

Empowering People Living with Human Immunodeficiency Virus and Other Patients Using mHealth

Dr Bertrand Lebouché, MD, PhD



EMPOWERING PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS AND OTHER PATIENTS USING mHEALTH

The healthcare system can sometimes be puzzling, and even unwelcoming, for people with chronic, complex, or multiple conditions. Many must spend long hours in waiting rooms, try to make sense of complicated scientific information, and book and attend multiple clinic appointments with clinicians from different specialities. Remaining up to date on patients' health data can be a challenge for healthcare professionals as well. Here, we present the critical work of **Dr Bertrand Lebouché** and his team at the McGill University Health Centre, who are seeking solutions in smartphone-based applications relevant to both patients and healthcare professionals.

An App to Navigate the Healthcare Maze

In 2018, a team composed of Laurie Hendren, a patient and researcher at McGill University, and members of the Department of Oncology, Tarek Hijal, John Kildea and Jamil Asselah, implemented a 'patient portal' at the Cedars Cancer Centre of the McGill University Health Centre. This patient portal, named Opal, was designed to address specific difficulties experienced by oncology patients, whose typical treatment requires multiple hospital appointments with clinicians from a variety of specialities. With the need for sometimes rapid care and appraisal, oncology patients and clinicians typically struggle with having access to current or 'real-time' patient health data, particularly when concurrently involved in complex interventions.

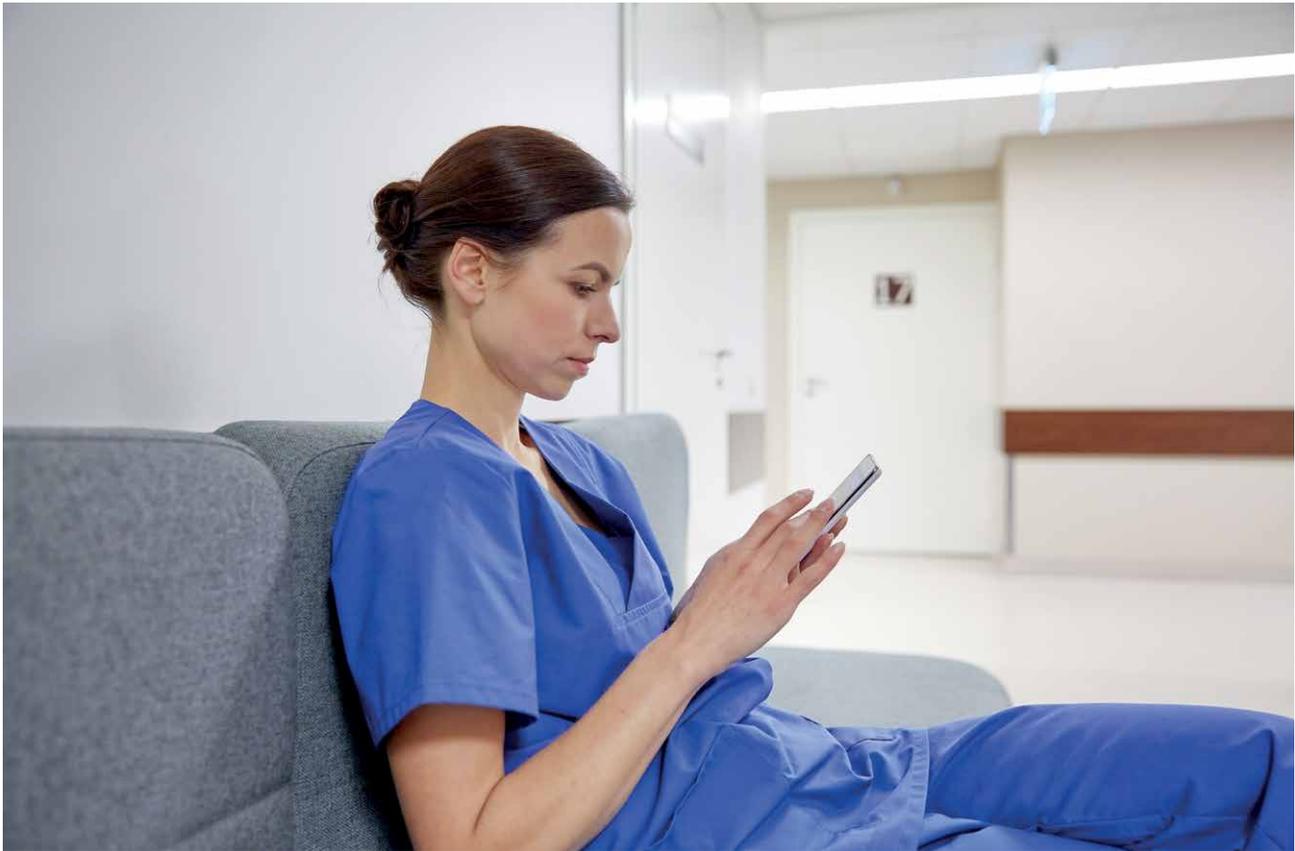
Opal was developed as a smartphone app that accords patients immediate

