

**Acceptability of introducing a patient portal for people living with HIV and their  
healthcare providers**

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## **Abstract**

Opal (opalmedapps.com), a patient portal in use at the Cedars Cancer Centre of the McGill University Health Centre (MUHC) (Montreal, Canada), gives cancer patients access to their medical records, collects information on questionnaires/patient-reported outcome measures (PROMs), and has demonstrated high levels of patient satisfaction. This acceptability study aims to evaluate a patient portal, based on Opal, and its potential acceptability in the context of HIV care. People living with HIV (PLWH) and their healthcare providers (HCPs) completed cross-sectional surveys from August 2019 to February 2020 at large HIV centers in Montreal (Canada), including the Chronic Viral Illness Service of the MUHC, the Centre Hospitalier de l'Université de Montréal, Clinique Médicale du Quartier Latin, and Clinique Médicale l'Actuel and in Paris (France) Hôpital Saint-Antoine. This study included 114 PLWH (mean age 48 years old, SD=12.4), including 84 (74%) men, 27 (24%) women, and 2 (2%) transgender or identified as other; and 31 HCPs (mean age 46.5 years old, SD=11.4), including 10 (32%) men, 20 (65%) women and 1 (3%) identified as other. Ownership of smartphones or tablets was high (106 (93%) PLWH, 30 (96%) HCPs), and participants were willing to use a patient portal (84 (74%) PLWH, 21 (68%) HCPs). Participants were interested in most patient portal functions and PROMs; particularly PROMs capturing quality of life (101 (89%) PLWH, 24 (77%) HCPs), experience of healthcare (98 (86%) PLWH, 30 (97%) HCPs), and HIV self-management (105 (92%) PLWH, 30 (97%) HCPs). Random forest analysis demonstrated high variable importance of the variables gender, income, and comfort accessing personal health information as predictors of willingness to use a patient portal. This descriptive cross-sectional survey study suggests considerable acceptability of introducing a patient portal for PLWH and their HCPs.

## Résumé

Opal (opalmedapps.com), un portail patient utilisé au Centre des Cèdres du cancer du Centre universitaire de santé McGill (CUSM) (Montréal, Canada), permet aux patients atteints du cancer d'accéder à leur dossier médical, recueille des informations à partir de questionnaires et de mesures patients (PROMS en anglais) et a démontré la satisfaction des patients à l'égard de son utilisation. Cette étude de faisabilité vise à évaluer l'acceptabilité potentielle de l'Opal dans le contexte des soins aux personnes atteintes du VIH. Les personnes vivant avec le VIH (PVVIH) et leurs professionnels de santé (PDS) ont répondu à des enquêtes transversales d'août 2019 à février 2020 dans de grands centres VIH à Montréal (Canada), dont le Service des maladies virales chroniques du CUSM, au Centre Hospitalier de l'Université de Montréal, la Clinique Médicale du Quartier Latin, et la Clinique Médicale l'Actuel et à Paris (France) dans le Service des Maladies Infectieuses de l'Hôpital Saint-Antoine. Cette étude a porté sur 114 PVVIH (âge moyen de 48 ans, écart-type = 12,4), dont 84 (74 %) d'hommes, 27 (24 %) de femmes et 2 (2 %) de transgenres ou autres ; et 31 PSS (âge moyen de 46,5 ans, écart-type = 11,4), dont 10 (32 %) d'hommes, 20 (65 %) de femmes et 1 (3 %) d'autres. Le taux de possession de smartphones et de tablettes était élevé (106 (93 %) de PVVIH, 30 (96 %) de PDS), et les participants étaient prêts à utiliser le portail patient Opal (74 % de PVVIH, 68 % de PDS). Les participants étaient intéressés par la plupart des fonctions d'Opal et des PROMs, en particulier les PROMs qui permettent de saisir la qualité de vie (101 (89 %) des PVVIH, 24 (77 %) des PDS), l'expérience des soins de santé (98 (86 %) des PVVIH, 30 (97 %) des PDS) et l'autogestion du VIH (105 (92 %) des PVVIH, 30 (97 %) des PDS). Notre analyse de forêt aléatoire a démontré une importance variable élevée du sexe, du revenu et de l'aisance à accéder aux informations de santé personnelles comme prédicteurs de la volonté

d'utiliser un portail patient. Cette étude suggère que l'utilisation d'un portail patient serait très bien acceptée et potentiellement utile, selon les retours des PVVIH et des professionnels de santé.

### *List of abbreviations*

AP-HP – Assistance Publique – Hôpitaux de Paris

ART – Antiretroviral therapy

CVIS – Chronic Viral Illness Service

EMR – Electronic medical record

HCP – Healthcare providers

HIV – Human Immunodeficiency Virus

HT – Health technology

MUHC – McGill University Health Centre

PHI – Personal health information

PLWH – People living with HIV

PROMs – Patient-reported outcome measures

REB – Research Ethics Board

SMIT – Service des Maladies Infectieuses et Tropicales

UHRESS – Unité hospitalière de recherche, d’enseignement et de soins sur le sida

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### *Manuscript publication*

The contents of this thesis were originally published in the Journal of Personalized Medicine (2021) special issue “PROomics: Patient Reported Outcome (PRO) and Self-Tracking for Personalized Medicine (see Supplemental S1). The full citation is as follows: Chu D, Schuster T, Lessard D, Mate K, Engler K, Ma Y, Abulkhir A, Arora A, Long S, de Pokomandy A, Lacombe K, Rougier H, Cox J, Kronfli N, Hijal T, Kildea J, Routy JP, Asselah J, Lebouché B. Acceptability of a patient portal (Opal) in HIV clinical care: a feasibility study. *J Pers Med*. 2021, 11(2): 134. <https://doi.org/10.3390/jpm11020134>.

In addition to the published manuscript, this thesis also includes a comprehensive review of the literature and a random forest analysis described in the methods, results, discussion, limitations, and conclusion.

### *Contribution of authors*

I, Dominic Chu, have contributed to the recruitment of PLWH and administration of surveys at the CVIS, collection of results, analysis of results, and manuscript and thesis writing. However, this study was only made possible as a result of the contributions of several co-authors.

Thank you to Drs. David Lessard, Kim Engler, and Kedar Mate who were involved in the review and editing process of our manuscript, while Dr. Lessard was also involved with project administration, and coordinated focus group discussions. Additionally, thank you to Hayette Rougier and Dr. Karine Lacombe at Assistance Publique – Hôpitaux de Paris (Paris, France) for coordinating and consenting French PLWH and HCPs for this study. This project was also supported by the efforts of my colleagues, Dr. Ayoub Abulkhir, Anish Arora, Yuanchao Ma, and Stephanie Long who assisted with survey administration to patients at the Chronic Viral Illness Service (CVIS), at the McGill University Health Centre. Lastly, our project was also dependent on the efforts of the clinicians at the CVIS, including Drs. Alexandra de Pokomandy, Jean-Pierre Routy, Nadine Kronfli, and Joseph Cox, who engaged patients at their clinic visits and encouraged patients to partake in our study.

## Introduction

Human Immunodeficiency Virus (HIV), like other chronic conditions, requires consistent, long-term self-management by people living with HIV (PLWH), including engagement in care and adherence to antiretroviral therapy (ART) <sup>1</sup>. Increasing age, co-morbidities, and disabilities can increase the burden on PLWH and their multidisciplinary healthcare providers (HCPs) <sup>2, 3</sup>. Additionally, PLWH may experience diverse psychosocial issues such as depression (34-42% of PLWH on ART), anxiety (21-40%), stigma or discrimination (42-83%), as well as unemployment, and limited formal education <sup>2, 4</sup>. In turn, these factors can negatively affect access to and engagement in care as well as ART uptake <sup>2, 3, 5</sup>.

To support PLWH and their HCPs in the management of HIV, a solution is a patient portal, which is an extension of the electronic medical record system which provides patients secure access to their lab results, progress notes, and appointment schedules <sup>6</sup>. Patient portals can also include features to enhance communication with HCPs (e.g., text messaging), facilitate treatment access (e.g., medication refill request processing), and provide appointment and medication reminders. The functionalities and services of patient portals are relevant for clinical practice, as they have been reported to empower patients, improve engagement in care, and allow patients to make shared informed decisions with their HCPs, and promote communication between PLWH and HCPs <sup>6-17</sup>. Moreover, some patient portals allow for convenient electronic administration of questionnaires and patient-reported outcome measures (PROMs) <sup>11, 18</sup> which provide health information from the patients' perspective, without revision or interpretation by a clinician <sup>19</sup>. PROMs can improve the clinical management of symptoms, side-effects, adherence, and psychosocial needs, among others <sup>20, 21</sup>, and are thus relevant in the context of HIV care <sup>2, 10, 22</sup>.

Opal (opalmedapps.com), an innovative and award-winning person-centered portal, was first piloted in 2018 at the Cedars Cancer Centre of the McGill University Health Centre (MUHC) <sup>6</sup>. The patient-facing component of Opal is a smartphone application that gives patients access to their appointment schedules, personal health information (including clinical notes and laboratory test results), personalized educational material tailored to diagnosis and stage of treatment, and administration of PROMs. Opal is unique given that it was designed through a participatory stakeholder co-design approach, patients and HCPs were engaged in all stages of Opal's development. In fact, it was a breast cancer patient and a McGill University computer science professor, the late Laurie Hendren, who identified the needs of patients that spurred the development of Opal <sup>23</sup>. Our goal is to configure a patient portal, based on Opal, to HIV care, as there is currently no HIV-specific patient portal in Canada.

Opal was designed with oncology patients and thus may not be directly transferable to other health conditions, such as HIV. Oncology and HIV care differ greatly in terms of affected populations, treatments, and care providers involved. Considering these differences, garnering the perspectives of end-users for using a patient portal was important, as the lack of stakeholder involvement was noted as a central reason for the failure of other early patient portals <sup>12, 24, 25</sup>. To ensure a patient portal's uptake in HIV care <sup>13</sup>, consistent with the approach initiated in oncology, HIV-specific stakeholder input was essential before offering a patient portal to PLWH <sup>26</sup>. Additionally, considering the inequity PLWH experience regarding access to healthcare <sup>27</sup> and smart devices, the inclusion of PLWH without smart devices was considered in this study. The research question for this acceptability study is "How acceptable is a patient portal for stakeholders in HIV care, our PLWH, and HCPs?". Feasibility studies that do not pilot aspects of an intervention or study

methodology, as is the case here, attempt to answer questions about whether some aspect of a future trial is achievable <sup>28</sup>. This can include determining the acceptability of an intervention or the perceived importance of types of outcomes <sup>26</sup>, which were among the study objectives. Acceptability can be considered as the agreeable or interested views of stakeholders towards a specified innovation, such as a patient portal and its functions <sup>29</sup>. Acceptability captures one's personal perspective; this may differ between two people who can view the same innovation or treatment, yet form contrasting judgements regarding whether it meets their needs or preferences <sup>29</sup>.

The overarching study hypothesis is that the majority of people living with HIV and their health care providers perceive patient portals as useful innovative technologies that have potential to improve their shared care experience and positively affect HIV care.

The general objective of this descriptive cross-sectional survey study was to evaluate the acceptability of introducing a patient portal for PLWH and their HCPs. The specific objectives entailed the assessment of the following five complementing facets: 1) the experience of PLWH and HCPs with healthcare applications and smart device ownership, 2) PLWH and HCPs interest in using a patient portal and their preferences for sharing their personal health information, 3) their anticipated benefits and inconveniences, 4) PLWH and HCPs' preferences among different PROMs implemented through the patient portal, and 5) the factors associated with PLWH willingness to use a patient portal.

## Literature Review

### *HIV, a chronic disease*

With the advent of novel and extremely potent ART, the previously fatal diagnosis of HIV is now a chronic condition, with the life expectancy of PLWH having a near-normal lifespan, once HIV is diagnosed and treated with HIV RNA levels below 200 copies per millimeter <sup>30</sup>. However, increased longevity requires prolonged self-management from PLWH who are at greater risk of several comorbidities and psycho-behavioral problems <sup>31</sup>, many of which rely on patient reports for detection <sup>32</sup>. It is also important to consider the prevalence of age-related, treatment side-effects, and co-morbidities arising with HIV <sup>33</sup>. For example, PLWH are at higher risk for cardiovascular disease, diabetes, renal impairment, mental health and substance use <sup>34</sup>, and osteoporosis, and experience these events at an earlier age compared to the general population <sup>35</sup>. <sup>36</sup>. The burden of these co-morbidities in conjunction with psycho-social inequity and vulnerability presents a foreboding challenge to HIV self-care and further complicates treatment <sup>34, 35</sup>. PLWHs' co-morbidities are not always clearly communicated to their HCPs in HIV care, for example, mental health, alcohol and substance use, cognitive function, or HIV stigma <sup>37</sup>. These miscommunications have been attributed to differences in prioritization of PLWH healthcare or assessment of PLWH symptoms <sup>22, 37</sup>, which have led to delays in the delivery of much-needed care. Hence, there is a need for screening tools to highlight patient-reported problems to bring attention to the needs of PLWH and offer patient-centered care<sup>38</sup>. PROMs are a form of screening tool that can report on the patients' health condition, reported directly from the patient, without clinician or others' interpretation <sup>39</sup>. PROMs can measure a variety of patients' perspectives of their own health, that may not be obvious or easy to highlight within the patient encounter, including depression, quality of life, fatigue, adherence, or activities of daily living. Clinicians can

measure several subjective measures, to supplement other objective findings, such as laboratory reports or diagnostic imaging. This concept of utilizing PROMs encompasses a holistic view of healthcare, placing the patients' priorities and needs first, and goes beyond the physical ailments experienced, by also considering the patients' illness and subjective experiences.

PLWH often report symptoms centered around mental health, such as depression and anxiety, which can lead to worsened clinical outcomes <sup>40</sup>. Such outcomes include diminished quality of life, mental health, and adherence to ART <sup>40</sup>. There is evidence that the use of PROMs in HIV care can improve some of these outcomes, including clinical decision-making <sup>41</sup>, identifying patient symptoms <sup>42</sup>, and facilitate patient-provider communication <sup>43</sup>. Additionally, prior literature highlights that PLWHs' experiences with ART and its side-effects are more effectively recorded than with physicians' clinical encounter notes alone <sup>44</sup>. Thus, PROMs can be implemented prior to the clinical encounter to provide the HCPs a direction and focus on PLWHs' current and most pressing needs. The use of PROMs can trigger specific clinical assessments and guide the clinical encounter to efficiently meet the needs of PLWH <sup>45</sup>.

### *I-Score Study*

The I-Score study (clinicaltrials.gov identifier: NCT02586584) has been led by Drs. Bertrand Lebouché and Kim Engler since January 2016 <sup>46</sup>. This study aims to develop and validate an electronically administered PROM's assessment of PLWH's perceived barriers to adherence to antiretroviral medication. Adherence refers to a person's uptake of a medication, corresponding to his or her clinician's prescription <sup>47</sup>. The I-Score involves an exploratory mixed-methods design and with the inclusion of multiple clinical sites in Canada and France. The conceptual framework of the PROM has been developed <sup>3</sup>, however, the final selection and generation of items are yet to

be finalized. The I-Score study is ongoing and requires the implementation of a patient portal (Opal) to provide accessible electronic administration of the I-Score PROMs. Thus, this acceptability study was carried out at the CVIS, MUHC, other Montreal-based HIV clinics, and AP-HP, Hôpital Saint-Antoine (Paris, France) prior to the pilot of the patient portal to other clinical sites.

### *Challenges of maintaining adherence, the importance of a patient-centered tool*

Many PLWH still experience challenges with maintaining a high level of adherence <sup>4</sup>. These challenges are often missed within the clinical encounter between clinician and patient, and therefore, such barriers to ART are insufficiently addressed <sup>48, 49</sup>. There are several barriers for PLWH to adhere to ART <sup>3</sup>. Many of these barriers were identified by Engler et al. (2018), which included broad themes such as cognitive and emotional aspects, lifestyle factors, characteristics of ART, health experience and state, social and material context, as well as healthcare services and systems <sup>27</sup>. These barriers can be temporary and/or transient for PLWH and vary between patients, thus, regular follow-up and communication must be conducted to continue to engage the patient and identify these barriers <sup>3</sup>. A separate meta-analysis of qualitative studies also highlighted the life demands and needs of one's family and expectations within the workplace as a barrier to linkage with healthcare services and patient retention <sup>50</sup>. Quality of care was also a prevalent concern, in the context of limited clinic hours, communication barriers involving language barriers, and explanations of complex medical information in lay-terms <sup>50</sup>.

