is an app they can use to facilitate their appointments and hospital activities."
– *Respondent CO14*

"

Patient voices on Opal's future

"I heard that there is a possibility that Opal will become unfunded as of December 2024. It greatly disappointed me to hear this. It feels like a step backwards… I have a lot more to say about this, but don't even know who to communicate it to." – *Clarice*

"Je vous encourage à continuer le projet Opal." – *Répondant RO41*

"I have heard that no decision has been made concerning the use of Opal beyond December 2024. I could (sort of) understand that the sharing of data with the patient depends on negotiations with the government. However, I would like to stress that all the aspects that concern appointment management are invaluable for the patients, and play a large role in reducing patient's stress. From my point of view, it is mandatory to keep at least those functions of Opal going." – *Christian*
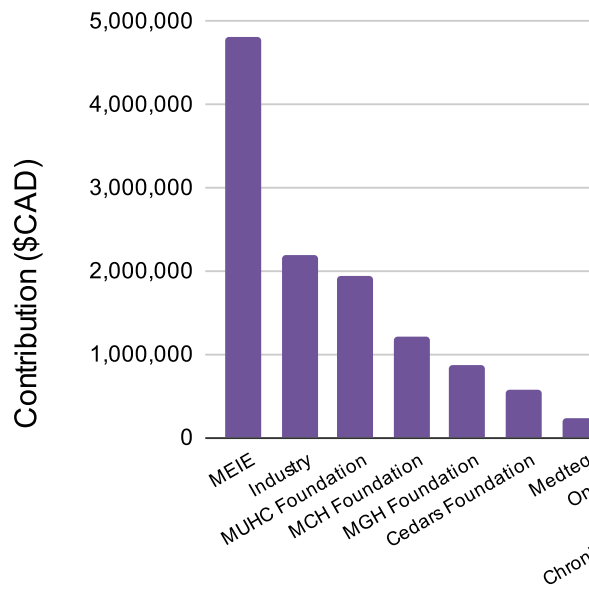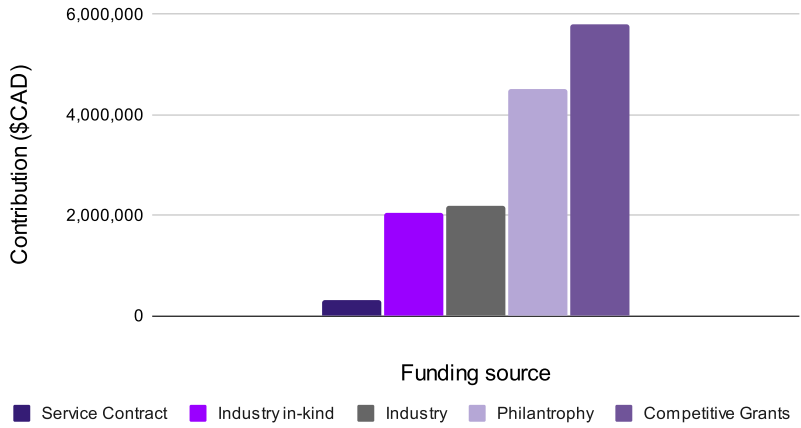
FUNDING

Non-commercial research

Supported by hospital foundations and research grants

Opal would not be possible without the donors and funding agencies that have generously supported it and shared its vision.

Opal funding by source since 2014

Opal funding by type since 2014

Initial funding that ultimately gave rise to the Opal project was secured via the Q+ competition at the MUHC, which was generously sponsored by the Montreal General Hospital Foundation and Corporation. Subsequent funding from the Cedars, MUHC, and Montreal Children's Hospital foundations along with competitive research grants (Principal investigator: John Kildea), and funding (cash and in-kind) from industry partners has ensured Opal's operation at the MUHC over the years.

The following page shows the logos of the financial partners who have generously contributed to the Opal project over the years, including partners in the Quebec SmartCare Consortium.