and portable access to their medical health record. Patients can consult their appointment schedule, their healthcare professionals' clinical notes, their laboratory test results including ongoing trends and changes, and their radiotherapy treatment plan and current status. In addition, patients are assisted in navigating complex treatment terminology and interventions through personalised educational material tailored to their diagnosis and stage of treatment. Opal reinforces patient-centred care by allowing healthcare professionals to administer patient-reported outcome measures electronically (ePROM) to their patients. Finally, Opal includes a check-in system notifying patients when their physician is ready to see them, reducing the time spent in waiting rooms.

Opal has won several awards and has been proven to successfully empower patients. It provides a practical interface



for patients and their healthcare professionals to store, communicate and share information, limiting face-to-face appointments. The use of this technology, known as mobile health (or mHealth), has a strong research track-record for improving engagement in care and health decision-making. Patient users have noted improvements in their perceived self-control and self-efficacy, which are critical factors in encouraging behaviour change and adherence to treatment regimens.



Dr Bertrand Lebouché's team, based at the McGill University Health Center, has integrated principles of patient and stakeholder involvement in their research. Dr Lebouché quickly saw the potential for utilising the Opal app platform for his own work with people living with human immunodeficiency virus (HIV) and hepatitis C virus, building on his work in the previous decade.

mHealth Solutions to Support Behaviour Change

To support HIV patients specifically, Dr Lebouché was looking for ways to better meet the needs, preferences, and specific circumstances of people living with HIV and their healthcare professionals.

HIV treatments dramatically improved since the 1990s. HIV is now treated as a life-long chronic condition. To maintain a near-normal quality and length of life, and to reduce the risk of transmission to sexual partners, people living with HIV need to adhere to their antiretroviral treatment, that is, take their treatment as prescribed. As with most long-term

drug regimens, maintaining adherence is often difficult, and only about 60% of people living with HIV take 90% or more of their antiretroviral drugs. The team determined that tools must be developed to support decision-making for patients facing complex situations, and to provide timely and useful data for healthcare providers about patients.

Dr Lebouché's team has been working on better understanding and improving adherence since 2012, while developing patient engagement approaches. In a project entitled the I-Score Study (for Interference Score), they have worked on developing an ePROM, an mHealth tool, for people living with HIV to identify barriers to taking their treatment and report these to their healthcare professionals prior to their clinic appointments. It is expected to enable improved patient-provider dialogue and management of these difficulties. To develop the ePROM, the team conducted a review of qualitative studies on barriers to adherence. They grouped these barriers into six domains and 20 subdomains, showing that they affect virtually all areas of life. The

identified domains were very similar to the World Health Organization's core barriers for patients with chronic illness across a range of conditions.

While initiating the I-Score Study, Dr Lebouché's team recruited ten people living with HIV to form an advisory committee, the I-Score Consulting Team. The Consulting Team was invited to provide their perspective and first-hand expertise at each step of the I-Score Study to ensure that the ePROM was responsive to the concerns of people living with HIV. The I-Score Consulting Team is also actively involved in disseminating I-Score research findings to the HIV community, healthcare providers and academics.

The work of Dr Lebouché's team identified deficiencies in the chronic care model that require improvement. Chronic patients generally self-manage significant amounts of their own care (for example, monitoring and taking medications at home), and as identified earlier, often struggle to maintain appropriate levels of self-care. With the growing use of smartphone



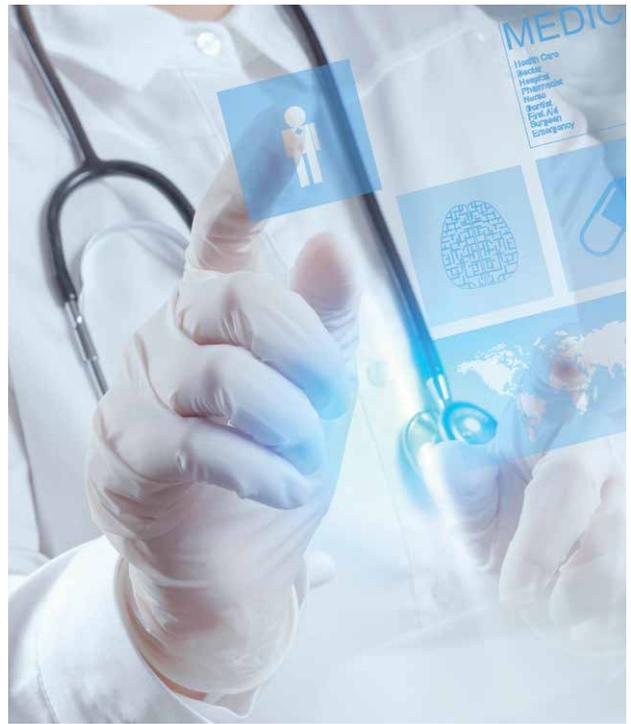
technology, including among older generations, mHealth appears to offer a highly flexible approach to promote self-management, guidance, access to health records and improved communication with healthcare providers. It thus has the potential to greatly empower patients to be more involved in medical decision-making about their health.