Therefore, to support PLWH through identifying and addressing such barriers, a patient-centered approach to HIV care should be considered. Such an approach engages PLWH in their care and



enables PLWH to form shared decision-making with their clinicians. Thus, consideration is for the use of a patient portal and patient portal-administered PROM (I-Score) that can optimize communication, barriers to adherence, and patient-reported adherence to complement the in-person patient assessment. However, the healthcare team at the CVIS understands that many PLWH experience inequity with care and smart device ownership, and thus, during the implementation of a patient portal, HIV care at the CVIS will include paper-based PROMs and education material. To optimize our healthcare delivery and communication, there needs to be a patient-oriented approach with stakeholder engagement, in which the perspectives of PLWH are taken into consideration to address the barriers affecting PLWH.

### *Stakeholder engagement*

Patient engagement can be defined as patients' meaningful and active involvement in their care, in which their experiences, perspectives, and expertise with regards to their healthcare and treatment are accounted for <sup>13,51</sup>. This process involves patients, caregivers, HCPs, and researchers, and can occur at any, if not all, stages of care <sup>46</sup>. Patient engagement emphasizes patients' values, shared decision-making <sup>52</sup>, patient autonomy <sup>53</sup>, accountability for patients' individual circumstances <sup>46</sup>, and partnerships to co-construct knowledge. To optimize HIV healthcare delivery and communication between PLWH and HCPs, PLWH and other key stakeholders (including HCPs) must be engaged within their care. Key stakeholders are individuals who are accountable for or are impacted by healthcare decisions. There is an increasing trend of the health system toward awareness of the importance of engaging key stakeholders in order to not only heighten the standard of care of PLWH but also to ensure that interventions, such as a patient portal, retain a high uptake and satisfaction amongst all users <sup>54</sup>. PLWH and their HCPs,

henceforth, referred to as stakeholders, can be engaged through an establishment of a collaborative relationship, as individuals or as a group through the use of a patient portal <sup>55</sup>. Through stakeholder engagement, shared decision-making can result regarding the selection, conduct, and use of research <sup>55</sup>. Thus, PLWH should be meaningfully involved through potentially all steps of research, where their perspective and experiences, concerning their health condition, treatment, or care can be accounted for <sup>56</sup>. This process of stakeholder engagement also highlights the importance of principles and discussion of shared healthcare decision-making <sup>52, 53</sup>, patient autonomy <sup>57</sup>, attentive listening, and the development of the participant-researcher relationship <sup>58</sup>.

Stakeholder engagement requires collaborative co-construction of knowledge to empower patients, share information, and diminish paternalism within healthcare <sup>59-62</sup>. The conduct and use of stakeholder engagement have been documented in numerous frameworks <sup>55, 59, 61, 63-68</sup>; these include: 1) educating stakeholders; 2) obtaining stakeholder input through consultation; 3) accounting for stakeholders' concerns with decision-making; 4) collaborating within decision-making; or 5) empowering stakeholders' decision-making capabilities <sup>67, 69, 70</sup>. Considering these principles, the research team under Dr. Lebouché has involved PLWH and their HCPs in his research program and has incorporated feedback from key stakeholders to ensure integrated knowledge translation and exchange throughout the study's methods and protocol <sup>46</sup>. For example, within the I-Score study, stakeholders were involved in the decision-making process, by which stakeholders were involved in in-person meetings consisting of deliberative discussion<sup>71</sup> to offer recommendations on problems perceived within the study. There was also close collaboration with investigators and stakeholders to ensure knowledge dissemination and effective presentation of research results.

*An electronic patient portal to support the I-Score PROM*

PROMs may be employed prior to the patient encounter, and during the appointment as a screening tool to highlight patients' highest priority needs <sup>72</sup>. Through electronic administration of PROMs, the clinician or researcher can avoid data entry errors, receive data in real-time, and send notifications to patients to complete PROMs and limit missing data <sup>19</sup>. PROMs are growing as a tool to provide holistic care which addresses the overall health and well-being of PLWH. PROMs can target a variety of issues, including patient perceptions of their health (including issues that are not always captured, such as depression, quality of life, or stigma), perceptions of their treatment and side effects, and ability to perform daily activities of living. Furthermore, PROMs may support HIV clinical practice through identifying and bringing attention to PLWHs' perceived barriers to care, while also accurately relaying PLWHs' ART adherence and experience of side-effects <sup>73, 74</sup>. This not only engages PLWH in their care, but also informs clinicians of key patient issues prior to the clinical encounter. Additionally, PROMs have also been found to be useful for improving clinical decision making <sup>41</sup>, highlighting patient symptoms <sup>42</sup>, facilitate clinician-patient dialogue <sup>43</sup>, and identify quality of life-related challenges <sup>75</sup>.

Currently, there is a shift towards the use of an electronic medical record, as well as an increasing use of mobile devices, such as smartphones, with advanced computational capabilities. Thus, a patient portal may be integrated within such mobile devices to offer PLWH accessible, real-time sharing of health information <sup>76</sup>. For those with access to smartphones, a patient portal can promote patient engagement and patient-centered care by offering patients access to their personal health

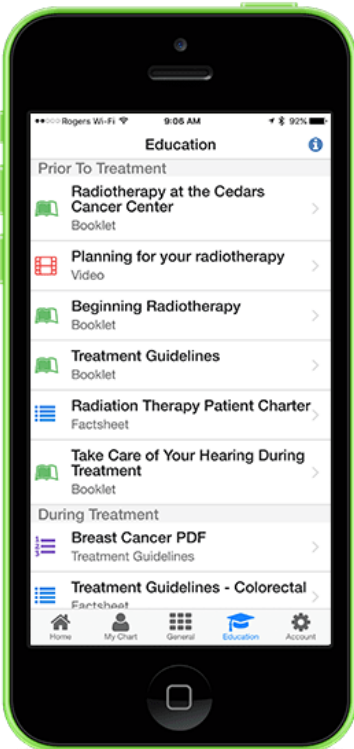
records, consultation notes, appointment schedules, and even PROMs, and personalized education material.

However, it is pivotal that the design of the patient portal be well-adapted to the specific needs of the stakeholders using the software. Stakeholders' needs may influence the functionality of the patient portal, highlight needs for improvement, and the content of the material within the patient portal. Their consideration is critical to facilitate the utility of the patient portal, uptake of the patient portal, and the satisfaction gained from using such software in HIV care.

#### *Patient portals: an example from oncology*

One such patient portal is that can be used to engage patients is Opal, which is an innovative, award-winning patient portal, first piloted at the Cedars Cancer Centre, MUHC <sup>6</sup>. Throughout the development of Opal, equal co-leadership, and participatory co-design was implemented to ensure the patient, computer science professor the late Laurie Hendren, as well as a medical physicist John Kildea, and a radiation oncologist Tarek Hijal were actively involved within all stages of the development, design, and piloting of Opal <sup>6</sup>. As the developmental process included patient engagement and principles of participatory co-design, patients and clinicians were involved with all stages of the design process, the piloted version followed the key values of patient-centered care. The Opal smartphone application allows patients to access their personal health information, including their consultation notes, laboratory results and trends, treatment plan, and appointment schedules. The application also allows for personalized education tailored to the cancer stage and specific treatment, check-in function at the hospital, and administration of PROMs. Additionally,

personalized health information is explained in detail to ensure the content is beneficial and empowering for patients.



*Figure 1. Screenshot of Opal in oncology from opalmedapps.com demonstrating the user interface and patient access to education material within the application.*

A patient portal based on Opal is a clear choice for a patient portal to implement the prior HIV-specific PROMs identified by Engler et al. (2017) <sup>77</sup>. These types of PROMs include quality of life, healthcare-related views and experiences, psychological challenges, symptoms, need for psychological resources, HIV-self management, HIV-related stigma, body and facial appearance, social support, sexual and reproductive health, and disability. Opal has been implemented, undergone multiple troubleshooting tests, and has demonstrated high levels of acceptance and satisfaction amongst stakeholders.

However, Opal is ultimately designed for oncology patients. The specialties of oncology and HIV care differ greatly, as do the patient population, patient needs, diagnostic methods, disease timeline, and treatment methods. Thus, further research must be conducted to ensure that Opal is adapted to the key stakeholders in HIV care, including PLWH, clinicians, nurses, social workers, pharmacists, clinical psychologists, and others who will be using the Opal patient portal.

### *Utility of patient portals*

The patient portal functions as a health care system to provide patients access to their electronic medical record (EMR) <sup>78</sup>. Patients can access a portion or majority of their personal health information – which can include patient notes, treatment plans, and laboratory results <sup>6, 79</sup>. Additionally, patient portals can provide a myriad of functions including, but not limited to: access to the electronic medical record, access to test results, medication refills, appointment scheduling, and reminders, obtaining referrals, a secure messaging platform between the patient and medical institution, and access to general medical guidelines <sup>80</sup>. In prior literature, patients preferred such functions that facilitated communication and convenience and offered more personalized care and a closer collaborative clinician-patient relationship <sup>13</sup>. By meeting patient needs and preferences, patient portals have been noted to facilitate patient engagement, although, the added personalization of patient portals has been described to further promote patient engagement as a possible intervention for chronic disease medication management <sup>81</sup>. Such an intervention may include personalized lists of preventative measures or sending personalized electronic notifications, such as alerting patients of the need to attend health screening services <sup>82, 83</sup>.

The impact of patient portals specifically within the HIV setting has not been well explored. Prior patient portal research often under-reported the specific features employed within the portal and did not readily consider several factors that had affected patient portal use and their impact on clinical outcomes (including psychosocial, and systemic factors) <sup>84</sup>. However, within available literature, patient portals have been viewed favourably by patients and healthcare professionals and have been associated with positive clinical outcomes, including increased patient engagement and doctor-patient communication <sup>11, 15-17</sup>. Evidence had noted that patients preferred to be kept involved and cognizant regarding any decisions in their medical care; indeed, evidence suggests an inability to fully inform patients of their condition and its management led to worsened outcomes, including treatment adherence <sup>85, 86</sup>. By providing patients access to patient health information, through a patient portal, HCPs had been able to better inform their patients, which allowed patients to organize themselves better for subsequent appointments <sup>87</sup>. Additionally, patient portals have demonstrated greater medication adherence <sup>88</sup>, patient safety, screening, and preventative care, and informed decision-making <sup>84</sup>. Patient portals have also been found to improve certain outcomes in other clinical settings such as in primary care and cardiology, where they have led to decreased office visit rates, increased messages sent, corrected medication regimen, and improved adherence to treatment <sup>11, 16, 89</sup>.

### *Concerns for patient portals*

Although findings for patient portals have generally been positive, there have been concerns regarding patient confidentiality, patient understanding of the content, and an increased workload for clinicians <sup>11, 90</sup>. Privacy and confidentiality issues were one of the most prevalent concerns amongst patients using patient portals <sup>12, 91</sup>. Patients prioritize privacy and were often reluctant to

share health information even amongst healthcare providers <sup>12</sup>. Further, security concerns regarding third parties' data and accessing and utilizing patient health data were common, despite reassurances of confidentiality<sup>92-95</sup>. Despite these concerns, a systematic review using electronic health records in primary care revealed that there were no reports of data breaches in security or privacy when using patient portals <sup>96</sup>.

Another concern centers on clinicians' doubts regarding patients understanding of health information, such as laboratory results, potentially leading to increased clinic calls and patient worries <sup>97</sup>. Additionally, the need to provide additional education or general patient support with the application is often perceived to be an additional workload for clinicians <sup>97, 98</sup>. Despite these concerns, prior patient portals that communicated laboratory tests to patients noted no differences in anxiety for patients receiving test results, versus those who did not receive test results <sup>99, 100</sup>. Prior literature noted that healthcare professionals reported no additional telephone or face-to-face activities <sup>91</sup> and the general workload of HCPs did not increase <sup>96</sup>.

Miscommunication issues previously impeded previous patient portal impact, as physicians and patients misunderstood each other due to the differences between what clinicians believe patients want to know, what patients should know, and what patients did know <sup>101</sup>. By forging a shared platform and utilising input from both parties, this communication barrier may no longer be present. In addition to these communication barriers, there are also ethnic (including cultural and language divides) and literacy barriers, which the development phase must identify and aim to mitigate <sup>11</sup>. As MUHC's CVIS works with many refugees and immigrants, this would be essential. To bridge such a communication gap, understanding such barriers can lead to successful uptake



and implementation <sup>76</sup>. This includes considering the social context in which the portal is being implemented and understanding the cultural shifts within the context of the patient population through engaging with stakeholders <sup>76</sup>. Within HIV care, some PLWH are also in lower-income brackets and may experience inequities related to accessing care and smart devices, and therefore, a patient portal <sup>102</sup>. Such inequity to accessing care and health technology can impact portal uptake and has been demonstrated in prior literature, where PLWH were less likely to use telehealth services if participants did not have access to a smartphone or computer, or if participants were not knowledgeable regarding the use of smartphones <sup>102</sup>.

#### *Adapting a patient portal to HIV care*

A framework for the development of such portals, or the adaptation of a patient portal from one chronic disease to another, has not been clearly defined <sup>18, 103</sup>. There is a growing amount of literature reporting on the development of various patient portals and how they performed in the clinical setting to provide guidance for novel software development <sup>104</sup>. There is also a plethora of attention given to the engagement of stakeholders and examining the socio-economic aspects of care and patient experiences linked to patient portal usage <sup>104</sup>. However, there are limited articles that highlight the challenges and solutions to securing stakeholder engagement, security and privacy, data governance, and financial sustainability in developing patient portals <sup>104</sup>. In a systematic review of the development of patient portals, Otte-Trojel et al. (2016) recommended forming portal designs and implementations on existing evidence, utilizing several iterations of the design process, and utilizing evidence from numerous patient portal types <sup>104</sup>. However, as mentioned, there are multiple challenges presented with the development and adaptation of patient portals, leading to limited patient and HCP portal usage <sup>104, 105</sup>. To facilitate stakeholder

engagement through participatory design approaches, prior literature suggested aiming to meet patients' needs, characteristics, and preferences, offer translation of portal content into minority languages, and train patients and staff regarding utilizing the patient portal <sup>105-107</sup>. To further encourage HCPs engagement, suggestions included a formal curriculum and teaching of the utility and functioning of patient portals <sup>108</sup>, utilization of workflow engineering to minimize workflow disruption <sup>109, 110</sup>, and a notification system to highlight urgent matters to support provider liability concerns <sup>104</sup>.

Another framework for developing a patient portal is Opal's participatory co-design, which utilised: 1) equal co-leadership, 2) patient preference determination, 3) security, governance, and legal input, 4) user evaluation and feedback, 5) continuous staff input, and 6) end-user testing <sup>6</sup>. Participatory co-design showed clear benefits, as patient co-leads successfully noted requirements for patient-centeredness, confirmed patient acceptability, and patient engagement to ensure complete stakeholder buy-in<sup>6</sup>. Kildea et al. (2019) acknowledged three key considerations in developing the smartphone application: 1) patients should decide their level of patient health information access, 2) all patient health information provided to patients should be contextualized with explanatory content, and 3) educational material should be personalized and tailored to the patient's immediate medical situation <sup>6</sup>.

Stakeholder engagement is particularly important in the configuration of a patient portal to HIV care, considering the vastly different needs and experiences of HIV patients from different, including women <sup>111</sup>, people who use drugs <sup>112</sup>, transgender women <sup>113</sup>, men who have sex with men <sup>114</sup>, and migrants <sup>115</sup>.

## Research questions

This descriptive cross-sectional survey study aims to quantify the level of acceptability as an indicator for the potential feasibility and usefulness of introducing a patient portal for HIV care. This study's overarching hypothesis is that the majority of people living with HIV and their health care providers perceive patient portals as useful technologies that have potential to improve their shared care experience and positively affect HIV care. Specifically, this study aims at answering the question "How acceptable is a patient portal for stakeholders in HIV care, our PLWH, and HCPs?" This study anticipated a moderate to high representation of study participants (PLWH) who own a smart phone (expected range between 65% and 83%)<sup>6, 116, 117</sup>. The literature on acceptance and willingness to use patient portals in the HIV context is scarce. However, evidence from specific subpopulations such as young men who have sex with men showed relatively high levels of willingness to use a patient portal and/or interest in patient portal functions and PROMs<sup>118</sup>. For instance, Jackman et al. (2020) showed that more than 78% of PLWH are willing to use a patient portal to share HIV test results<sup>116</sup> and Kildea et al. (2018) found that >60% of patients had an interest in patient portal functions and PROMs in the context of implementing a successful patient portal<sup>6</sup>; thus this study anticipated moderate to high levels of interest in using a patient portal as well as interest in its functions and PROMs. Hence the study data will enable estimation of acceptability levels in an exploratory (i.e., non-confirmatory) manner. To do so, our objective is to assess key stakeholders' acceptability of a patient portals' existing design, and functions for HIV care. Thus, this study's objectives were to assess five complimenting facets: 1) the experience of PLWH and HCPs with healthcare applications and smart device ownership, 2) PLWH and HCPs interest in a patient portal and their preferences for sharing their personal health information, 3)

their anticipated benefits and inconveniences of a patient portal, 4) PLWH and HCPs interest in different PROMs, and 5) the factors that predict PLWH willingness to use a patient portal.