PARTNERS

Thank you!

Opal's generous partners

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APPENDIX

Patient feedback

Shared verbatim

Over the last few years we have received feedback from hundreds of patients, both solicited via our surveys, focus groups, and interviews, and unsolicited through the feedback form in the Opal patient portal and emails to the Opal support team.

For readability we arranged just a small subset of the feedback throughout the report, where relevant. The remainder of the feedback that supports the identified themes is gathered below and arranged by theme, in order to preserve and acknowledge the valuable input of our patient stakeholders.

Patients love Opal

"I have been a happy Opal App user for over two years and find it an invaluable tool for managing my lab results between the different doctors I see at the MUHC. Bravo to the Opal Team!" – *Rudy*

"I have applauded your work before and reiterate that Opal is excellent. " – *Andrew*

"J'apprécie grandement ce service. Merci" – *Lise*

"Wonderful. It is an important tool for patients. Helps us keep track of all our appointments! Thank you for making this available." – *Anna*

"... I also really liked the appointment calendar during radiation and immunotherapy. The blood tests were not as important to me then… but getting appointments sometimes 2 months in advance was really nice." – *Respondent CB15*

"A very useful app." – *Respondent CO222*

"I think this app is wonderful…" – *Respondent CO227*

"Having gone through Cancer, this application has made my journey much easier to process and understand. Thank you for creating such a fabulous app. Especially for us who have a lot of brain fog. It's a great reference to have." – *Respondent RO20*

"Opal is a great tool to access information about your treatment, it should be made available as soon as you have your diagnosis and are set up with your oncologist." – *Myriam*

"Opal is amazing and is underutilized because staff are not allowed to inform patients of its existence. If everyone knew their journeys would be transformed. Knowledge is power, knowledge is required for informed consent and decision making. Withholding patients' own information is unacceptable and based on inaccurate assumptions." – *Respondent CO283*

"Je trouve cette application exceptionnelle." – *Répondant CO149*

"OPAL Is just fantastic !" – *Respondent CB34*

Patients love Opal

"I love it for my diagnostic notes. Timeline of my operation, treatments, blood work, appointments. It's great! I don't have to rely on my memory. Lol!"
– *Respondent CO136*

"Je trouve cette application géniale, et tout ajout ou modification ne ferait qu'augmenter l'expérience et la satisfaction du patient."
– *Respondent CO101*

"I love how it is oriented towards the patient in terms of ease of use and language. Thanks for developing and implementing this app." – *Respondent CO79*

" Real-time test results are essential

"Ça permet de m'impliquer davantage dans ma santé.
- Je peux poser des questions plus précises sur ma santé à mon médecin.
- Ça me permet d'être plus consciente de certains aspects de ma santé et d'ajuster certains aspects de mon mode de vie et de mon alimentation.
- Je peux y remédier rapidement.
- Ça me rassure et me permet de voir l'évolution de mes données au fil du temps et de m'en souvenir!
- Cet aspect d'Opal a vraiment changé ma vie pour le mieux.
- Ma filleule qui est infirmière le voudrait !" – *Répondant CB103*

"Même si je reçois mes résultats de test sanguin je ne suis pas capable de les interpréter, mais je peux les présenter à mon médecin de famille si je le vois." – *Répondant CB46*

"Just keep this feature please."
– *Respondent CB185*

"Seeing my blood test results as they become available, provides a significant sense of relief."
– *Respondent CB133*

"This is a huge improvement over the Quebec system to receive immediate results. I am informed and don't need to call my doctor to understand my results. It's also my experience in Florida to receive immediate test results."
– *Respondent CB309*

"I think the blood test results are amazing fast and efficient."
– *Respondent CB288*

Having the results before I meet my doctors is helpful and empowering."
– *Respondent CB51*

"I like having my blood test results immediately so I know what questions to ask when I get to see my doctor."
– *Respondent CB169*