Integration with Opal

With the successful launch and usage of the Opal app for oncology, Dr Lebouché's team started work to adapt Opal to meet their objectives for people living with HIV and their healthcare professionals. The team administered a survey to 114 people living with HIV on the potential use of Opal. Nearly three-quarters of respondents said they would use Opal, with features such as appointments and educational material being widely appreciated. Understandably, concerns were raised over confidentiality and the wider sharing of personal data.

Meanwhile, the research team has also been working with Sofiane Achiche, Professor at Polytechnique Montreal, on an 'intelligent conversational agent' (ICA), a chatbot named MARVIN (Minimal ARV Interference). They had the idea for MARVIN while considering solutions to barriers identified by the I-Score ePROM that could be addressed with practical information. A multidisciplinary group of patients, physicians, pharmacists and engineers took a user-centred approach to work on the conception of the ICA. Software engineering students from Polytechnique Montréal then built a prototype for early-stage validation by PLHIV testers, leading to a much-improved final version.

An automated AI-based solution, like a chatbot, has the benefit of being available 24 hours a day, is confidential and can send



automated reminders. Although still in its early stages, MARVIN will be designed as a retrieval-based ICA trained to have a naturalistic conversation with users via text or voice messaging, to support people living with HIV to overcome some of their adherence barriers. The three areas MARVIN will focus on are guidance for effectively using antiretroviral treatment (e.g., time management, taking it with or without food), dealing with the financial costs of ART, and managing ART when travelling or away from home. A usability study will be conducted with MARVIN in autumn 2020.

Could Opal Be Useful for COVID-19?

With the recent COVID-19 pandemic and its associated social distancing and minimal contact measures, Dr Lebouché and his team proposed that Opal could support COVID-19 patients, especially when they are self-isolating and medical support is limited. In Quebec, about 95% of COVID-19 patients have been required to self-isolate at home and follow strict hygiene rules for a minimum of two weeks, which many reported to be stressful and difficult to follow and maintain. Opal provides a promising tool to accompany patients at home, allowing them to monitor their symptoms and be linked to healthcare services, when needed, including teleconsultations and mental health support for anxiety and depression. Dr Lebouché and his team are currently conducting a pilot study of the Opal app with 50 COVID-19 patients, to daily self-monitor their health status and well-being, and to evaluate its feasibility for this use.

These innovations by Dr Lebouché and his team, combining patient engagement and genuine stakeholder input into the design and development process, illustrate the vast potential for the development of cost-effective tailored apps to improve the health of a wide spectrum of potential patient groups.

Meet the researcher



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Dr Bertrand Lebouché, MD, PhD, is a General Practitioner, an Associate Professor in Family Medicine, and a researcher with professional experience and formal training in HIV/AIDS and hepatitis co-infections, HIV and STI prevention, and medical ethics. Dr Lebouché completed his medical training in the treatment of HIV/AIDS and hepatitis co-infections in Lille and Lyon, France. In 2010, he obtained a PhD specialising in Theology at Laval University followed by postdoctoral training at McGill University. He is currently a Clinician Scientist with the Research Institute of the McGill University Health Centre (MUHC). In December 2012, he received a medical and academic appointment in family medicine, as an attending physician at the MUHC's Chronic Viral illness Service. As an esteemed clinical researcher with an impressive publication record, Dr Lebouché has received substantial funding to support his vital work in family medicine. He has a long-standing commitment to patient and stakeholder engagement and the Canadian Institutes of Health Research awarded him a mentorship chair in patient-oriented research to develop innovative clinical trials in HIV. More recently, he has invested in the development of innovative patient-centred tools to improve the care of people living HIV, in particular, within the field of mHealth.

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Role: Co-Principal Applicant with Dr Marie-Pascale Pomey

Title: Real time evaluation of the deployment of connected technologies and of the partnership of services and care during the COVID-19 sanitary crisis – the Techno-COVID-Partnership program

Term: 05/2020–05/2021

Source: Merck Global

Role: Principal Applicant

Digital App for improving care in persons living with human immunodeficiency virus

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FURTHER READING

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