## **Materials and Methods**

### *Study design*

This acceptability study employed a cross-sectional design using two distinct surveys, developed using validated tools, including individual electronic surveys with PLWH and paper surveys with HCPs <sup>119</sup>.

This study was conducted as part of a broader research program (the I-Score program) with sites in Canada and France aimed at improving ART adherence among PLWH using electronically administered PROMs <sup>120</sup>. In the HIV context, our goal is to first implement a patient portal in a pilot study at the CVIS, one of the largest public hospital-based HIV clinics in Quebec, Canada, which provides comprehensive multidisciplinary care to over 1600 PLWH. Subsequently, our goal is to implement a patient portal across Quebec and in France as well, therefore, this study recruited participants from Hôpital Saint-Antoine (Paris, France).

### *Study sites*

Recruitment occurred at five sites; however, recruitment was focused on the CVIS. A patient portal is expected to be eventually implemented in other urban HIV care centers in Montreal and Paris, thus, PLWH and HCPs were recruited from the CVIS at MUHC in Montreal and Service de Maladies Infectieuses et Tropicales (SMIT) at Hôpital Saint-Antoine, Paris. HCPs were also recruited from three Montreal-based non-CVIS sites specializing in HIV care, including, 1) HIV Unit (Unité hospitalière de recherche, d'enseignement et de soins sur le sida, UHRESS) at the Centre Hospitalier de l'Université de Montréal, 2) private HIV clinic, Clinique Médicale du Quartier Latin, and 3) Clinique Médicale l'Actuel. Research ethics approval was obtained from

the MUHC Research Ethics Board (study number: 2020-5910), where two co-investigators were based. According to French public health legislation <sup>121</sup>, no ethical approval was needed in France. A confidentiality and data transfer agreement were signed between l'Assistance Publique – Hôpitaux de Paris (AP-HP) at the Hôpital Saint-Antoine and the MUHC, thus not requiring a separate REB for Hôpital Saint-Antoine. This study also met the standards set by the Declaration of Helsinki.

### *Study design and participant eligibility*

This descriptive cross-sectional survey study aimed at estimating relative frequencies in the target population of 1600 PLWH registered with the CVIS. The desired minimum precision, i.e. the width of respective 95% confidence intervals generated from the sample data was set to be  $\pm 10$  percentage points. Under this requirement, a total sample of approximately  $n=110$  was needed. This sample size implied that in the absence (zero count) of a specific response category, the respective estimated proportion for the target population would be consistent with a prevalence of  $<3\%$ , applying a 95% exact confidence interval. Convenience sampling was used to recruit PLWH, i.e. the first 110 eligible PLWH who presented for an appointment at participating HCPs from the CVIS were recruited into the study. To be included in the study, PLWH must have met the following inclusion criteria: 1) be over 18 years of age, 2) receive care for HIV, and 3) no cognitive impairments. PLWH who did not own a smartphone, or any other smart devices were also included, as our research team acknowledged PLWH who experience inequitable access to healthcare and smart devices. The inclusion criterion for HCPs included those with at least 6 months of clinical experience in HIV care. Exclusion criteria for both PLWH and HCPs included:

1) participants who could not communicate with the research team in French or English or 2) participants with a schedule that did not permit participation in the study.

The principal investigator recruited HCPs through personal email invitations following a convenience sampling approach. The goal was to recruit representatives of various disciplines within HIV care to garner multiple perspectives. Hence, the approached HCPs included individuals who would be potentially interested in using a patient portal to facilitate HIV care, comprising physicians, pharmacists, nurses, social workers, and administrative staff. To facilitate the sampling, available email addresses of HCPs from the respective study sites were retrieved through liaising with higher level site administrators and clinicians.

To achieve a fair representation of the HCP target population (clinical staff across the 5 sites) within the study sample, a total of 30 HCP was anticipated to be included in the study i.e., in expectation, six HCPs per site. This sample size enabled a minimum precision (95% confidence interval widths of estimated proportions within the HCP study population) of  $\pm 20$  percentage points.

#### *Data collection – questionnaires and surveys*

Data were collected from August 2019 to February 2020.

The two distinct questionnaires for PLWH and HCPs were developed to address each objective by referencing and adapting validated tools from the literature <sup>6, 77, 122-125</sup>. Tools were selected based

on their relevance to Opal <sup>6</sup>, HIV-specific PROMs <sup>77</sup>, patient engagement through electronic patient portals <sup>122</sup>, sharing HIV-related patient data <sup>123</sup>, acceptability and self-efficacy of health technology <sup>124</sup>, and assessing implementation outcome measures such as acceptability <sup>29</sup>. The PLWH questionnaire (73 items) (Document S1) captured demographics and addressed: our first objective, by measuring smart device use, and healthcare technology self-efficacy <sup>124</sup>; our second objective, by evaluating interest in a patient portal's functions and willingness to share personal health information <sup>6, 123, 125</sup>; our third objective, by collecting data on the anticipated impact of accessing physicians' clinical notes <sup>122</sup>; and our fourth objective, by acquiring PLWH's interest in different HIV-specific PROMs <sup>77, 123, 125</sup>. The questionnaire for HCPs (55 items) (Document S2) was shorter. It documented their demographic characteristics and addressed: our first objective by collecting information on their perspective on smart device use, healthcare applications, and self-efficacy <sup>124</sup>; our second objective, by capturing interest in a patient portal's functions <sup>6, 123, 125</sup>; our third objective, by assessing the anticipated impact of PLWH access to physicians' clinical notes <sup>122</sup>, anticipated compatibility of a patient portal with their work <sup>126</sup>; and our fourth objective, by measuring interest in different types of HIV-specific PROMs <sup>77, 123, 125</sup>. Various types of HIV-specific PROMs were identified in a review by Engler et al. (2017), and were presented to PLWH and HCPs on each questionnaire <sup>27</sup>. However, this list has not been finalized for the patient portal's clinical implementation to HIV care. A systematic review is planned to identify which PROMs have been used in HIV clinical practice to best inform patient care. These results are to be presented to stakeholders during the implementation of a patient portal to guide PROM selection. For example, within prior HIV clinical care, the QuaLiv <sup>127</sup>, PROgress <sup>128</sup>, Positive Outcomes <sup>129</sup>, and AmbuFlex PRO system <sup>130</sup> all contain PROM domains including physical activity, drug use, and mental health. Our PROM package will likely contain similar outcomes to meet local PLWH



needs. The specific PROM types presented to participants in this study are further documented in the appendix (*Questionnaire for people living with HIV, Questionnaire for HIV healthcare professionals*).

Item response options included multiple choice and 5 to 7-point Likert scales. For items with 5 or 6-point Likert scale, responses were collapsed into three categories; “not at all interested” and “not interested” were classified as “not interested”; neutral responses “I don’t know” and/or “undecided” (6-point Likert scales included both responses) were classified as “undecided”; while positive responses “a little interested”, and “very interested” were classified as “interested”. For items with a 7-point Likert scale, responses were collapsed into three categories; negative responses, “completely disagree”, “disagree”, “somewhat disagree”, were classified as “disagree”; neutral responses, “undecided” remained as “undecided”; and positive responses “agree” “somewhat agree”, and “completely agree”, were classified as “agree”.

PLWH and HCPs were provided an in-person 5-minute PowerPoint presentation on Opal’s main functions (Presentation S1) and were offered a chance to ask questions to ensure participants fully understood how a patient portal may fit into their care or work. HCPs were also introduced to how a patient portal could be used in their work to support their management of PLWH, for example, through using a clinic check-in system, or integrating data from PROMs into the clinical encounter. HCPs had also participated in focus group discussions prior to completing their questionnaires; however, results from the focus groups were presented separately. A researcher administered the in-person survey to PLWH electronically, by presenting PLWH each item and their possible responses, before recording each answer; while HCPs completed a paper questionnaire. Data were

then entered into a secure online platform, REDCap© (version 9.1.15), which conferred ease of administration and storage of data <sup>131, 132</sup>.

### *Statistical analysis*

All statistical analyses were performed using R statistical software (version 1.2) <sup>133</sup> and the R package ‘randomForest’ <sup>134</sup>. The distribution of continuous variables was described by their means, standard deviations, and ranges; for categorical variables, relative frequencies were reported. To express uncertainty in estimates of proportions, 95% confidence intervals were reported. Random forests were applied to predict the willingness of persons living with HIV to use a patient portal based on survey responses and patient demographics. Each random forest employed 500 classification trees. To illustrate prevalent variable interactions implied by the random forest, a final classification tree was fitted to the dataset, depicting patient characteristics that were associated with relatively lower or higher levels of willingness to use a patient portal.

The random forest analysis was a secondary analysis and was applied to explore possible interactions between variables <sup>135</sup>. The potential predictor variables were chosen based on barriers and facilitators of patient portal use highlighted in prior literature, such as income, age, gender, education, socioeconomic status, and health technology self-efficacy <sup>92</sup>. To establish a variable importance ranking, the relative decrease in classification accuracy associated with removing (permuting) a respective predictor variable from the random forest was reported as a percentage. Random forests maximize the overall accuracy of predicting the outcome variable when being trained on data. Hence, imbalances in the representation of respective outcome categories can lead to undesirably low sensitivity or specificity values as it is most rewarding for the model to correctly

predict the most prevalent category. To mitigate such overfitting, the training data was weighted to equally represent cases with the outcome of interest and cases with complement outcome status. Due to the limited available sample size, no random forest analysis was conducted for the co-primary outcome variable ‘willingness of health care providers to use a patient portal’.

## Results

### *Sample characteristics*

Table 1 shows the characteristics of the PLWH and HCP participants. PLWH (n=114) included 86 men (74%), 28 women (24%), and 2% identified as transgender or ‘other’. A total of 106 (93%) PLWH were recruited from the CVIS (Montreal), while 8 (7%) were from SMIT (Paris). CVIS clinic data from 2019 shows that of the 1679 registered PLWH, 63% were men, and 37% were women. For the CVIS clinic data, the mean age of PLWH was 51.2 years old (SD=12.7), compared with 47.8 (SD=12.4), in the present study sample.

**Table 1.** *Descriptive characteristics of people living with HIV and healthcare providers who participated in the study.*

|  | People living with HIV (n=114)<br>Mean (SD) or n (%) | Healthcare providers (n=31)<br>Mean (SD) or n (%) |
|--|--|---|
| Age (years)                                    | 47.8 (12.4)  | 46.5 (11.4)                                       |
| Range  | 27, 74   | 25, 68  |
| Gender   |  |   |
| Male   | 84 (74)  | 10 (32)   |
| Female   | 27 (24)  | 20 (65)   |
| Other / Transgender                            | 3 (2)  | 1 (3)   |
| Sexual orientation                             |  |   |
| Heterosexual                                   | 55 (48)  |   |
| Men who have sex with men                      | 47 (41)  | N/A   |
| Bisexual                                       | 10 (9)   |   |
| Unsure or other                                | 2 (2)  |   |
| Marital status                                 |  |   |
| Single   | 54 (47)  |   |
| Married  | 43 (38)  | N/A   |
| Divorced or widow(er)                          | 17 (15)  |   |
| Level of education                             |  |   |
| University or higher                           | 41 (36)  |   |
| CEGEP*, trade/vocational school or high school | 60 (53)  | N/A   |
| Up to high school                              | 13 (11)  |   |
| Paid work                                      |  |   |
| Student  | 9 (8)  |   |
| Part-time                                      | 16 (14)  |   |
| Full-time                                      | 40 (35)  | N/A   |
| Unemployed, retired, or disabled               | 49 (43)  |   |

|   |          |         |
|---|----------|---------|
| Income (CAD)                              |          |         |
| 1 to < 19 999                             | 38 (33)  | N/A     |
| 20 000 to 39 999                          | 33 (29)  |         |
| 40 000 to 59 999                          | 17 (15)  |         |
| >60 000                                   | 16 (14)  |         |
| None or missing                           | 10 (9)   |         |
| Ethnicity                                 |          |         |
| Caucasian or White                        | 41 (36)  | N/A     |
| Black, African, or Caribbean              | 35 (31)  |         |
| Latino, Latin American, or South American | 23(20)   |         |
| North African or Middle Eastern           | 7 (6)    |         |
| Asian or Pacific Islander                 | 5 (4)    |         |
| Indian or South Asian                     | 1 (1)    |         |
| Other                                     | 3 (3)    |         |
| Aboriginal, First Nations, or Métis       | ---      |         |
| Occupation                                |          |         |
| Physician                                 |          | 13 (42) |
| Pharmacist                                |          | 8 (26)  |
| Nurse                                     | N/A      | 6 (19)  |
| Social worker                             |          | 2 (6)   |
| Administrative staff                      |          | 2 (6)   |
| Smart devices owned                       |          |         |
| Smartphone                                | 103 (90) | 27 (87) |
| Computer (desktop or laptop)              | 74 (65)  | 26 (84) |
| Tablet                                    | 44 (39)  | 9 (29)  |
| iPod or phablet                           | 9 (8)    | 6 (19)  |
| Smartwatch                                | 4 (4)    | 3 (10)  |
| Other                                     | 1 (1)    | ---     |
| None                                      | 4 (4)    | ---     |

--- represents no responses.

\*CEGEP is the first level of post-secondary education exclusive to Quebec, Canada.

HCPs' (n=31) mean age was 46.5 years (SD=11.4) and included 20 women (65%), 10 men (32%).

Of the HCPs recruited, 16 (52%) were from the CVIS (Montreal), 8 (26%) were from non-CVIS

Montreal sites, and 7 (22%) from SMIT (Paris).

### *Smart device ownership and experience and comfort using healthcare applications*

Overall, 109 (96%) PLWH and 31 (100%) HCPs owned at least one type of smart device including computers (desktops or laptops), smartphones, and/or tablets, three devices capable of operating Opal. However, the current patient-operated side of Opal can only be operated through smartphones and tablets. PLWH still demonstrated high ownership (n=106, 93%) when accounting for only these two devices; however, smartphone and tablet use for PLWH above 50 years of age was lower (n=39, 85%).

There were 93 (82%) PLWH and 19 (61%) HCPs who indicated very little to no experience using healthcare applications, including any applications targeted towards improving user health (for example, other patient portals, calorie counters, step counter, etc.); yet 84 (74%) PLWH were willing to use a patient portal and 21 (68%) HCPs were willing to use a patient portal in their work to support the management of PLWH. For HCPs, this would entail using a patient portal to facilitate HIV care. Of those willing to use a patient portal, 67 (80%) PLWH and 13 (60%) HCPs reported very little to no experience with healthcare applications. With a patient portal, 70 (61%) PLWH wanted immediate and comprehensive access to personal health information (PHI), while 29 (25%) PLWH preferred to only access PHI after review with their HCPs (see Table 2).

