Opal Health Informatics Group

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The open-source patientin-the-loop data platform





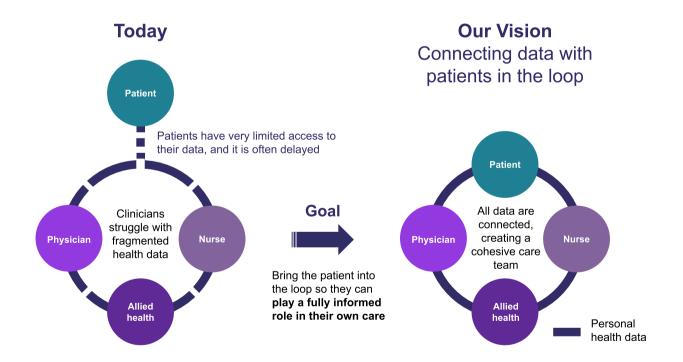
An award-winning platform that measurably improves the patient experience and increases patient engagement

PATIENT-IN-THE-LOOP DATA

Bringing patient partnership to the doctor's office

Patient partnership is a hot topic in modern healthcare. And rightly so. Patient involvement has led to meaningful improvements in the quality and safety of research and clinical care. But, for the vast majority of patients, partnership ends at the doctor's office. Why? Because few patients have the same access to their health data that their clinicians have. As such, most patients are second-class citizens in their own care teams...

The Opal Health Informatics Group is working to change this by promoting and facilitating **patient-in-the-loop data**. We define patient-in-the-loop data as health data, with appropriate explanations, that are shared in real-time with the patient (or their informal caregivers) just as they are with the other (professional) members of the patient's care team.



OPAL IN A NUTSHELL

Patients, clinicians, and researchers

The Opal platform consists of a **patient portal**, a **live clinic management dashboard**, and a **databank framework** for the collection of real-world "donated" data with patient e-consent.

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The Opal patient portal provides patients with:

- Appointment information, including maps and "how to prepare" instructions,
- Real-time clinical data (lab results, clinical notes, diagnoses, etc),
- Treating team messages,
- Forms (e-consent, PROMs, PREMs, research study instruments, surveys),
- Personalized informational resources (booklets, videos, factsheets), and
- Waiting room management resources (virtual check-in and call-in).

Opal's **live clinic management dashboard** provides:

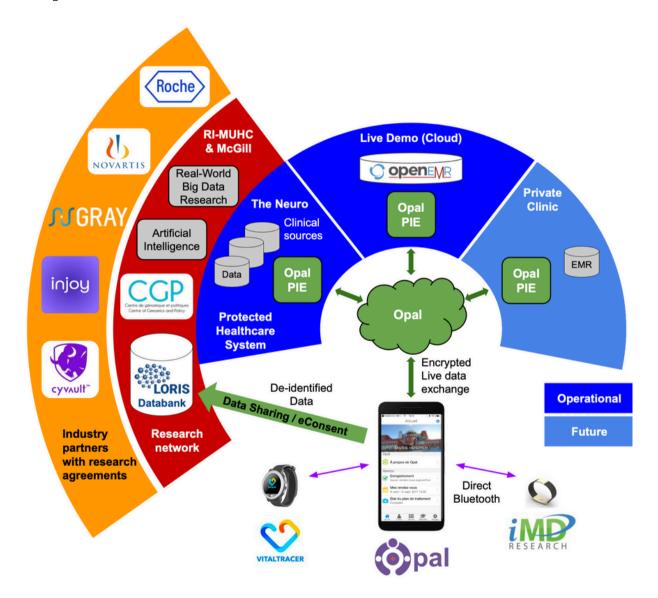
- Clinicians with a virtual waiting room for:
 - Patient call-in,
 - $_{\circ}\,$ Access to PROMs from the Opal app,
 - Access to test results.
- Patients with appointment check/call-in via:
 - Kiosks, the Opal app, an SMS service, and waiting room TV screens.

Opal's databank framework provides:

- Researchers with:
 - e-consenting,
 - A harvesting solution for real-world patient-donated data,
 - Integration with the open-source LORIS databank platform from the Montreal Neurological Institute.

SMART CARE

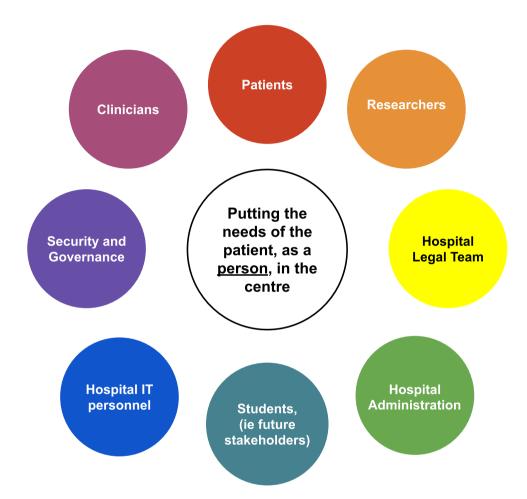
Leveraging Opal's unique patient-in-theloop data infrastructure



The recently-completed <u>Quebec SmartCare Consortium</u> project (2021-2024) was a \$10M research project funded by Quebec's Ministry of Economy, Innovation, and Energy and multiple private partners. It leveraged Opal's patient-in-the-loop data infrastructure to connect the technologies of its partners and showcased the power of simultaneous data-sharing between patients, clinicians, and researchers.

PARTICIPATORY CO-DESIGN

Working together for a win-win for all stakeholders



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. As shown, the patient is not considered as the centre of the effort–it is not "patient-centered" as such. Rather, the team, which **includes patients as equal stakeholders**, endeavours to put their diverse needs, as people with lives beyond their diagnoses and treatments, at the centre of the effort.