"Obviously, seeing good blood test results contribute to less anxiety, but I experience more anxiety if results are not optimal" – *Respondent CB318*

"I love that there is the feature that gives an explanation to of the various results." – *Respondent CB102*

"

" Real-time test results are essential

"No concerns, I want to know asap my condition. Since I am at my 3rd cancer."
– *Respondent CB104*

"We are unable to interpret the results correctly but I'd still rather see my results right away." – *Respondent CB149*

"I appreciate having results show in real time and seeing real numbers rather than just being told that the numbers are 'fine' or 'other.'" – *Respondent CB39*

"Je peux connaître rapidement mes résultats. Je consulte chaque résultat inscrit sur la feuille en regardant l'information explicative de chacun des tests. Je clique sur cette information essentielle pour mieux comprendre. Au moment d'en parler avec le médecin ou spécialiste, je suis plus en mesure de poser des questions pour mieux comprendre la suite de mes traitements si c'est le cas" – *Répondant CB4*

"Makes me less anxious till I see my oncologist."– *Respondent CB291*

"I am glad to have the blood tests in Opal before going in to my onco appointment."
– *Respondent CB88*

"I love this option to receive right away."
– *Respondent CB319*

"Seeing my results lets me be prepared if I have any questions. On the spot is not enough time to check and be prepared if I have a question and once you're gone from the doctor's office it's too late."
– *Respondent CB223*

"I like knowing I can view my blood test results anytime and see the progress or where I feel improvement could come in play."
– *Respondent CB284*

"Love love love having quick and direct access to my blood results."
– *Respondent CB40*

"J'adore avoir les résultats dans l'heure suivant la prise de sang"
– **Répondant CB313**

"Je suis très satisfait surtout en ce a trait la rapidité et l'accessibilité des résultats Opal par l'usager."
– *Répondant CO67*

"Need to know WBC & neutrophils Also want to see results of cancer markers as this causes me anxiety."
– *Respondent CB225*

"It makes me feel like I'm in charge"
– *Respondent CB141*

"

" Real-time test results are essential

"I find it convenient to receive blood test results in Opal instead of running to thearchives every time."
– *Respondent CB273*

"I like Opal very much. I am a Breast Cancer patient that is participating in a TBC Research Study. Opal notifies me of my follow up appointments in Oncology and also the results of my blood tests from the Lab. I get the results of my blood tests before my Research Team even knows. I like that very much." – *Nancy*

"This is brilliant. I get a snapshot of how I am doing before I see my doctor and can prepare relevant questions."
– *Respondent CB155*

"Depuis que je suis inscrite a Opal, j'apprécie beaucoup recevoir le résultat de mes tests sanguins lorsque je suis en attente de voir mon médecin. De plus, l'option de voir l'historique des résultats me permet de mieux comprendre comment mon corps réagit à ma chimiothérapie et les résultats problèmes. Je suis suivie depuis 2018, j'en suis à ma 3e session de chimio de 6 séances chacune alors j'ai appris à interpréter mes résultats.
– *Répondant CB278*

"Like the fact that I can see bloodtests results as soon as they are ready."
– *Respondent CB320*

"If a result that is worrisome is published on a Friday afternoon, you might only be able to contact the clinic the next Monday, so that can cause stress for a user. In that sense, I think the test results should be published at a time where the treatment team will be able to answer questions about them"
– *Respondent CB235*

"Part of following up my health. My medical file." – *Respondent CB147*

"I like that I can see my results ASAP." – *Respondent CB128*

"Voir les résultats pour que je puisse les comprendre"
– *Répondant CB180*

"Opal m'aide à mieux comprendre ma condition et les raisons pour lesquelles on me prescrit un traitement." – *Répondant CB299*

"Cette fonctionnalité est au delà de mes attentes; valeurs cibles, historiques, graphiques, wow."
– *Répondant CB293*