**Table 2.** *Participants' healthcare application experience, willingness to use a patient portal, preferences for accessing medical records, healthcare application self-efficacy, and acceptability of a patient portal (Opal).*

|                                   | People living with<br>HIV (n=114)<br>n (%) | Healthcare<br>providers (n=31)<br>n (%) |
|-----------------------------------|--|---|
| Healthcare application experience |  |   |
| None to very little               | 93(82)                                     | 19(61)                                  |
| Moderate to extensive             | 21(18)                                     | 11(35)                                  |
| Willing to use a patient portal   |  |   |

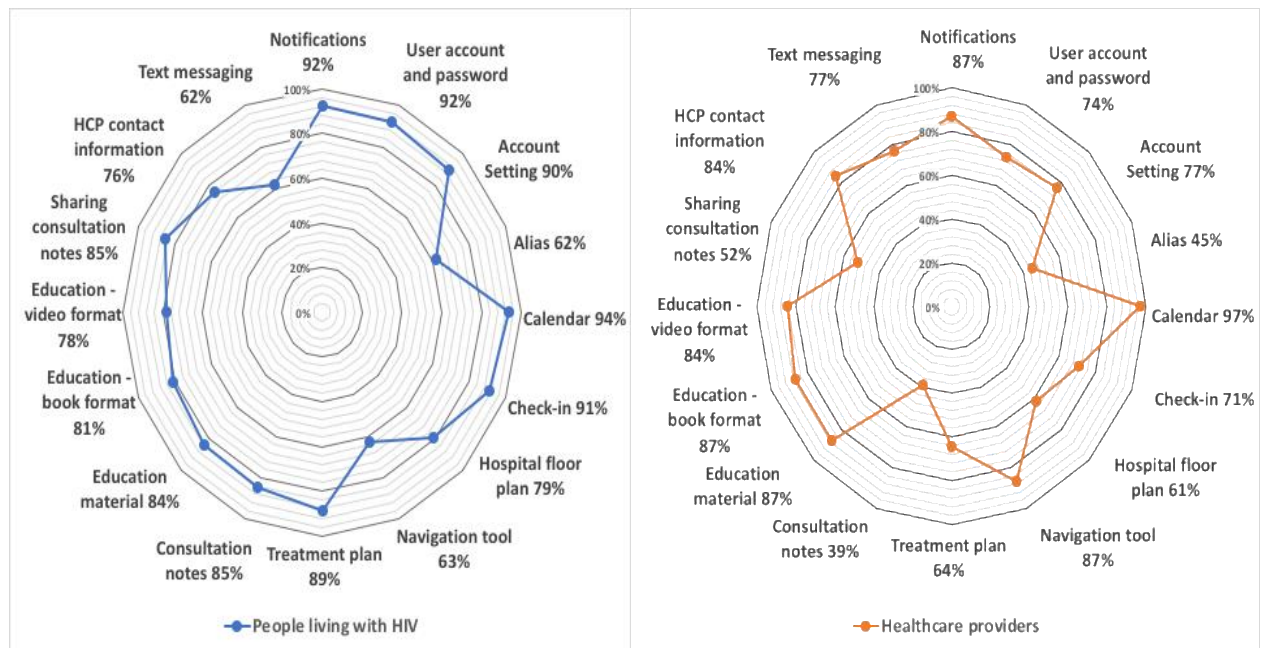
|   |         |        |
|---|---------|--------|
| Yes   | 84(74)  | 21(68) |
| No  | 25(22)  | 3(10)  |
| Uncertain   | 5(4)    | 6(19)  |
| Access to personal health information                   |         |        |
| Immediate access  | 70(61)  | N/A    |
| Following physician review                              | 29(25)  |        |
| No access   | 11(10)  |        |
| Only need-to-know information                           | 4(4)    |        |
| Healthcare application self-efficacy                    |         |        |
| Capacity to use healthcare applications                 | 103(90) | 28(90) |
| Comfortable using healthcare applications               | 88(77)  | 25(81) |
| Ease of healthcare application use                      | 87(76)  | 24(77) |
| Confidence pressing the right buttons to promote health | 83(73)  | 26(84) |
| Acceptability the proposed Opal patient portal          |         |        |
| Opal is appealing                                       | 103(90) | 30(97) |
| Opal has my approval                                    | 102(89) | 27(87) |
| I would welcome Opal in HIV care                        | 102(89) | 25(81) |
| I like Opal   | 87(76)  | 25(81) |
| N/A represents not applicable                           |         |        |

Most participants reported the capacity to use healthcare applications (n=103, 90% PLWH; n=28, 90% HCPs). Of the ten PLWH who did not agree they could use healthcare applications, of which three were over the age of 50 years. Among the three HCPs who did not feel capable of using healthcare applications, two were over 50 years old. Additionally, the proposed patient portal was perceived as appealing by most participants (n=103, 90% PLWH; n=30, 97% HCPs), and was met with approval by 102 (89%) PLWH and 27 (87%) HCPs.

#### *Interest in patient functions and willingness to share personal health information*

The patient portal functions that most interested the two groups included the appointment schedule (n=107, 94% PLWH; n=30, 97% HCPs), user account and password (n=105, 92% PLWH; n=23, 74% HCPs), and notifications and reminders (n=105, 92% PLWH; n=27, 87% HCPs) (see Figure 2). Among the functions deemed more useful by HCPs than PLWH were a navigational tool (n=72,

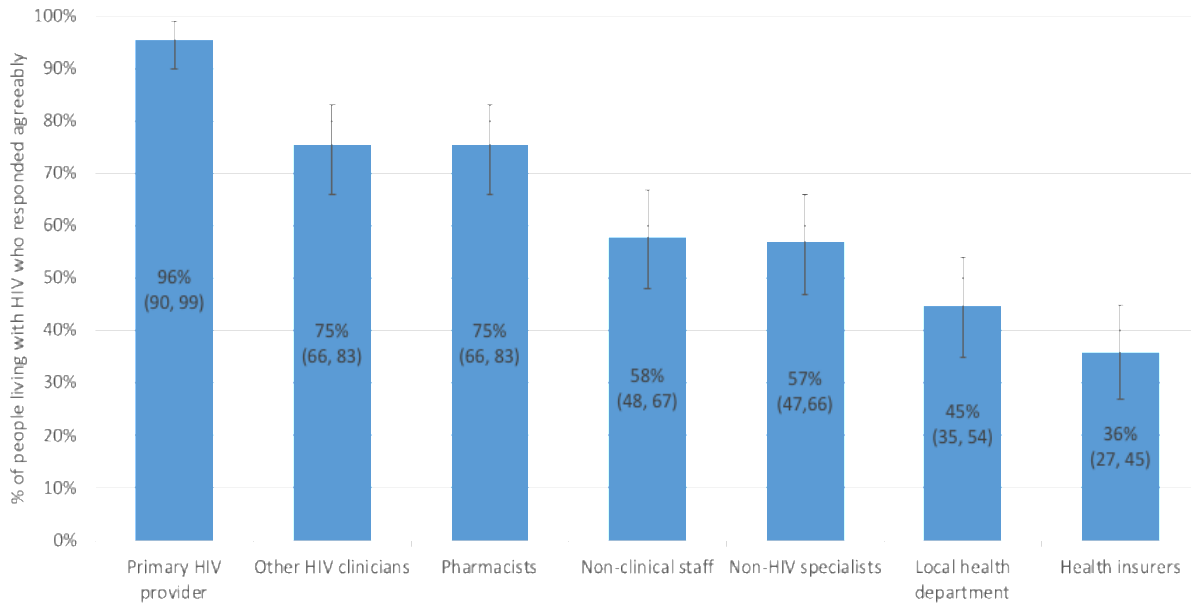
63% PLWH; n=27, 87% HCPs) and text messaging (n=71, 62% PLWH; n=24, 77% HCPs). Compared to PLWH, HCPs were less interested in functions for PLWH to access treatment plans (n=101, 89% PLWH; n=20, 64% HCPs), access consultation notes (n=97, 85% PLWH; n=12, 39% HCPs), and share consultation notes (n=97, 85% PLWH; n=16, 52% HCPs).



**Figure 2.** Participant interest in proposed patient portal functions.

Using a patient portal, PLWH would have the option to share their personal health information. PLWH were most comfortable sharing their HIV health data with their primary HIV healthcare provider (n=109, 96%, 95% CI =90, 99), followed by pharmacists (n=86, 75%, 95% CI =66,83) and other HIV specialists at their clinic (n=86, 75%, 95% CI =66, 83) (see Figure 3). However, PLWH were more reluctant to share information with public health (n=51, 45%, 95% CI =35, 54) and health insurers (n=41, 36%, 95% CI =27, 45).

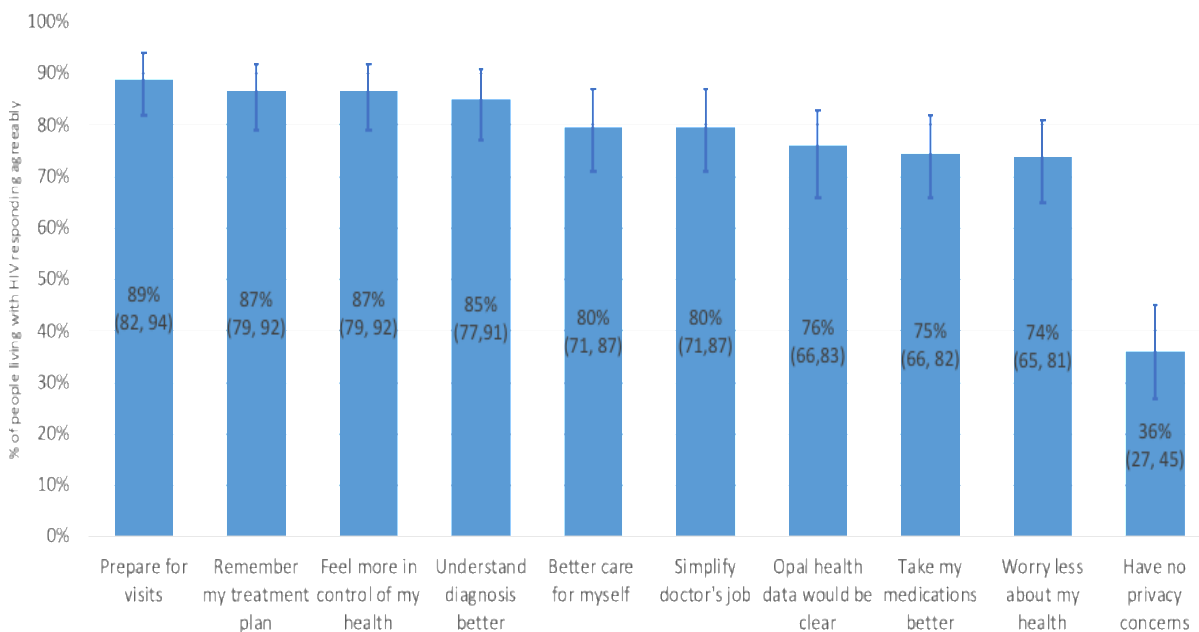




**Figure 3.** Willingness of people living with HIV who agree to share their personal health information with others. Percentages are displayed with 95% confidence intervals in brackets.

#### *Anticipated benefits and inconveniences of a patient portal*

Most PLWH believed a patient portal could provide various benefits, including better preparing themselves for clinical visits (n=101, 89%), remembering their HIV care plan (n=99, 87%), and feeling more in control of their healthcare (n=99, 87%) (see Figure 4). However, nearly two-thirds of PLWH (n=73, 64%) noted concerns about their privacy if using a patient portal.



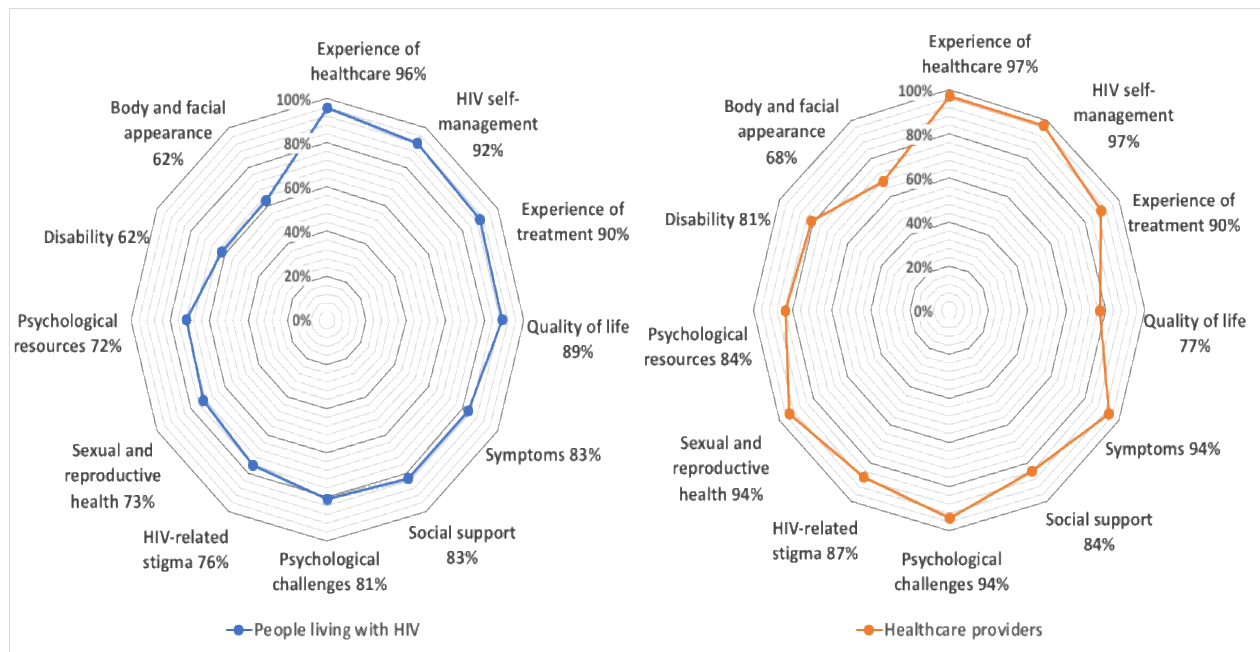
**Figure 4.** People living with HIV who responded agreeably to anticipated benefits and inconveniences of a patient portal. Percentages are displayed with 95% confidence intervals in brackets.

As for HCPs, almost two-thirds of physicians (n=8, 62%) were worried PLWH would contact them with questions about consultation notes, nearly half (n=6, 46%) of physicians had concerns PLWH may find significant errors in their consultation notes, and 6 (46%) physicians were concerned PLWH would request changes to their consultation notes. Lastly, approximately two-thirds (n=20, 64%) of all HCPs thought a patient portal would fit into the way they work.

#### *Interest in different patient-reported outcome measures*

At least 60% of all participants were interested in each of the PROM types evaluated (see Figure 5), particularly those regarding the experience of healthcare (n=109, 96% PLWH; n=30, 97% HCPs), HIV self-management (n=105, 92% PLWH; n=30, 97% HCPs), and the experience of treatment (n=103, 90% PLWH; n=28, 90% HCPs). The PROM types of least interest were body

and facial appearance (n=77, 68% PLWH; n=19, 62% HCPs) and disability (n=71, 62% PLWH; n=25, 81% HCPs).

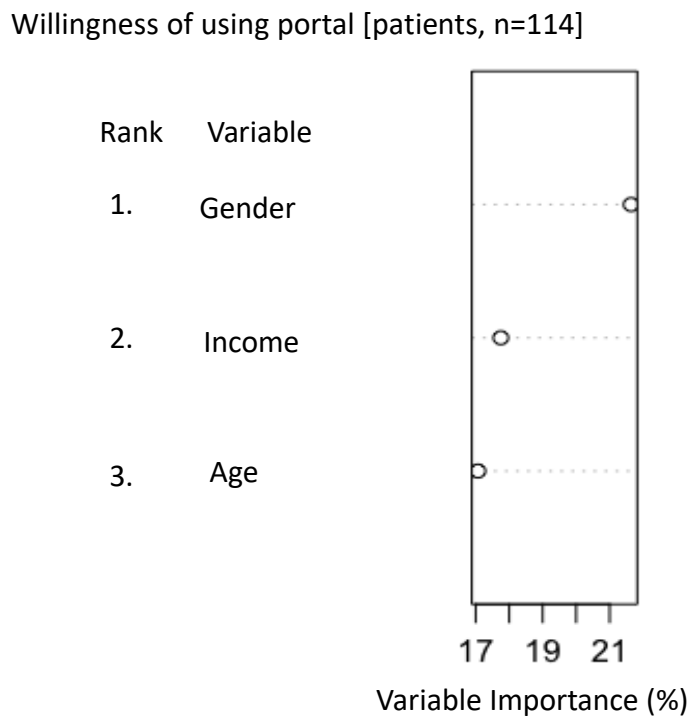


**Figure 5.** Participant interest in types of HIV-specific PROMs for administration via a patient portal.

### Random forest analyses

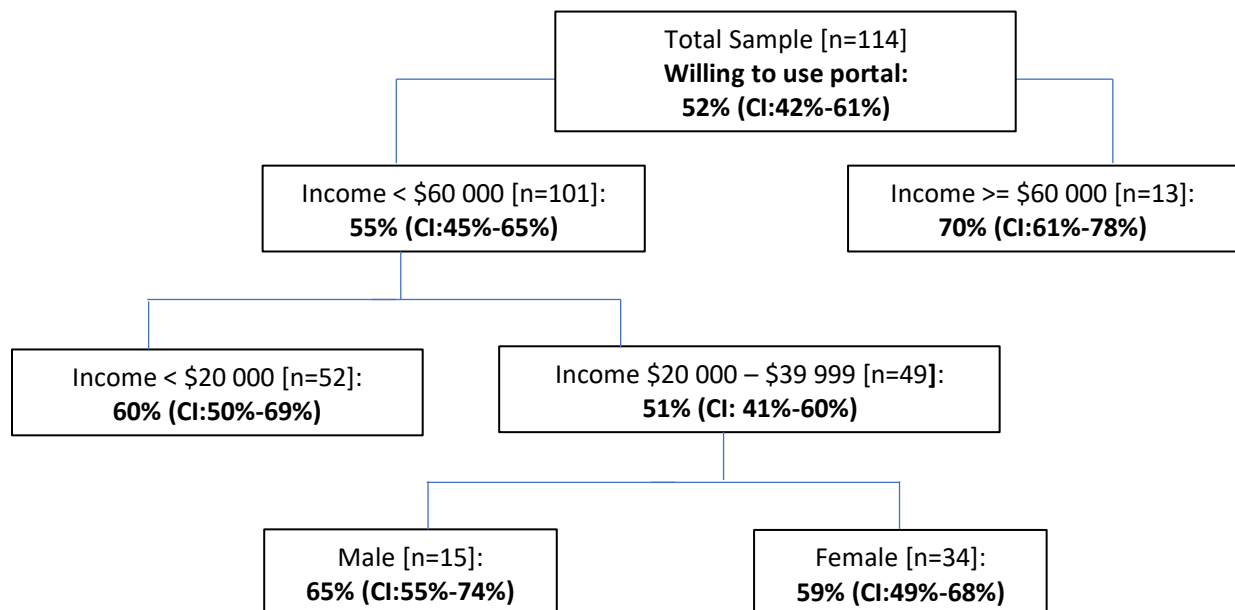
For PLWH, demographics and multiple survey response variables were analyzed to predict their willingness to use a patient portal. Factors that were most predictive, in order from most to least, were gender, income, and age, with a classification error rate of 39.4% (see Figure 6). Based on the random forest model, variable cut-offs were derived that maximize the accuracy of predicting ‘willingness to use a patient portal’. The respective cut-off for the variable age was 31 years, and for income \$60 000. Accordingly, among PLWH of 31 years and above, 56% were willing to use a patient portal, of which 74 were men (52% willing), and 32 were women (73% willing). PLWH with an annual income less than \$60 000 (n=101), 55% (n=55) were willing to use a patient portal,

while 70% (n=9) of those with an income equal to or greater than \$60 000 were willing (see Figure 7). Additionally, of those with an income less than \$60 000, 73% (n=73) of PLWH reported having none to limited experience with health technology but were still willing to use a patient portal, while 53% (n=53) of PLWH with some to very extensive health technology experience were willing to use a patient portal.