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

OPEN-EMR AND OPAL

A strategic open-source partnership



OpenEMR is the world's leading open-source medical practice management software. It is used to manage the records of an estimated 90 million patients worldwide. But its in-built patient portal is rudimentary. To make Opal available to the OpenEMR community, in March 2025, the OpenEMR Foundation and the Opal Health Informatics Group agreed on a strategic partnership to work towards out-of-the-box compatibility between OpenEMR and Opal.

A live cloud-hosted Opal-OpenEMR demo is available via the Opal open-source community documentation page - <u>docs.opalmedapps.com/user</u>.

Opal's source code is published at github.com/opalmedapps.

PATIENT VOICES

Feedback about Opal

Over the years, the Opal Health Informatics Group has gathered feedback from Opal users. To date, almost 1,500 patients have answered surveys, participated in interviews and focus groups, or provided unsolicited feedback. From these data, five themes emerge:

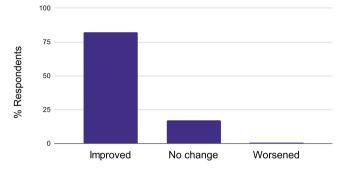


Each theme is presented in detail in the Opal Impact Report that is available on the Opal website - <u>opalmedapps.com</u>.

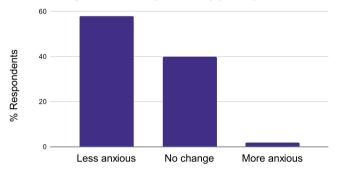
PERTINENT FEEDBACK

Survey results

How has Opal affected your experience at the McGill University Health Centre? [n=646]



In your experience, how has receiving your blood test results in real time using Opal affected your anxiety [n=480]

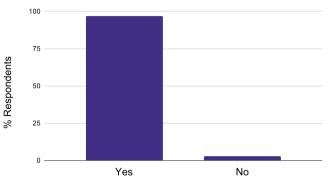


Which feature in Opal is most important to you as a patient?

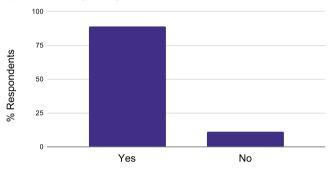
[n=646]



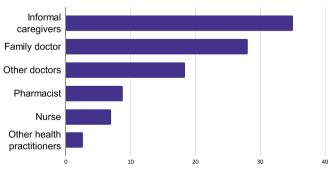
Would you recommend Opal to another patient? [n=646]



If Opal was available at another hospital/clinic, would you sign up for it there? [n=646]



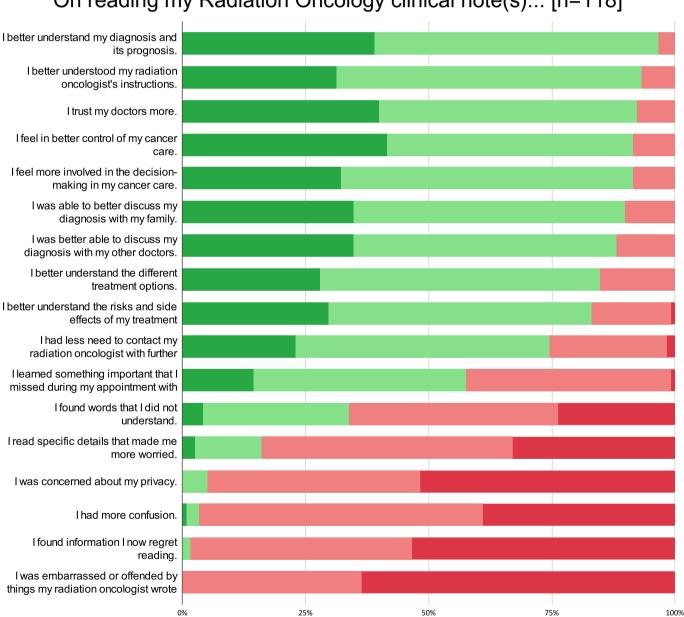
Who have you have you shared your Radiation Oncology clinical notes with? [n=114]



PERTINENT FEEDBACK

Open Notes

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 2024. Questions were adapted from a similar study conducted at UCLA in 2019 (Shaverdian et al., Pract Radiat Oncol, 2019). The results demonstrate the benefits of open notes.



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

📕 Strongly Agree 📕 Agree 📕 Disagree 📕 Strongly Disagree

PATIENT TESTIMONIALS

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

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

"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** "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*

"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*

"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**

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. – *Pierre*

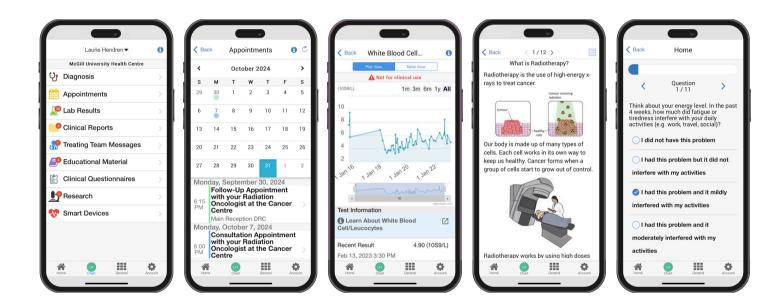


Who helped make Opal





Empowering patients with their data



For more information and a demo, please contact John Kildea, visiting scholar from McGill University at Queen's University Belfast john.kildea@mcgill.ca.

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