" Real-time test results are essential

"Il est certain que la lecture des résultats de tests sanguins génère un peu d'anxiété qui est par contre largement compensée par une meilleure préparation à la consultation médicale." – *Répondant CB83*

"Knowing my results helps me have an educated conversation with my doctor and treatment plan"
– *Respondent CB32*

"It may make me anxious but it would also prepare me to ask questions when I see the team."
– *Respondent CB300*

"I love to be informed and it's important to see improvement of my health :)" – *Respondent CB57*

"It's a bit worrisome but I want them."
– *Respondent CB265*

"I do not look at them as it would make me anxious. I don't want to misinterpret my results."
– *Respondent CB207*

"I appreciate knowing asap about my blood results."
– *Respondent CB68*

"I like that results are available promptly and to avoid delays at the pharmacy." – *Respondent CB201*

"Sometimes I want to see them right away, some other times I prefer looking after my meeting with my doctor." – *Respondent CB9*

"J'aime bien recevoir les résultats rapidement car lors de mon rendez-vous avec le médecin j ai déjà les résultats en main et si j'ai des questions je peu toujours demandé."
– *Répondant CB143*

"When I see the results I have a good idea of what is going on with my health." – *Respondent CB324*

"Very happy to see my results asap. It makes me feel secure, confident, and less anxious." – *Respondent CB112*

"Comparing results from previous tests is what I find helpful."
– *Respondent CB242*

"*Résultats accessibles et bien présentés.*" – *Répondant CB107*

"*Very good to see results.*"
– *Respondent CB302*

" Real-time test results are essential

"Opal in general has been great. We are able to get blood test results as soon as if not before the Dr. The only thing I would like to see is have cancelled appointments removed and notices that have been cancelled removed. Thanks"
– *Joanne*

"J'aime bien les graphiques de synthèse des mesures." - *Répondant CB181*

"I find it very helpful to see the past and present results as it gives me a comparison on how I am doing as well as be more prepared for my appointment with my specialist."
– *Respondent CB67*

"I enjoy this application on my phone. It is very helpful with regard to upcoming appointments, test results, etc."
– *Heather*

"This is a very convenient tool. I often see my doctor before the results are available. They always say they will call if anything is wrong, but with the app, I can refer to my results and have peace of mind that all is well instead of wondering if I will get a call."
– *Respondent CB110*

"Glad to have direct access to them."
– *Respondent CB216*

"Les résultats permettent de réagi plus rapidement."
– *Répondant CB24*

"It is amazing to see the chart of a specific test with historical data."
– *Respondent CB8*

"I think it is a great feature to have access to the blood test results."
– *Respondent CB282*

"Je ne comprend pas grand chose pour les résultats, mais c'est intéressant de voir tous les tests faits. Je demanderai au médecin si je m'en rappelle." – *Répondant CB262*

"Les résultats des tests sanguins dans Opal est très important parce que connaît ses résultats avant de rencontrer le Médecin."
– *Répondant CB178*

"Les résultats ont une fonction éducative. Les résultats me permettent de comparer avec les résultats précédents. Connaissance de ma situation."
– *Répondant CB197*

"I like being able to see them and share with other health specialist"
– *Respondent CB192*

" Real-time test results are essential

"Having my blood results prior a medical appointment permits me to have an informed intelligent discussion with physician." – *Respondent CB76*

"Could cause anxiety if I don't understand something or if the results are bad, but waiting is probably worse than getting results as soon as they are ready." – *Respondent CB94*

"Like the explanation associated with the results." – *Respondent CB211*

"Ce serait bien d'indiquer lors de résultats anormaux si quelque chose peut être fait pour corriger les résultats. Par exemple, éviter de manger tel type d'aliments." – *Répondant CB184*

"Being transfusion dependent most of my life, it is essential that I know where my hemoglobin in particular is at. I am constantly worried about my blood levels. Now I am constantly worried about cancer markers as well."
– *Respondent CB121*