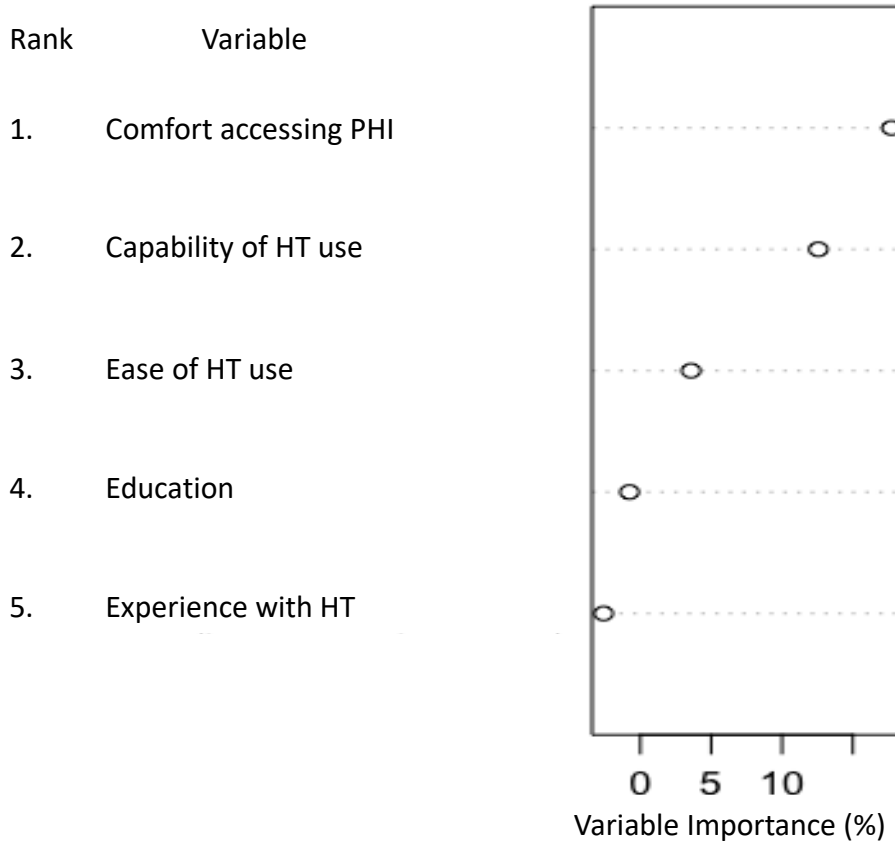
**Figure 6.** Variable Importance based on Random Forest analysis predicting willingness of people living with HIV to use a patient portal including the predictor variables gender, income, and age.

Additionally, questionnaire items concerning comfort using health technology and PLWH capability using health technology were also strong predictive factors (see Figure 8). Of PLWH capable using health technology (n=104, 79%), were willing to use a patient portal and of those individuals, while 86% of PLWH (n= 63) with no experience using health technology were willing, and 68% (n=41) of those with experience with health technology were willing to use a patient portal (see Figure 9).

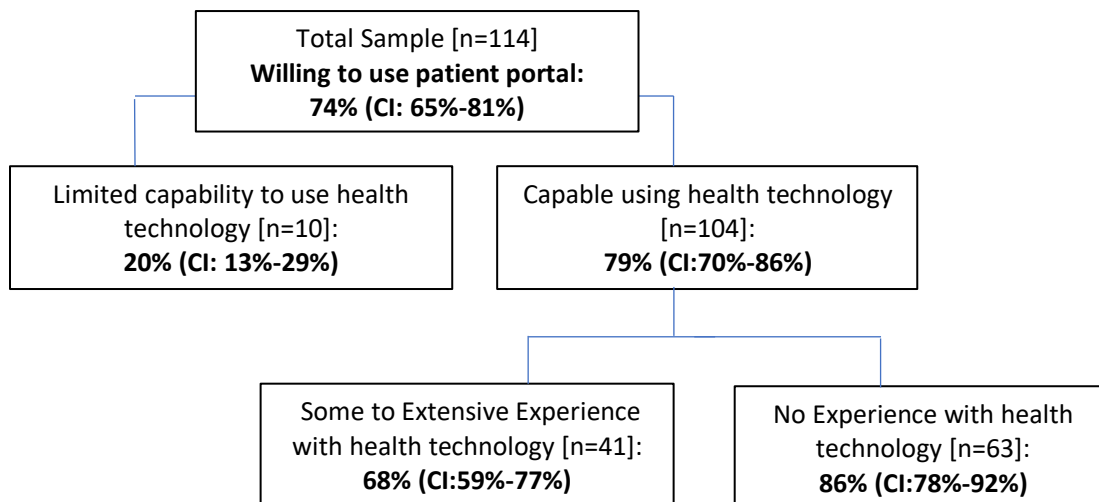


**Figure 7.** Classification tree demonstrating the association between income, gender, and age on willingness to use a patient portal. Each split delineates a class prediction of the variable with the greatest predictive importance. Age is not shown due to its relatively lower variable importance. Ninety-five percent confidence intervals are shown in brackets. This classification tree model demonstrates only the sub-groups of men and women to visualize the predictive value of different levels of income.

# Willingness of patients to use a patient portal



**Figure 8.** Variable Importance based on Random Forest analysis predicting patient willingness to use a patient portal using variables related to access to personal health information (PHI) , health technology (HT) self-efficacy and education.



**Figure 9.** Classification tree demonstrating HIV patients' willingness to use a patient portal. Factors examined include experience using health technology, technology self-efficacy, educational background, and comfort with accessing personal health information. Education was not displayed due to lower variable importance. Ninety-five percent confidence intervals are displayed in brackets.

## Discussion

This study sought to ascertain the acceptability of using a patient portal in HIV care with key stakeholder input obtained through a cross-sectional survey. The majority of PLWH and HCPs were willing to use a patient portal, meeting our overarching hypothesis. Beyond this, these results highlight a high prevalence of smart device ownership, acceptability of most patient portal functions, and acceptability of most PROMs, as well as several perceived benefits and inconveniences of a patient portal, and. Considering these results, a patient portal may be feasible for use in HIV care.

### *Smart device ownership, experience with healthcare applications, and health info preferences*

Critical to implementing a patient portal is the consideration of factors such as user access to smart devices, experience with healthcare applications, and willingness to use a patient portal<sup>136-140</sup>. Our sample revealed a high use of smart devices across all age groups for all participants, by which they could access a patient portal. This high ownership of smart devices had also met this study's anticipated smart device ownership, which coincided with the prevalence of smart device use in prior HIV mobile health-related literature<sup>116, 118</sup>. Although the ownership of smartphones was high within this sample (90%), it was consistent with Canadian smartphone ownership in 2020 (84.4%)<sup>141</sup>. Given sample uncertainties and sampling errors, the ownership of smartphones between the sample and population did not differ greatly. However, the uptake of smartphones or tablets was relatively lower in age groups above 50 years (85% of PLWH) compared to younger age groups. Similarly, prior studies noted lower access to and uptake of patient portals with older age<sup>138, 139</sup>. The mean age of the entire CVIS clinic was also above 50 years old and may affect the overall uptake of a patient portal.

The proportion of PLWH and HCPs willing to use a patient portal was less than the proportions reported within prior literature (78%) <sup>116</sup>. Most participants had limited healthcare application experience, although this did not reduce participants' interest in using the patient portal. However, participants with greater experience with health technology were less likely to use a patient portal, which may explain individuals' limited willingness to use a patient portal. This lends concern to portal uptake for these individuals. Considering prior health technology innovations such as patient portals, those with prior experience with health technology may have had negative experiences due to concerns over confidentiality and privacy, as well as an inability to meet the specific needs of end-users <sup>12, 91, 104, 105</sup>. Further engagement and consultation of these individuals with greater experience with health technology should be considered for the implementation of a patient portal due to its implications on patient portal uptake and satisfaction with the patient portal.

Interestingly, the proportion of PLWH preferring immediate access to medical records and patient portal access after physician review were similar to the preferences of oncology patients in the initial Opal study <sup>6</sup>. It was important to consider Opal's initial success in oncology care, considering their utilization of a patient-centered approach, where patients had chosen their preferred level of access to personal health information <sup>6</sup>. Given the varying preferences for access to personal health information in the HIV care context, it would be imperative to offer PLWH the option to choose their preferred level of access to personal health information during end-user testing to optimize PLWH uptake and satisfaction with a patient portal.



### *Interest in patient portal functions*

PLWH met anticipated levels of interest for most proposed patient portal functions including access to their treatment plan, consultation notes, and sharing consultation notes, however, HCPs were less receptive to these functions. The only function that did not meet this study's anticipated interest was the alias for HCPs, however, given concerns for confidentiality, using a patient's photo or alias in HIV care was understandable. Concerns for certain functions mirror those reported in prior literature, specifically, HCP worried that their workload may increase due to an influx of PLWH messages or phone calls with these types of portal functions <sup>142</sup>. However, prior studies that examined patient portal use showed that allowing access to consultation notes through patient portals had not increased clinician workload, and in some cases, even decreased the need for telephone calls and reduced unnecessary appointments <sup>143, 144</sup>.

### *Anticipated benefits and inconveniences of a patient portal*

Patient portals have been reported to be useful for monitoring the health of PLWH as they could meet the changing needs and expectations of PLWH <sup>94, 145</sup>. The anticipated benefits of a patient portal for PLWH, such as allowing for better clinic visit preparation and understanding of their HIV diagnosis, were consistent with these observations <sup>145</sup>. Despite the many anticipated benefits of using a patient portal, there were concerns as well. A patient portal raised privacy issues for many PLWH surveyed, which was congruent with prior literature citing concerns with data security theft, confidentiality, privacy, and HIV-related stigma as barriers to patient portal use and implementation <sup>12, 94, 95, 142, 146-149</sup>.

### *Interest in different types of PROMs*

Participants met this study's anticipated levels of interest in types of PROMs, which highlighted the various topics and issues they preferred to discuss, particularly PLWH-perceived experiences of healthcare, symptoms, psychological challenges, and social support. PROMs capturing body and facial appearance received the least amount of interest amongst all participants as some PLWH have not been exposed to the complications of outdated ART regimens. While a PROM capturing disability was received less interest from PLWH compared to HCPs. Interestingly, compared to HCPs, PLWH showed less interest in PROMs related to psychological challenges and resources, as well as to HIV-related stigma, despite their well-documented prevalence among PLWH <sup>150</sup>.

### *Random forest analyses to predict willingness to use a patient portal*

Several co-variates compared to willingness to use a patient portal were based on facilitators and barriers to patient portal adoption highlighted in prior literature <sup>13</sup>. These included age, social-economic status, and health literacy, and experience with technology <sup>147, 151, 152</sup>. Variables such as income, age, comfort with accessing PHI, prior health technology experience, and self-efficacy were good predictors. Similar to prior literature, those with an income below \$60 000 per year were less inclined than those with a higher income to use a patient portal <sup>13</sup>. This finding may be explained by patients' lower income and thus, these PLWH may have limited access to smart devices and access to care <sup>153, 154</sup>. Additionally, those with greater capability and ease of using health technology were more willing to use a patient portal. However, perceived capability and ease of health technology use did not suggest PLWH had prior experience with health technology, as PLWH with greater experience with health technology were associated with less willingness to use a patient portal. This finding may be explained by PLWH who have had negative prior

experiences with health technology, as previously mentioned. Therefore, during the implementation phase, it is imperative to engage and consult these individuals to optimize patient portal uptake.

By considering the most predictive variables for patient willingness to use a patient portal, several considerations can be made to refine the implementation of a patient portal in HIV care. Firstly, implementation of a patient portal can be catered to cohorts more interested in using a patient portal, to secure early adoption, including those with greater income, men, and limited experience with health technology. Secondly, research efforts can be made to identify recommendations of those who are less likely to use a patient portal, including those with less income, previous experience with health technology, and women. For example, those with lower income face greater health inequities and limited access to care, therefore, alternative, more accessible methods of care must be considered (i.e., home visits, paper-based PROMs, and education material) to promote engagement to care <sup>155</sup>.

### *Limitations*

A limitation of this acceptability study was the lack of equivalent participant recruitment from all sites to allow for site-to-site comparison; however, the goal was to implement a patient portal at the CVIS first, therefore recruitment was predominantly from the CVIS. Additionally, the use of convenience sampling of PLWH may have resulted in volunteer bias and social desirability bias; while convenience sampling of HCPs may have led to a sampling bias, more specifically, self-selection bias, by which HCPs were more inclined to respond, if they were interested in the use of a patient portal. However, the sampling of HCPs intended to include a variety of HIV-related

healthcare specialists in terms of role and expertise. Additionally, for the random forest analyses, the HCP sample size was too small and thus, could not be adequately performed for this cohort.

Due to convenience sampling biases for PLWH, the data reflected a high rate of smart device ownership but may not be representative of all PLWH in Canada. The research team prioritized the inclusion and equity of all PLWH and understood that not all PLWH and HCPs had equitable access to smart devices, and thus, cannot use a patient portal within their HIV care during its implementation. However, this study aimed to include even PLWH without smart device ownership to include their perspectives. Additionally, for those who cannot use smart devices during the patient portal implementation, the CVIS aims to offer certain patient portal functions such as paper-based PROM administration and educational material.

### *Future Considerations*

Understanding the acceptability of using a patient portal and the needs of PLWH and their HCPs was an initial step prior to piloting the implementation of a patient portal in HIV clinical care. This study aims to continue engaging with key stakeholders to optimize the patient portal for pilot development and testing. To optimize a patient portal for use in HIV care, the HIV research team aims to discuss further design considerations with stakeholders that could optimize portal uptake, utility, and usability.

## **Conclusions**

This study assessing the acceptability of configuring a patient portal to HIV care revealed several considerations for using a patient portal for PLWH and their HCPs, primarily for a large HIV clinic such as the CVIS. The results obtained suggest that a patient portal's implementation at the CVIS is feasible and meets this study's overarching hypothesis that the majority of PLWH and HCPs perceived a patient portal within HIV care to be useful and positively affect HIV care. Additionally, for both PLWH and HCPs, there was a high rate of smart device ownership, comfort with using healthcare applications, and interest in most patient portal functions and proposed PROMs, as well as several anticipated benefits of using a patient portal. By consulting key stakeholders, end-users of the patient portal, this study also offer insight into a framework for future patient portal adaptations from one specialty to another. Through the random forest model, the research team's understanding of the factors that predict willingness to use a patient portal can inform its implementation by catering a patient portal to patient cohorts most likely to use the patient portal, thus securing early adopters. Our next step, within my future PhD studies in the Department of Family Medicine at McGill University, hopes to utilize these results and inform the patient portal pilot implementation at the MUHC.

