

INTERACTIVE PATIENT PORTALS

EXPLORING HOW INTERACTIVE DIGITAL TOOLS CAN MAKE HEALTHCARE MORE INCLUSIVE FOR ALL PATIENTS



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Background

Standpoint epistemology emphasizes that patient experience is as valuable as clinical expertise. Interactive portals **enact this principle** by enabling lived experience to inform care and EMR data. This perspective guides the inclusion of marginalized groups as both **subjects and actors** in this research.

The **call for unity and intersectionality** within activism, as emphasized by the disability justice movement encourages **solidarity across diverse communities**. Consequently, the project **intentionally focuses on multiple groups**.

How IPPs can foster inclusivity

- Reduce exposure to bias and microaggressions
- Allow self-identification and gender affirmation
- Enhance privacy and safety
- Improve communication equity
- Facilitate trust and engagement

Community-based research

Community organizations are actively involved in **co-creating the research** process, including the development of study tools and the adaptation of the design to reflect the needs of their members. This project is supported and guided by the following community partners:

COLLECTIF LGBTQ* DU MANITOBA

LA JARNIGOINE

Moelle épinière et motricité Québec
On réinvente l'autonomie depuis 1946

What is a Patient Portal ?

A patient portal is a web interface that allows **users to view their health information**. Patient portals have **several demonstrated benefits**: better disease management, improved medication adherence, greater use of preventive health services, higher patient satisfaction, and increased organizational efficiency (Otte-Trojel & al., 2016; Han & al., 2019).

Why Interactive Patient Portals are so cool !

IInteractive patient portals (IPPs) allow patients to contribute to their electronic medical records (EMRs) by **adding/reviewing data** and engaging in their care. Interactive portals have a **positive effect on patient-reported outcomes (PROs)** such as satisfaction and care usage (Brands and al., 2022). Their functions can be especially useful for marginalized groups:



Edit demographics (gender, pronouns, ...), habits, medical history, ...

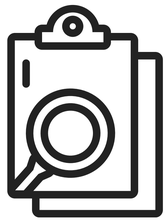
Set granular confidentiality settings for your data





Online scheduling, precription renewal, messaging, ...

Review and comment clinical notes



Inequities in research

Marginalized communities remain underrepresented in research and design related to Patient-Reported Outcomes (PROs) (Ramirez et al., 2024). As a result, it is still unclear whether the potential benefits of (IPPs) are being **realized for these groups**.

Significant inequities persist in access to **digital health technologies** across multiple marginalized populations. Many existing patient portals are primarily designed to meet the **needs of healthcare providers** rather than patients themselves (Goedhart et al., 2021). This provider-centered design approach often **overlooks the specific needs, identities, and barriers faced by marginalized users**, leading to lower engagement and reduced trust in these digital tools.

Objectives

We aim to compare key **patient-reported outcomes** (PROs) related to **inclusivity and accessibility** within interactive patient portals. These outcomes are operationalized through variables such as **comfort in disclosing identities, care avoidance, and trust in healthcare**. The study will compare *(P) patients from diverse marginalized groups* and *(I/C) different types of patient portals* using a **sequential exploratory mixed-methods design**.

Methodology

Focus groups: Conduct inclusive, identity-specific (non-mixed) focus groups stratified by patient diversity (e.g., LGBTQ+, disabled, BIPOC). These sessions will explore perceptions of inclusivity, accessibility, and user experience across various portal types.

1

Online questionnaire : Develop and distribute a mixed-methods questionnaire—including Likert-scale and open-ended questions—to quantitatively and qualitatively compare perceived inclusivity and accessibility across portal types and populations.

2

What's next?

This project is looking for funding and collaboration, idealy in the form of a **funded doctoral program (any recommendations?)**

- **Researchers**: Collaborate or supervise.
- **Community organizations**: Help ensure diverse representation.
- **Funders**: Join us in supporting in inclusive innovation !

References

Brands, Martijn R & al. "Patient-Centered Digital Health Records and Their Effects on Health Outcomes: Systematic Review." [In English]. Review. J Med Internet Res 24, no. 12 (2022): e43086.
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Otte-Trojel, Terese & al. "What Do We Know About Developing Patient Portals? A Systematic Literature Review." Journal of the American Medical Informatics Association 23, no. e1 (2016): e162-e68.
Ramirez, Lourdes G & al. "Understanding Health Equity in Patient-Reported Outcomes." The journal of allergy and clinical immunology: in practice 12, no. 10 (2024): 2617-24.

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