"Très bonne application pour le suivi des rendez-vous et résultat des visites." – *Gabriel*

"It is good to track my health."
– *Respondent CB77*

"Having access to blood test results is extremely beneficial to aid with choosing healthy food plans."
– *Respondent CB312*

"It's great, I think the patient should have access to all test/scan results as soon as they are available, waiting for the results till you see the doctor is adding extra stress."
– *Respondent CB152*

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" Patients want all their data in Opal

"Que tous les rendez-vous et rapportsde médecins soit mis à notre disposition. Après tout c'est ma santé, ma vie et la seule que je possède. Je veux être au courant de tout, pour pouvoir prendre des décisions éclairées. Merci!" – *Répondant CO150*

"Don't [have access to] blood test results from other clinics"
– *Respondent CB213*

"More features need to be added like a list of meds we received and current ones." – *Respondent CB250*

"Would like to see blood test results from other hospitals."
– *Respondent CB272*

"I don't think this is an issue with Opal but would be nice to see all blood tests sent to my doctor. Right now I only see those done at the MUHC."
– *Respondent CB316*

"All departments should use not just for blood tests but for scans."
– *Respondent CB323*

"Expanded access to my entire integrated medical files!"
– *Respondent CO15*

"Should be for all hospitals at the MUHC not just Cedars."
– *Respondent CO54*

"Opal pourrait afficher tous les rendez-vous plutôt que seulement ceux d'oncologie. Par exemple les rendez-vous d'imagerie."
– *Répondant CO95*

"En me donnant accès à toutes mes infos, ce que je n'ai pas souhaité avoir au début."
– *Répondant CO125*

"I love Opal! I see my medical appointments for Radiologist and Oncology here. Keeps me organized! But the Breast clinic appointments and any testing they organize for me (imaging in other departments) do not appear and not connected to Opal? So not all my appointments at MUHC - here at the Royal Victoria Hospital are not available in Opal. Makes it hard to have some appointments appear but not all!" – *Respondent CO138*

"Je la trouve très bien, mais si on pourrais avoir plus de résultats, ce serait bien." – *Répondant CO9*

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" Patients want all their data in Opal

"One system showing everything would be the best and easiest and would be more efficient." – *Respondent CO58*

"Would like to see all appointments and results for my health care in Opal."
– *Respondent CO86*

"C'est un outil magnifique qui doit être développé et amélioré pour assurer une coordination avec toutes les parties prenantes du dossier médical (médecins, hôpitaux, prestataires, carnet santé Québec)."
– *Répondant CO88*

"Information from different specialist doctors." – *Respondent CO94*

"I would like to be able to see my appointments with my orthopaedic surgeon in the Cancer Centre in Opal."
– *Respondent CO102*

"Ajouter les rdvs des autres médecins, des Scan et IRM."
– *Répondant CO104*

"Add others beside blood test results such as patho, radio oncology, etc."
– *Respondent CO229*

"Would it be possible to include appointments made for the Breast Clinic (6th floor RVH) in the Opal app calendar? Currently, only appointments for the Radiation department and Cedars Cancer Center are included in the Opal app calendar." – *Respondent CO132*

"Accès à tous les rdv et informations médicales incluant les tests sanguins, les médicaments prescrits et le protocole de traitement." – *Répondant CO49*

"If Opal would include my other appointments at the MUHC such as scans, ultrasounds it would be beneficial. Overall, Opal fits my needs and has been helpful in staying organized."
– *Respondent CO60*

"It could be better to have more information, as much as possible"
– *Respondent CO27*

" Patients want all their data in Opal

"En y ajoutant les rapports de tests et examens comme CTScan, radiographie, Bone Scan.
Aussi ce ne sont pas tous les services de McGill qui l'utilisent. Je souhaiterais que ce soit utilisé par tous les départements pour une meilleure intégration.