## References

1. Goodman RA, Posner SF, Huang ES, Parekh AK, Koh HK. Defining and measuring chronic conditions: imperatives for research, policy, program, and practice. *Prev Chronic Dis*. Apr 25 2013;10:E66. doi:10.5888/pcd10.120239
2. Lowther K, Selman L, Harding R, Higginson IJ. Experience of persistent psychological symptoms and perceived stigma among people with HIV on antiretroviral therapy (ART): a systematic review. *Int J Nurs Stud*. Aug 2014;51(8):1171-89. doi:10.1016/j.ijnurstu.2014.01.015
3. Engler K, Lenart A, Lessard D, Toupin I, Lebouche B. Barriers to antiretroviral therapy adherence in developed countries: a qualitative synthesis to develop a conceptual framework for a new patient-reported outcome measure. *AIDS Care*. Jan - Dec 2018;30(sup1):17-28. doi:10.1080/09540121.2018.1469725
4. Mills EJ, Nachega JB, Buchan I, et al. Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. *JAMA*. Aug 9 2006;296(6):679-90. doi:10.1001/jama.296.6.679
5. Lessard D, Toupin I, Engler K, Lenart A, Team ISC, Lebouche B. HIV-Positive Patients' Perceptions of Antiretroviral Therapy Adherence in Relation to Subjective Time: Imprinting, Domino Effects, and Future Shadowing. *J Int Assoc Provid AIDS Care*. Jan-Dec 2018;17:2325958218759208. doi:10.1177/2325958218759208
6. Kildea J, Battista J, Cabral B, et al. Design and Development of a Person-Centered Patient Portal Using Participatory Stakeholder Co-Design. *J Med Internet Res*. Feb 11 2019;21(2):e11371. doi:10.2196/11371
7. Williams EC, Achtmeyer CE, Thomas RM, et al. Factors Underlying Quality Problems with Alcohol Screening Prompted by a Clinical Reminder in Primary Care: A Multi-site Qualitative Study. *J Gen Intern Med*. Aug 2015;30(8):1125-32. doi:10.1007/s11606-015-3248-z
8. Johnson M, Jackson R, Guillaume L, Meier P, Goyder E. Barriers and facilitators to implementing screening and brief intervention for alcohol misuse: a systematic review of qualitative evidence. *Journal of Public Health*. 2010;33(3):412-421. doi:10.1093/pubmed/fdq095
9. Oster NV, Jackson SL, Dhanireddy S, et al. Patient Access to Online Visit Notes: Perceptions of Doctors and Patients at an Urban HIV/AIDS Clinic. *J Int Assoc Provid AIDS Care*. Jul-Aug 2015;14(4):306-12. doi:10.1177/2325957414526783
10. Fredericksen R, Crane PK, Tufano J, et al. Integrating a web-based, patient-administered assessment into primary care for HIV-infected adults. *J AIDS HIV Res*. Feb 2012;4(2):47-55. doi:10.5897/jahr11.046
11. Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: a systematic review of controlled trials. *J Med Internet Res*. Nov 26 2012;14(6):e162. doi:10.2196/jmir.2238
12. Ryan BL, Brown JB, Terry A, Cejic S, Stewart M, Thind A. Implementing and Using a Patient Portal: A qualitative exploration of patient and provider perspectives on engaging patients. *J Innov Health Inform*. Jul 4 2016;23(2):848. doi:10.14236/jhi.v23i2.848
13. Irizarry T, DeVito Dabbs A, Curran CR. Patient Portals and Patient Engagement: A State of the Science Review. *J Med Internet Res*. Jun 23 2015;17(6):e148. doi:10.2196/jmir.4255
14. Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *J Med Internet Res*. Feb 10 2015;17(2):e44. doi:10.2196/jmir.3171
15. Lin CT, Wittevrongel L, Moore L, Beaty BL, Ross SE. An Internet-based patient-provider communication system: randomized controlled trial. *J Med Internet Res*. Aug 5 2005;7(4):e47. doi:10.2196/jmir.7.4.e47

16. Zhou YY, Garrido T, Chin HL, Wiesenthal AM, Liang LL. Patient access to an electronic health record with secure messaging: impact on primary care utilization. *Am J Manag Care*. Jul 2007;13(7):418-24.
17. Osborn CY ML, Wallston KA, Johnson KB, Elasy TA. Understanding patient portal use: implications for medication management. *J Med Internet Res*. 2013;15(7):e133. doi:10.2196/jmir.2589
18. Baudendistel I, Winkler E, Kamradt M, et al. Personal electronic health records: understanding user requirements and needs in chronic cancer care. *J Med Internet Res*. May 21 2015;17(5):e121. doi:10.2196/jmir.3884
19. Deshpande PR, Rajan S, Sudeepthi BL, Abdul Nazir CP. Patient-reported outcomes: A new era in clinical research. *Perspect Clin Res*. Oct 2011;2(4):137-44. doi:10.4103/2229-3485.86879
20. Boyce MB, Browne JP. Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review. *Qual Life Res*. Nov 2013;22(9):2265-78. doi:10.1007/s11136-013-0390-0
21. Bristowe K, Clift P, James R, et al. Towards person-centred care for people living with HIV: what core outcomes matter, and how might we assess them? A cross-national multi-centre qualitative study with key stakeholders. *HIV Med*. Sep 2019;20(8):542-554. doi:10.1111/hiv.12758
22. Edelman EJ, Gordon K, Justice AC. Patient and provider-reported symptoms in the post-cART era. *AIDS Behav*. May 2011;15(4):853-61. doi:10.1007/s10461-010-9706-z
23. News C. 'She's still living, in some sense': Woman's app for patients wins award, days after her death. *CBC News*. June 4. <https://www.cbc.ca/news/canada/montreal/opal-app-cancer-patients-laurie-hendren-1.5161267>
24. van Limburg M, Wentzel J, Sanderma R, van Gemert-Pijnen L. Business Modeling to Implement an eHealth Portal for Infection Control: A Reflection on Co-Creation With Stakeholders. *JMIR Res Protoc*. Aug 13 2015;4(3):e104. doi:10.2196/resprot.4519
25. Greenhalgh T, Hinder S, Stramer K, Bratan T, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. *BMJ*. Nov 16 2010;341:c5814. doi:10.1136/bmj.c5814
26. Eldridge SM, Lancaster GA, Campbell MJ, et al. Defining Feasibility and Pilot Studies in Preparation for Randomised Controlled Trials: Development of a Conceptual Framework. *PLoS One*. 2016;11(3):e0150205. doi:10.1371/journal.pone.0150205
27. Engler K, Toupin I, Vicente S, Ahmed S, Lebouche B. A review of HIV-specific patient-reported measures of perceived barriers to antiretroviral therapy adherence: what themes are they covering? *J Patient Rep Outcomes*. Jun 27 2019;3(1):37. doi:10.1186/s41687-019-0124-3
28. Orsmond GI, Cohn ES. The Distinctive Features of a Feasibility Study: Objectives and Guiding Questions. *OTJR (Thorofare N J)*. Jul 2015;35(3):169-77. doi:10.1177/1539449215578649
29. Weiner BJ, Lewis CC, Stanick C, et al. Psychometric assessment of three newly developed implementation outcome measures. *Implement Sci*. Aug 29 2017;12(1):108. doi:10.1186/s13012-017-0635-3
30. Saag MS. HIV Infection - Screening, Diagnosis, and Treatment. *N Engl J Med*. Jun 3 2021;384(22):2131-2143. doi:10.1056/NEJMcp1915826
31. Remien RH, Stirratt MJ, Nguyen N, Robbins RN, Pala AN, Mellins CA. Mental health and HIV/AIDS: the need for an integrated response. *AIDS*. Jul 15 2019;33(9):1411-1420. doi:10.1097/QAD.0000000000002227
32. Lerner AM, Eisinger RW, Fauci AS. Comorbidities in Persons With HIV: The Lingering Challenge. *JAMA*. Jan 7 2020;323(1):19-20. doi:10.1001/jama.2019.19775
33. Nanditha NGA, Paiero A, Tafessu HM, et al. Excess burden of age-associated comorbidities among people living with HIV in British Columbia, Canada: a population-based cohort study. *BMJ Open*. Jan 8 2021;11(1):e041734. doi:10.1136/bmjopen-2020-041734

34. Hendricks L, Eshun-Wilson I, Rohwer A. A mega-aggregation framework synthesis of the barriers and facilitators to linkage, adherence to ART and retention in care among people living with HIV. *Syst Rev*. Feb 11 2021;10(1):54. doi:10.1186/s13643-021-01582-z
35. Pourcher V, Gourmelen J, Bureau I, Bouee S. Comorbidities in people living with HIV: An epidemiologic and economic analysis using a claims database in France. *PLoS One*. 2020;15(12):e0243529. doi:10.1371/journal.pone.0243529
36. Guaraldi G, Orlando G, Zona S, et al. Premature age-related comorbidities among HIV-infected persons compared with the general population. *Clin Infect Dis*. Dec 2011;53(11):1120-6. doi:10.1093/cid/cir627
37. Fredericksen RJ, Edwards TC, Merlin JS, et al. Patient and provider priorities for self-reported domains of HIV clinical care. *AIDS Care*. 2015;27(10):1255-64. doi:10.1080/09540121.2015.1050983
38. Kall M, Marcellin F, Harding R, Lazarus JV, Carrieri P. Patient-reported outcomes to enhance person-centred HIV care. *Lancet HIV*. Jan 2020;7(1):e59-e68. doi:10.1016/S2352-3018(19)30345-5
39. U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research: Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes*. 2006;4:79.
40. Nanni MG, Caruso R, Mitchell AJ, Meggiolaro E, Grassi L. Depression in HIV infected patients: a review. *Curr Psychiatry Rep*. Jan 2015;17(1):530. doi:10.1007/s11920-014-0530-4
41. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf*. Jun 2014;23(6):508-18. doi:10.1136/bmjqs-2013-002524
42. Etkind SN, Daveson BA, Kwok W, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *J Pain Symptom Manage*. Mar 2015;49(3):611-24. doi:10.1016/j.jpainsymman.2014.07.010
43. Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA*. Dec 18 2002;288(23):3027-34. doi:10.1001/jama.288.23.3027
44. Dobrozsi S, Panepinto J. Patient-reported outcomes in clinical practice. *Hematology Am Soc Hematol Educ Program*. 2015;2015:501-6. doi:10.1182/asheducation-2015.1.501
45. Schougaard LM, Larsen LP, Jessen A, et al. AmbuFlex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases. *Qual Life Res*. Mar 2016;25(3):525-34. doi:10.1007/s11136-015-1207-0
46. Lessard D, Engler K, Toupin I, Team ISC, Routy JP, Lebouche B. Evaluation of a project to engage patients in the development of a patient-reported measure for HIV care (the I-Score Study). *Health Expect*. Apr 2019;22(2):209-225. doi:10.1111/hex.12845
47. Organization WH. Defining Adherence. Accessed May 25, 2016. [http://www.who.int/chp/knowledge/publications/adherence\\_Section1.pdf](http://www.who.int/chp/knowledge/publications/adherence_Section1.pdf)
48. Laws MB, Beach MC, Lee Y, et al. Provider-patient Adherence Dialogue in HIV Care: Results of a Multisite Study. *AIDS and Behavior*. 2013;17(1):148-159. doi:10.1007/s10461-012-0143-z
49. Roberts KJP. Physician Beliefs about Antiretroviral Adherence Communication. 2000;14(9):477-484. doi:10.1089/108729100438854
50. Flores D, Leblanc N, Barroso J. Enrolling and retaining human immunodeficiency virus (HIV) patients in their care: A metasynthesis of qualitative studies. *Int J Nurs Stud*. Oct 2016;62:126-36. doi:10.1016/j.ijnurstu.2016.07.016
51. Patient engagement. Canadian Institutes of Health Research. Updated 2019-05-27. 2021. <https://cihr-irsc.gc.ca/e/45851.html>.



52. Diaz Del Campo P, Gracia J, Blasco JA, Andradas E. A strategy for patient involvement in clinical practice guidelines: methodological approaches. *BMJ Qual Saf.* Sep 2011;20(9):779-84. doi:10.1136/bmjqs.2010.049031
53. Bruni RA, Laupacis A, Levinson W, Martin DK. Public involvement in the priority setting activities of a wait time management initiative: a qualitative case study. *BMC Health Serv Res.* Nov 16 2007;7:186. doi:10.1186/1472-6963-7-186
54. Kupchunas WR. Personal health record: new opportunity for patient education. *Orthop Nurs.* May-Jun 2007;26(3):185-91; quiz 192-3. doi:10.1097/01.NOR.0000276971.86937.c4
55. Concannon TW, Meissner P, Grunbaum JA, et al. A new taxonomy for stakeholder engagement in patient-centered outcomes research. *Journal of general internal medicine.* 2012;27(8):985-91. doi:10.1007/s11606-012-2037-1
56. Research CloH. Patient Engagement. Accessed March 31, 2017. <http://www.cihir-sc.gc.ca/e/45851.html>
57. Grande SW, Faber MJ, Durand MA, Thompson R, Elwyn G. A classification model of patient engagement methods and assessment of their feasibility in real-world settings. *Patient education and counseling.* May 2014;95(2):281-7. doi:10.1016/j.pec.2014.01.016
58. Forbat L, Hubbard G, Kearney N. Patient and public involvement: models and muddles. *J Clin Nurs.* Sep 2009;18(18):2547-54. doi:10.1111/j.1365-2702.2008.02519.x
59. Pomey MP, Flora L, Karazivan P, et al. Le <<Montreal model>> : enjeux du partenariat relationnel entre patients et professionnels de la santé. *Sante publique (Vandoeuvre-les-Nancy, France).* 2015;27(1)
60. Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expectations.* 2015;18(5):1151-1166. doi:10.1111/hex.12090
61. Carman KL, Dardess P, Maurer M, et al. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs.* 2013;32(2):223-231. doi:10.1377/hlthaff.2012.1133
62. Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res BMC Health Services Research.* 2014;14(1):1-9.
63. Mallery C, Ganachari D, Fernandez J, Smeeding L, Robinson S, Moon M. *Innovative Methods in Stakeholder Engagement: An Environmental Scan.* 2012.
64. Involve. *Briefing notes for researchers: involving the public in NHS, public health and social care research.* 2012.
65. Mosconi P, Colombo C, Satolli R, Liberati A. PartecipaSalute, an Italian project to involve lay people, patients' associations and scientific-medical representatives in the health debate. *Health expectations : an international journal of public participation in health care and health policy.* 2007;10(2):194-204.
66. Oliver SR, Rees RW, Clarke-Jones L, et al. A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations.* 2008;11(1):72-84.
67. Services AH. A resource toolkit for engaging patient and families at the planning table. Alberta Health Services. Accessed 22 November, 2017. <http://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-engage-toolkit.pdf>
68. Kirwan JR, de Wit M, Frank L, et al. Emerging Guidelines for Patient Engagement in Research. *Value Health.* Mar 2017;20(3):481-486. doi:10.1016/j.jval.2016.10.003
69. Bellows M, Kovacs Burns K, Jackson K, Surgeoner B, Gallivan J. Meaningful and effective patient engagement: What matters most to stakeholders. *Patient Experience Journal.* 2015;2(1):18-28.
70. Nelimarkka M, Nonnecke B, Krishnan S, et al. Comparing Three Online Civic Engagement Platforms using the "Spectrum of Public Participation" Framework. 2014:

71. Evans R KI. Qualitative research and deliberative methods: promise or peril? *Qual res.* 2009;9(5):625-643.
72. Sinha N, Yang A, Pradeep A, et al. Feasibility and acceptability of a psychosocial and adherence electronic patient reported outcomes (PROs) system at an HIV care center in southern India. *AIDS Care.* May 2020;32(5):630-636. doi:10.1080/09540121.2019.1668532
73. Toupin I, Engler K, Lessard D, et al. Developing a patient-reported outcome measure for HIV care on perceived barriers to antiretroviral adherence: assessing the needs of HIV clinicians through qualitative analysis. *Qual Life Res.* Feb 2018;27(2):379-388. doi:10.1007/s11136-017-1711-5
74. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of Patient-Reported Outcomes in Routine Medical Care. *Am Soc Clin Oncol Educ Book.* May 23 2018;38:122-134. doi:10.1200/EDBK\_200383
75. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why? *Qual Life Res.* Feb 2009;18(1):115-23. doi:10.1007/s11136-008-9430-6
76. Rigby M, Georgiou A, Hypponen H, et al. Patient Portals as a Means of Information and Communication Technology Support to Patient- Centric Care Coordination - the Missing Evidence and the Challenges of Evaluation. A joint contribution of IMIA WG EVAL and EFMI WG EVAL. *Yearb Med Inform.* Aug 13 2015;10(1):148-59. doi:10.15265/IY-2015-007
77. Engler K, Lessard D, Lebouche B. A Review of HIV-Specific Patient-Reported Outcome Measures. *Patient.* Apr 2017;10(2):187-202. doi:10.1007/s40271-016-0195-7
78. Gheorghiu B, Hagens S. Use and Maturity of Electronic Patient Portals. *Stud Health Technol Inform.* 2017;234:136-141.
79. Irizarry T DD, Curran CR. . Patient portals and patient engagement: a state of the science review. *J Med Internet Res.* 17(6):e148. doi:10.2196/jmir.4255
80. Bourgeois FC, Mandl KD, Shaw D, Flemming D, Nigrin DJ. Mychildren's: integration of a personally controlled health record with a tethered patient portal for a pediatric and adolescent population. *AMIA Annu Symp Proc.* Nov 14 2009;2009:65-9.
81. Stewart MT, Hogan TP, Nicklas J, et al. The Promise of Patient Portals for Individuals Living With Chronic Illness: Qualitative Study Identifying Pathways of Patient Engagement. *J Med Internet Res.* Jul 17 2020;22(7):e17744. doi:10.2196/17744
82. Krist AH, Woolf SH, Bello GA, et al. Engaging primary care patients to use a patient-centered personal health record. *Ann Fam Med.* Sep-Oct 2014;12(5):418-26. doi:10.1370/afm.1691
83. Sequist TD, Zaslavsky AM, Colditz GA, Ayanian JZ. Electronic patient messages to promote colorectal cancer screening: a randomized controlled trial. *Arch Intern Med.* Apr 11 2011;171(7):636-41. doi:10.1001/archinternmed.2010.467
84. Antonio MG, Petrovskaya O, Lau F. The State of Evidence in Patient Portals: Umbrella Review. *J Med Internet Res.* Nov 11 2020;22(11):e23851. doi:10.2196/23851
85. Stevenson FA CK, Britten N, Dundar Y. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. *Health Expectations.* 2014;7(3):235-245.
86. Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. *Patient Educ Couns.* Jan 2012;86(1):9-18. doi:10.1016/j.pec.2011.02.004
87. Arnold CW, McNamara M, El-Saden S, Chen S, Taira RK, Bui AA. Imaging informatics for consumer health: towards a radiology patient portal. *J Am Med Inform Assoc.* Nov-Dec 2013;20(6):1028-36. doi:10.1136/amiajnl-2012-001457
88. Saberi P, Catz SL, Leyden WA, et al. Antiretroviral Therapy Adherence and Use of an Electronic Shared Medical Record Among People Living with HIV. *AIDS Behav.* Jun 2015;19 Suppl 2:177-85. doi:10.1007/s10461-014-0982-x

89. Ross SE, Moore LA, Earnest MA, Wittevrangel L, Lin CT. Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. *J Med Internet Res*. May 14 2004;6(2):e12. doi:10.2196/jmir.6.2.e12
90. Ferreira A, Correia A, Silva A, et al. Why facilitate patient access to medical records. *Stud Health Technol Inform*. 2007;127:77-90.
91. de Lusignan S, Ross P, Shifrin M, Hercigonja-Szekeres M, Seroussi B. A comparison of approaches to providing patients access to summary care records across old and new europe: an exploration of facilitators and barriers to implementation. *Stud Health Technol Inform*. 2013;192:397-401.
92. Sakaguchi-Tang DK, Bosold AL, Choi YK, Turner AM. Patient Portal Use and Experience Among Older Adults: Systematic Review. *JMIR Med Inform*. Oct 16 2017;5(4):e38. doi:10.2196/medinform.8092
93. Turner AM, Osterhage K, Hartzler A, et al. Use of Patient Portals for Personal Health Information Management: The Older Adult Perspective. *AMIA Annu Symp Proc*. 2015;2015:1234-41.
94. Zettel-Watson L, Tsukerman D. Adoption of online health management tools among healthy older adults: An exploratory study. *Health Informatics J*. Jun 2016;22(2):171-83. doi:10.1177/1460458214544047
95. Kerai P, Wood P, Martin M. A pilot study on the views of elderly regional Australians of personally controlled electronic health records. *Int J Med Inform*. Mar 2014;83(3):201-9. doi:10.1016/j.ijmedinf.2013.12.001
96. Mold F, de Lusignan S, Sheikh A, et al. Patients' online access to their electronic health records and linked online services: a systematic review in primary care. *Br J Gen Pract*. Mar 2015;65(632):e141-51. doi:10.3399/bjgp15X683941
97. Miller DP LC, Melius KA, Quandt SA, Arcury TA. Primary care provider's' views of patient portals: interview study of perceived benefits and consequences. *J Med Internet Res*. 2016;18(1):e8. doi:10.2196/jmir.4953
98. Giardina TD CJ, Georgiou A, Westbrook JI, Greisinger A, Esquivel A, Forjuoh SN, Parrish DE, Singh H. Releasing test results directly to patients: a multisite survey of physician perspectives. *Patient Educ Couns*. 2015;98(6):788-96.
99. Mak G, Smith Fowler H, Leaver C, Hagens S, Zelmer J. The Effects of Web-Based Patient Access to Laboratory Results in British Columbia: A Patient Survey on Comprehension and Anxiety. *J Med Internet Res*. Aug 4 2015;17(8):e191. doi:10.2196/jmir.4350
100. MyUHN Patient Portal. Accessed November 17, 2019, 2019. <http://imaginationchallenge.ca/wp-content/uploads/2017/02/myUHN-Patient-Portal.pdf>.
101. Alston C BZ, Brownlee S, Elwyn G, Fowler FJ Jr, LK Hall, et al. Shared decision making strategies for best care: patient decision. *AIDS*. 2014;
102. Dandachi D, Dang BN, Lucari B, Teti M, Giordano TP. Exploring the Attitude of Patients with HIV About Using Telehealth for HIV Care. *AIDS Patient Care STDS*. Apr 2020;34(4):166-172. doi:10.1089/apc.2019.0261
103. Otte-Trojel T, de Bont A, Aspria M, et al. Developing patient portals in a fragmented healthcare system. *Int J Med Inform*. Oct 2015;84(10):835-46. doi:10.1016/j.ijmedinf.2015.07.001
104. Otte-Trojel T, de Bont A, Rundall TG, van de Klundert J. What do we know about developing patient portals? a systematic literature review. *J Am Med Inform Assoc*. Apr 2016;23(e1):e162-8. doi:10.1093/jamia/ocv114
105. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc*. Mar-Apr 2006;13(2):121-6. doi:10.1197/jamia.M2025
106. Garrido T, Meng D, Wang JJ, Palen TE, Kanter MH. Secure e-mailing between physicians and patients: transformational change in ambulatory care. *J Ambul Care Manage*. Jul-Sep 2014;37(3):211-8. doi:10.1097/JAC.0000000000000043

107. Larsen E, Mydske PK. Developing electronic cooperation tools: a case from norwegian health care. *Interact J Med Res*. Jun 19 2013;2(1):e9. doi:10.2196/ijmr.2346
108. Ganann R, Ciliska D, Thomas H. Expediting systematic reviews: methods and implications of rapid reviews. *Implement Sci*. Jul 19 2010;5:56. doi:10.1186/1748-5908-5-56
109. Wynia MK, Torres GW, Lemieux J. Many physicians are willing to use patients' electronic personal health records, but doctors differ by location, gender, and practice. *Health Aff (Millwood)*. Feb 2011;30(2):266-73. doi:10.1377/hlthaff.2010.0342
110. Lapsia V, Lamb K, Yasnoff WA. Where should electronic records for patients be stored? *Int J Med Inform*. Dec 2012;81(12):821-7. doi:10.1016/j.ijmedinf.2012.08.008
111. O'Brien N, Greene S, Carter A, et al. Envisioning Women-Centered HIV Care: Perspectives from Women Living with HIV in Canada. *Womens Health Issues*. Nov - Dec 2017;27(6):721-730. doi:10.1016/j.whi.2017.08.001
112. Ng C, Chayama KL, Krusi A, Small W, Knight R. Perspectives of HIV-positive and -negative people who use drugs regarding the criminalization of HIV non-disclosure in Canada: a qualitative study. *BMC Public Health*. Aug 10 2020;20(1):1220. doi:10.1186/s12889-020-09291-3
113. Lacombe-Duncan A, Kia H, Logie CH, et al. A qualitative exploration of barriers to HIV prevention, treatment and support: Perspectives of transgender women and service providers. *Health Soc Care Community*. Nov 25 2020;doi:10.1111/hsc.13234
114. Scheim AI, Travers R. Barriers and facilitators to HIV and sexually transmitted infections testing for gay, bisexual, and other transgender men who have sex with men. *AIDS Care*. Aug 2017;29(8):990-995. doi:10.1080/09540121.2016.1271937
115. Boggild AK, Geduld J, Libman M, et al. Spectrum of illness in migrants to Canada: sentinel surveillance through CanTravNet. *J Travel Med*. Feb 1 2019;26(2)doi:10.1093/jtm/tay117
116. Jackman KM, Latkin CA, Maksut JL, Trent ME, Sanchez TH, Baral SD. Patient Portals as Highly Acceptable Tools to Support HIV Preventative Behaviors Among Adolescent and Young Sexual Minority Men. *J Adolesc Health*. Aug 2020;67(2):278-281. doi:10.1016/j.jadohealth.2020.03.029
117. Lenhart A PK, Smith A, Zickuhr K. Social media and mobile internet use among teens and young adults. Pew Internet. Accessed October 10, 2021, 2021. <https://www.webcitation.org/6nddOu1JM>
118. Holloway IW, Winder TJ, Lea CH, III, Tan D, Boyd D, Novak D. Technology Use and Preferences for Mobile Phone-Based HIV Prevention and Treatment Among Black Young Men Who Have Sex With Men: Exploratory Research. *JMIR Mhealth Uhealth*. Apr 13 2017;5(4):e46. doi:10.2196/mhealth.6436
119. Dillman DA, Smyth JD. Design effects in the transition to web-based surveys. *Am J Prev Med*. May 2007;32(5 Suppl):S90-6. doi:10.1016/j.amepre.2007.03.008
120. Engler KL, David & Toupin, Isabelle & Lènnart, Andràs & Lebouche, Bertrand. . Engaging Stakeholders into an Electronic Patient-Reported Outcome Development Study: on Making an HIV-Specific e-PRO Patient-Centered. . *Health Policy and Technology* 2016;doi:10.1016/j.hlpt.2016.11.002.
121. française R. Décret n° 2017-884 du 9 mai 2017 modifiant certaines dispositions réglementaires relatives aux recherches impliquant la personne humaine Paris: LegiFrance. 2021. <https://www.legifrance.gouv.fr/eli/decret/2017/5/9/2017-884/jo/texte>
122. Leveille SG, Walker J, Ralston JD, Ross SE, Elmore JG, Delbanco T. Evaluating the impact of patients' online access to doctors' visit notes: designing and executing the OpenNotes project. *BMC Med Inform Decis Mak*. Apr 13 2012;12:32. doi:10.1186/1472-6947-12-32
123. Maiorana A, Steward WT, Koester KA, et al. Trust, confidentiality, and the acceptability of sharing HIV-related patient data: lessons learned from a mixed methods study about Health Information Exchanges. *Implementation Science*. 2012/04/19 2012;7(1):34. doi:10.1186/1748-5908-7-34
124. Rahman MS, Ko M, Warren J, Carpenter D. Healthcare Technology Self-Efficacy (HTSE) and its influence on individual attitude: An empirical study. *Computers in Human Behavior*. 2016;58:12-24. doi:10.1016/j.chb.2015.12.016

125. Weiner BJ, Lewis CC, Stanick C, et al. Psychometric assessment of three newly developed implementation outcome measures. *Implementation Science*. 2017/08/29 2017;12(1):108. doi:10.1186/s13012-017-0635-3
126. Moore GC, Benbasat I. Development of an instrument to measure the perceptions of adopting an information technology innovation. *Information systems research*. 1991;2(3):192-222.
127. Barger D, Leleux O, Conte V, et al. Integrating Electronic Patient-Reported Outcome Measures into Routine HIV Care and the ANRS CO3 Aquitaine Cohort's Data Capture and Visualization System (QuAliV): Protocol for a Formative Research Study. *JMIR Res Protoc*. Jun 7 2018;7(6):e147. doi:10.2196/resprot.9439
128. Fredericksen RJ, Tufano J, Ralston J, et al. Provider perceptions of the value of same-day, electronic patient-reported measures for use in clinical HIV care. *AIDS Care*. Nov 2016;28(11):1428-33. doi:10.1080/09540121.2016.1189501
129. Bristowe K, Murtagh FEM, Clift P, et al. The development and cognitive testing of the positive outcomes HIV PROM: a brief novel patient-reported outcome measure for adults living with HIV. *Health Qual Life Outcomes*. Jul 6 2020;18(1):214. doi:10.1186/s12955-020-01462-5
130. Kjaer A, Rasmussen TA, Hjollund NH, Rodkjaer LO, Storgaard M. Patient-reported outcomes in daily clinical practise in HIV outpatient care. *Int J Infect Dis*. Apr 2018;69:108-114. doi:10.1016/j.ijid.2018.02.015
131. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software platform partners. *J Biomed Inform*. Jul 2019;95:103208. doi:10.1016/j.jbi.2019.103208
132. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. Apr 2009;42(2):377-81. doi:10.1016/j.jbi.2008.08.010
133. *R: A language and environment for statistical computing*. Version 1.2. R Core Team; 2020. <http://www.rstudio.com/>
134. M. LAaW. Classification and Regression by randomForest. *R News*. 2002;2(3):18-22.
135. L B. Random Forests. *Machine Learning*. 2001;45:5-32. doi:<https://doi.org/10.1023/A:1010933404324>
136. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care*. Oct 2006;15(5):307-10. doi:10.1136/qshc.2005.016527
137. Ancker JS, Osorio SN, Cheriff A, Cole CL, Silver M, Kaushal R. Patient activation and use of an electronic patient portal. *Inform Health Soc Care*. 2015;40(3):254-66. doi:10.3109/17538157.2014.908200
138. Gordon NP, Hornbrook MC. Differences in Access to and Preferences for Using Patient Portals and Other eHealth Technologies Based on Race, Ethnicity, and Age: A Database and Survey Study of Seniors in a Large Health Plan. *J Med Internet Res*. Mar 4 2016;18(3):e50. doi:10.2196/jmir.5105
139. Latulipe C, Gatto A, Nguyen HT, et al. Design Considerations for Patient Portal Adoption by Low-Income, Older Adults. *Proc SIGCHI Conf Hum Factor Comput Syst*. Apr 2015;2015:3859-3868. doi:10.1145/2702123.2702392
140. Franklin P, Chenok K, Lavalee D, et al. Framework To Guide The Collection And Use Of Patient-Reported Outcome Measures In The Learning Healthcare System. *EGEMS (Wash DC)*. Sep 4 2017;5(1):17. doi:10.5334/egems.227
141. Canada S. Telecommunications: Connecting Canadians. Updated 22-09-2021. Accessed 27-09-2021, 2021. [https://www.statcan.gc.ca/eng/subjects-start/digital\\_economy\\_and\\_society/telecommunications](https://www.statcan.gc.ca/eng/subjects-start/digital_economy_and_society/telecommunications)

142. McInnes DK, Solomon JL, Bokhour BG, et al. Use of electronic personal health record systems to encourage HIV screening: an exploratory study of patient and provider perspectives. *BMC Res Notes*. Aug 15 2011;4:295. doi:10.1186/1756-0500-4-295
143. Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. *Health Aff (Millwood)*. Mar-Apr 2009;28(2):323-33. doi:10.1377/hlthaff.28.2.323
144. Hess R, Bryce CL, Paone S, et al. Exploring challenges and potentials of personal health records in diabetes self-management: implementation and initial assessment. *Telemed J E Health*. Oct 2007;13(5):509-17. doi:10.1089/tmj.2006.0089
145. Lingg M, Lutschg V. Health System Stakeholders' Perspective on the Role of Mobile Health and Its Adoption in the Swiss Health System: Qualitative Study. *JMIR Mhealth Uhealth*. May 11 2020;8(5):e17315. doi:10.2196/17315
146. Lober WB, Zierler B, Herbaugh A, et al. Barriers to the use of a personal health record by an elderly population. *AMIA Annu Symp Proc*. 2006:514-8.
147. Schnipper JL, Gandhi TK, Wald JS, et al. Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. *Inform Prim Care*. 2008;16(2):147-55. doi:10.14236/jhi.v16i2.686
148. Hourcade JP, Chrischilles EA, Gryzlak BM, et al. Design Lessons for Older Adult Personal Health Records Software from Older Adults. Springer Berlin Heidelberg; 2011:176-185.
149. Price MM, Pak R, Müller H, Stronge A. Older adults' perceptions of usefulness of personal health records. *Universal Access in the Information Society*. 2013/06/01 2013;12(2):191-204. doi:10.1007/s10209-012-0275-y
150. Rueda S, Mitra S, Chen S, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open*. Jul 13 2016;6(7):e011453. doi:10.1136/bmjopen-2016-011453
151. Taha J, Sharit J, Czaja SJ. The impact of numeracy ability and technology skills on older adults' performance of health management tasks using a patient portal. *J Appl Gerontol*. Jun 2014;33(4):416-36. doi:10.1177/0733464812447283
152. Haggstrom DA, Saleem JJ, Russ AL, Jones J, Russell SA, Chumbler NR. Lessons learned from usability testing of the VA's personal health record. *J Am Med Inform Assoc*. Dec 2011;18 Suppl 1:i13-7. doi:10.1136/amiajnl-2010-000082
153. Goel MS BT, Williams A, Hasnain-Wynia R, Thompson JA, Baker DW. Disparities in Enrollment and Use of an Electronic Patient Portal. *Journal of General Internal Medicine*. 2011;26:1112-1116.
154. Sarkar U, Karter AJ, Liu JY, et al. The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system-results from the diabetes study of northern California (DISTANCE). *J Health Commun*. 2010;15 Suppl 2:183-96. doi:10.1080/10810730.2010.499988
155. Apter AJ, Localio AR, Morales KH, et al. Home visits for uncontrolled asthma among low-income adults with patient portal access. *J Allergy Clin Immunol*. Sep 2019;144(3):846-853 e11. doi:10.1016/j.jaci.2019.05.030

## Appendix A

### Questionnaire for people living with HIV

---

#### Demographics

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1. What is your date of birth?