- Gyneco-oncologie ne l'utilise pas ou peu..
- Général Oncologie oui pour Rv et prise de sang mais les rapports du médecin n'y sont pas ajoutés.
- Clinique du sein ?
- Radiothérapie.. oui assez bonne utilisation" – *Répondant CO134*

"Très belle initiative donnant aux patients un accès immédiat aux résultats d'analyse, j'espère qu'elle sera étendue à d'autres données, et d'autres centres hospitaliers/clsc. Le calendrier de rendez-vous est aussi une excellente fonctionnalité, avec les mises à jour et notifications." – *Répondant CO277*

"Just please add all other tests' result. Thank you! – *Respondent CO144*

"Access to more information"
– *Respondent CO151*

"Comme je le disais, j'aimerais avoir accès à mon dossier au complet, incluant les images des •scans en 3 dimensions, •mammos, •radiographies et les documents pour les •prochaines prises de sang (imprimables), car je suis une patiente en traitement de chimio.
* Aussi, quand les traitements sont terminés, il serait bon de savoir ce qui est conseillé et pas conseillé de faire. Ex: une opération en chirurgie esthétique que j'avais faite en 2XXX: Dr XXXX m'a dit que c'était une mauvaise idée pour mon système immunitaire, mais je ne l'ai pas su avant, car j'avais été traitée pour un cancer du sein en 2XXX. Merci de vous renseigner sur nos besoins, c'est très apprécié."
– *Répondant CO213*

"It is a fantastic app. Would love to see Ct scans, mri results, x rays etc in this app." – *Respondent CO38*

"Opal doit couvrir tout les domaines de la santé desservir sur toute l'étendu du territoire Québécois faire profiter tous le monde."
– *Répondant CO163*

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" Patients want all their data in Opal

"That all doctors use it. My oncologist didn't write any updates of my chart but my radio oncologist would write every appointment. Her summary of my visit was clear which I could read and update my family. My oncologist never used it."
– *Respondent CO98*

"Adding physician notes and imagery is important to me as it's important to me that I know exactly what information and results are in my medical file. I need to know what I'm dealing with regarding my health. Thank you for all the work you do in improving the Opal program, much appreciated." – *Respondent CO70*

"Make it available in all hospitals in the province of Quebec."
– *Respondent CO112*

"Ajout de la clinique Home TPN de l'hôpital général à Opal."
– *Répondant CO209*

"As mentioned before, Opal should provide access to all areas of a patients care." – *Respondent CO121*

"The more information you can access the better it would be."
– *Respondent CO135*

"Je suis assez satisfaite d'Opal. Ajoutez plus de résultats médicaux car vous êtes plus rapides que le Carnet Santé Québec."
– *Répondant CO93*

"Information d'autres hôpitaux."
– *Répondant CO218*

"More info available (oncology notes)"
– *Respondent CO220*

"Link to other hospitals."
– *Respondent CO186*

"Being able to see all medical records and images, and being able to share it." – *Respondent CO196*

"Rajouter davantage de fonctionnalités et de rdvs d'autres secteurs de l'hôpital."
– *Répondant CO231*

"Certaines informations sont absentes: exemple, rendez-vous en RX." – *Répondant CO258*

"Update my doctors. Show all, not just some, appointments."
– *Respondent CO266*

"

Patients want all their data in Opal

"Let's start listing all and any medical appointments with the various MUHC in the same way appointments are listed for the cancer care clinic. This will certainly relieve anxiety and stress among patients." – *Respondent CO48*

"It would be great if we could access our CT Scan reports and MRI reports! THANK YOU!" – *Respondent CO123*

"It should make effort to integrate medical data sharing between hospitals, family doctors and other external experts report for individual patient." – *Respondent CO139*

"Plus d'infos sur le dossier médical et la gestion des rendez-vous." – *Répondant CO55*

"List all appointments from the departments. Access to all reports and notes from departments used, ie: scans, X-rays, etc." – *Respondent CO56*

"As said earlier, I would like my imaging included." – *Respondent CO59*

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