\_\_\_\_/\_\_\_\_/\_\_\_\_  
DD/MMM/YYYY

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2. What is your gender (select all that apply)?

Female ☐

Male ☐

Trans ☐

Other ☐ Specify: \_\_\_\_\_

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3. With respect to your sexual orientation, how do you currently identify? (check all that apply)

Heterosexual/straight ☐

Lesbian ☐

Gay ☐

Bisexual ☐

Other (queer, two-spirited,  
etc.) ☐

Specify: \_\_\_\_\_

Unsure ☐

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4. What is your marital status?

Single ☐

Married or common-law ☐

Divorced ☐

Widow(er) ☐

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5. If a refugee or immigrant:

Year of entry in

Canada: \_\_\_\_\_

Country of origin: \_\_\_\_\_

---

6. What ethnic group(s) or family background(s) do you identify with? (check all that apply)

Caucasian or White ☐

Black, African, or Caribbean ☐

Asian or Pacific Islander ☐

Indian or South Asian ☐

North African or Middle  
Eastern ☐  
Aboriginal, First Nations, or  
Métis ☐  
Other ☐ Specify: \_\_\_\_\_

---

**7. What is the highest level of education that you have completed?**

No formal education ☐  
Elementary ☐  
Some high school but did not graduate ☐  
High school diploma or a high school  
equivalency certificate ☐  
Trade, vocational, or technical diploma  
certificate ☐  
Some post-secondary education but no  
certificate or diploma ☐  
University, college diploma, or certificate  
less than a bachelor's degree ☐  
Bachelor's degree ☐  
Graduate (PhD or Masters) or  
professional degree (medical, law, etc.) ☐  
Other ☐ Specify: \_\_\_\_\_

---

**8. What is your current employment status? (check all that apply)**

Student ☐  
Part-time employment ☐  
Full-time employment ☐  
Unemployed ☐  
Homemaker ☐  
Retired ☐  
Sick leave or work-related illness/injury  
leave ☐  
Long-term disability ☐

---

**9. What was your total income for last year, from all paid work and other sources before taxes and other deduction?**

\$0 or No income ☐  
\$1 - \$19,999 ☐  
\$20,000 - \$39,999 ☐  
\$40,000 - \$59,999 ☐  
\$60,000 - \$79,999 ☐  
\$80,000 - \$99,999 ☐



\$100,000 or more ☐

---

**10. What is the first language that you  
learned?**

\_\_\_\_\_

---

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**11. What is your preferred language of communication at the service where you receive HIV care?**

French ☐

English ☐

Other ☐ Specify: \_\_\_\_\_

---

**12. How much time, in minutes, does it take you to travel from your home to the service where you receive HIV care?**

\_\_\_\_\_ minutes

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**13. What mode of transportation do you use to go to the service where you receive HIV care?**

On foot / Walking ☐

Car ☐

Public transit (bus, metro, train,  
etc.) ☐

Bicycle ☐

Other ☐ Specify: \_\_\_\_\_

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#### **HIV care and use of digital applications**

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**1. When did you learn you were HIV-positive?**

\_\_\_\_/\_\_\_\_  
MM/YYYY

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**2. Do you currently use any of the following smart devices? (check all that apply)**

Smartphone ☐

iPod, phablet ☐

Tablet ☐

Smartwatch ☐

Computer, laptop ☐

Other ☐ Specify: \_\_\_\_\_

I do not use any of these devices ☐

---

**3. Do you currently use an application (app) on a smart device in relation to your health or HIV care?**

Yes ☐ Specify: \_\_\_\_\_

No ☐

---

**4. How much experience do you have with health-related applications (apps) on smart devices?**

None ☐

Very little ☐

- Average ☐  
Quite extensive ☐  
Very extensive ☐

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**A *patient portal* is a secure website or application (app) that gives you access to your medical records, as well as other services (for example, a mobile check-in function and messaging with care providers).**

**Your *medical records* include: your diagnosis; personal and medical information; a list of your appointments; your treatment plan and medication; your physician's consultation notes; and your lab test results.**

- 5. Would you use a patient portal to access your personal health information relative to your HIV care?**

- Yes ☐  
No ☐  
I don't know ☐

- 
- 6. What is your level of comfort with accessing your personal health information on a smart device?**

I would like access to all my ☐  
medical records as soon as the  
information is available.

I would like access to all my ☐  
medical records, after I have  
reviewed them with my doctor.

I would like access to just my ☐  
appointments and other need-  
to-know information (for  
example, instructions on how to  
go to the clinic).

I do not want access to my ☐  
medical records on a smart  
device.

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The term *health technology* refers here to any health-related application (app) or software.

**7. Please indicate to which extent you agree with the following statements**

| Statements   | 1<br>Strongly<br>disagree | 2<br>Somehow<br>disagree | 3<br>Disagree            | 4<br>Undecided           | 5 Agree                  | 6<br>Somehow<br>agree    | 7<br>Strongly<br>agree   |
|--|---------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| It is easy for me to use health technology.  | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have the capability to use health technology.  | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I do not feel comfortable using health technology.                                       | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| When using health technology, I worry I might press the wrong button and risk my health. | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Comments:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Patient-reported outcome measures (PROM)

A *patient-reported outcome measure* is a questionnaire or survey about a given aspect of their health or illness, in which answers come directly from patients. They capture answers from patients, with no input from a physician or health professional. They are not blood test results (for example, viral load, CD4 counts).

### 1. Please specify your level of interest in filling out these different types of patient-reported outcome measures:

| Types of patient-reported outcome measures   | 1<br>Not at all<br>interested | 2<br>Not<br>interested   | 3<br>Undecided           | 4<br>A little<br>interested | 5<br>Very<br>interested  | I<br>don't<br>know       |
|--|-------------------------------|--------------------------|--------------------------|-----------------------------|--------------------------|--------------------------|
| <b>Quality of life</b>   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Experience of treatment</b><br>(e.g., attitudes towards treatment, side effects, satisfaction with treatment) | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Experience of healthcare</b><br>(e.g., patient needs, quality of care, barriers to care)                      | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Psychological challenges</b><br>(e.g., stress, depression)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Symptoms</b><br>(e.g., symptoms of HIV, fatigue, psychomotor slowness)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Psychological resources</b><br>(e.g., perceived control, spiritual beliefs and activities, resiliency)        | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>HIV self-management / self-care</b><br>(e.g., adherence to treatment)   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>HIV-related stigma</b>  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Body and facial appearance</b><br>(e.g., body image)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Social support</b><br>(e.g., unsupportive social interactions)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Sexual and reproductive health</b><br>(e.g., motivation for childbearing, HIV status disclosure, safer sex)   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Disability</b>  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Others,</b><br><b>specify:</b> _____<br>_____   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |

## Functions of Opal

*The staff administering this questionnaire will now show you different functions considered for the Opal application (app).*

**1. For each function considered for Opal, please specify how useful it is for you:**

| Functions                                | 1<br>Not at<br>all<br>useful | 2<br>Not<br>useful       | 3<br>Undecided           | 4<br>A little<br>useful  | 5<br>Very<br>useful      | I<br>don't<br>know       |
|--|------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Welcome message                          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Appointment schedule                     | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Appointment check-in                     | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Appointment map                          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Navigation tool, top left                | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Contacts                                 | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Notifications                            | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Treatment plan                           | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Consultation Note                        | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Messages                                 | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Educational material                     | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Booklet                                  | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Video                                    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Notes                                    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Account setting                          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Allow an alias for the<br>screen display | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Comments:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

### Acceptability, benefits, and risks of Opal

**1. Please indicate to which extent you agree with the following statements:**

| Statements             | 1<br>Completely<br>disagree | 2<br>Somehow<br>disagree | 3<br>Somehow<br>agree    | 4<br>Completely<br>agree | I don't<br>know          |
|------------------------|-----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Opal meets my approval | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

|  |                          |                          |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Opal is appealing to me  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I like Opal  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I welcome Opal   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b><i>Using a secure electronic network, I am willing to allow my personal health information to be shared with...</i></b> |                          |                          |                          |                          |                          |
| ...my primary HIV care provider.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ... other clinicians at my HIV clinic.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ... the non-clinical staff at my HIV clinic.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ... non-HIV specialists.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ... pharmacists.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ... my health insurers.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ... the local health department.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b><i>With Opal...</i></b>   |                          |                          |                          |                          |                          |
| ...I would better understand my health and medical conditions.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would better remember the plan for my care.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would take better care of myself.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would be more likely to take my medications as prescribed.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would feel more in control of my health care.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would be better prepared for visits.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would worry more  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...I would be concerned about my privacy.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...the information would be more confusing than helpful.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ...it could make my doctor's job more difficult.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Comments:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Questionnaire for HIV healthcare providers

### Demographics

1. What is your date of birth?

\_\_\_\_/\_\_\_\_/\_\_\_\_  
DD/MMM/YYYY

2. What is your gender (select all that apply)?

Female ☐

Male ☐

Trans ☐

Other ☐ Specify: \_\_\_\_\_

Prefer not to answer ☐

3. What is your occupation at the Chronic Viral Illness Service?

Physician ☐

Nurse ☐

Psychologist ☐

Psychiatrist ☐

Social worker ☐

Pharmacist ☐

Other ☐ Specify: \_\_\_\_\_

4. What is the first language that you learned?

\_\_\_\_\_

5. What is your preferred language of communication when you provide HIV care?

French ☐

English ☐

Other ☐ Specify: \_\_\_\_\_



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**HIV care and use of digital applications**

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**1. Do you currently use any of the following smart devices? (check all that apply)**

- Smartphone ☐  
iPod, phablet ☐  
Tablet ☐  
Smartwatch ☐  
Computer, laptop ☐  
Other ☐ Specify: \_\_\_\_\_  
I do not use any of these devices ☐
- 

**2. Do you currently use an application (app) on a smart device for your work as an HIV care provider?**

- Yes ☐ Specify: \_\_\_\_\_  
No ☐
- 

**3. Do you know of any digital, smartphone, or web-based application (app) currently used by your HIV patients for their HIV health care?**

- Yes ☐ Specify: \_\_\_\_\_  
No ☐
- 

**4. How much experience do you have with health-related applications (apps) on smart devices?**

- None ☐  
Very little ☐  
Average ☐  
Quite extensive ☐  
Very extensive ☐
- 

***A patient portal is a secure website or application (app) that gives you access to your medical records, as well as other services (for example, a mobile check-in function and messaging with care providers).***

***Patients' medical records include: their diagnosis; their personal and medical information; a list of their appointments; their treatment plan and medication; their physician's consultation notes; and their lab test results.***

**5. Would you use a patient portal for your HIV patients that allows them to access their medical records?**

- Yes ☐  
No ☐  
I don't know ☐
-

**7. Please indicate to which extent you agree with the following statements**

| Statements  | 1<br>Strongly<br>disagree | 2<br>Somehow<br>disagree | 3<br>Disagree            | 4<br>Undecided           | 5 Agree                  | 6<br>Somehow<br>agree    | 7<br>Strongly<br>agree   |
|---|---------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| It is easy for me to use health technology.                           | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have the capability to use health technology.                       | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I do not feel comfortable using health technology.                    | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| When using health technology, I worry I might press the wrong button. | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Comments:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Patient-reported outcome measures (PROM)

**1. Please specify your level of interest in having your HIV patients fill out patient-reported outcome measures via Opal for each of the following types:**

| Types of patient-reported outcome measures   | 1<br>Not at all<br>interested | 2<br>Not<br>interested   | 3<br>Undecided           | 4<br>A little<br>interested | 5<br>Very<br>interested  | I<br>don't<br>know       |
|--|-------------------------------|--------------------------|--------------------------|-----------------------------|--------------------------|--------------------------|
| <b>Quality of life</b>   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Experience of treatment</b><br>(e.g., attitudes towards treatment, side effects, satisfaction with treatment) | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Experience of healthcare</b><br>(e.g., patient needs, quality of care, barriers to care)                      | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Psychological challenges</b><br>(e.g., stress, depression)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Symptoms</b><br>(e.g., symptoms of HIV, fatigue, psychomotor slowness)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Psychological resources</b><br>(e.g., perceived control, spiritual beliefs and activities, resiliency)        | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>HIV self-management / self-care</b><br>(e.g., adherence to treatment)   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>HIV-related stigma</b>  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Body and facial appearance</b><br>(e.g., body image)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Social support</b><br>(e.g., unsupportive social interactions)  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Sexual and reproductive health</b><br>(e.g., motivation for childbearing, HIV status disclosure, safer sex)   | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Disability</b>  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Others,</b><br><b>specify:</b> _____  | <input type="checkbox"/>      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>    | <input type="checkbox"/> | <input type="checkbox"/> |

## Functions of Opal

*The staff administering this questionnaire will now show you different functions considered for the Opal application.*

**2. For each function considered for Opal, please specify how useful it is for you:**

| Functions                                | 1<br>Not at<br>all<br>useful | 2<br>Not<br>useful       | 3<br>Undecided           | 4<br>A little<br>useful  | 5<br>Very<br>useful      | I<br>don't<br>know       |
|--|------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Welcome message                          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Appointment schedule                     | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Appointment check-in                     | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Appointment map                          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Navigation tool, top left                | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Contacts                                 | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Notifications                            | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Treatment plan                           | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Consultation Note                        | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Messages                                 | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Educational material                     | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Booklet                                  | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Video                                    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Notes                                    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Account setting                          | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Allow an alias for the<br>screen display | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Comments:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Acceptability, benefits, and risks

**1. Please indicate to which extent you agree with the following statements:**

| Statements | 1<br>Completely<br>disagree | 2<br>Somehow<br>disagree | 3<br>Somehow<br>agree | 4<br>Completely<br>agree | I don't<br>know |
|------------|-----------------------------|--------------------------|-----------------------|--------------------------|-----------------|
|------------|-----------------------------|--------------------------|-----------------------|--------------------------|-----------------|

|   |                          |                          |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Opal meets my approval  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Opal is appealing to me   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I like Opal   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I welcome Opal  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b><i>For physicians only:</i></b>  |                          |                          |                          |                          |                          |
| <b><i>Knowing that Opal may give patients access to their physician's consultation notes...</i></b> |                          |                          |                          |                          |                          |
| Patients will disagree with what I write in their visit notes                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patients will request changes to the content of visit notes   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patients will find significant errors in the notes  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patients will contact me or my practice with questions about their notes                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**2. Please indicate to which extent you agree with the following statements:**

| Statements  | 1<br>Strongl<br>y<br>disagree | 2<br>Someho<br>w<br>disagree | 3<br>Disagre<br>e        | 4<br>Undecide<br>d       | 5<br>Agre<br>e           | 6<br>Someho<br>w agree   | 7<br>Strongl<br>y agree  |
|---|-------------------------------|------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Using Opal is compatible with all aspects of my work          | <input type="checkbox"/>      | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Using Opal is completely compatible with my current situation | <input type="checkbox"/>      | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I think that using Opal fits well with the way I like to work | <input type="checkbox"/>      | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Using Opal fits into my work style                            | <input type="checkbox"/>      | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Comments:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## **Appendix B**

### **Ethics and related certificates**

MUHC approval (Supplemental S2) to conduct ethical research with people was received on August 21, 2019 through the completion of CITI Program's Good Clinical Practice – Canada (Supplemental S3), Standard Operating Procedures of the MUHC, and Health Canada Division 5 training.