



**Co-designing care improvements for women living with HIV:  
a patient-oriented deliberative dialogue workshop in  
Montréal, Québec.**

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Abstract:	<p><b>Background</b> Care services have not been sufficiently adapted to meet the comprehensive care needs of women living with HIV. Our study objective was to engage patients and providers in co-designing care recommendations to improve care for this population in Québec.</p> <p><b>Methods</b> We conducted a deliberative dialogue workshop as the final phase of a mixed methods study. Participants included eight patients (women living with HIV) and eight HIV care providers (i.e., doctors, nurses, pharmacists). The workshop was professionally facilitated and included a synthesis of the evidence, small group deliberations, large panel</p>

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	<p>discussions, and voting on care recommendations. The deliberation took place over one afternoon in April 2019, in Montréal, Québec.</p> <p><b>Results</b> Patients and providers identified four relatively rapid care improvements and three longer-term improvements. The rapid care improvements included: 1) delegating medical acts to members of multidisciplinary care teams; 2) greater involvement of HIV community members within care settings and healthcare decision-making; 3) creating a women’s health information booklet; and 4) increasing HIV education amongst all healthcare providers and increasing women’s health care education amongst HIV care providers. The longer-term care improvements included: 1) advocating for complete financial coverage of antiretroviral therapy within the government-sponsored Medicare program; 2) facilitating access to allied care providers (e.g. physiotherapists and psychologists), and 3) launching a population-wide campaign to increase awareness about the initiative know as Undetectable=Untransmissible (U=U) and other HIV advances.</p> <p><b>Interpretation</b> The deliberative dialogue workshop yielded evidence-based, stakeholder-driven recommendations to improve the comprehensive care of women living with HIV in Québec.</p>



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3 **Co-designing care improvements for women living with HIV: a patient-oriented**  
4 **deliberative dialogue workshop in Montréal, Québec.**  
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## ABSTRACT

### Background

Care services have not been sufficiently adapted to meet the comprehensive care needs of women living with HIV. Our study objective was to engage patients and providers in co-designing care recommendations to improve care for this population in Québec.

### Methods

We conducted a deliberative dialogue workshop as the final phase of a mixed methods study. Participants included eight patients (women living with HIV) and eight HIV care providers (i.e., doctors, nurses, pharmacists). The workshop was professionally facilitated and included a synthesis of the evidence, small group deliberations, large panel discussions, and voting on care recommendations. The deliberation took place over one afternoon in April 2019, in Montréal, Québec.

### Results

Patients and providers identified four relatively rapid care improvements and three longer-term improvements. The rapid care improvements included: 1) delegating medical acts to members of multidisciplinary care teams; 2) greater involvement of HIV community members within care settings and healthcare decision-making; 3) creating a women's health information booklet; and 4) increasing HIV education amongst all healthcare providers and increasing women's health care education amongst HIV care providers. The longer-term care improvements included: 1) advocating for complete financial coverage of antiretroviral therapy within the government-sponsored Medicare program; 2) facilitating access to allied care providers (e.g. physiotherapists and psychologists), and 3) launching a population-wide campaign to increase awareness about the initiative know as Undetectable=Untransmissible (U=U) and other HIV advances.

### Interpretation

The deliberative dialogue workshop yielded evidence-based, stakeholder-driven recommendations to improve the comprehensive care of women living with HIV in Québec.

## PLAIN LANGUAGE SUMMARY

Due to effective treatments people living with HIV now have a life expectancy approaching that of the general population. For those with access to treatment HIV is now considered a manageable, chronic disease. Yet, despite these medical advances women living with HIV in Canada experience challenges in accessing care, and report important gaps in their HIV, reproductive, and primary care needs. In order to improve care for this population we assembled patients (women living with HIV) and care providers (doctors, nurses, pharmacist) to co-create appropriate and feasible care recommendations. This research was conducted as the closing phase of a larger study conducted with women living with HIV from 2011-2019. In this research, sixteen patients and providers met over one afternoon to review research findings and, based on their experience, discuss their top priorities for care improvements, and identify what changes could be applied to improve care. The workshop was conducted in Montréal Québec and was led by a professional moderator. Patients and providers made multiple care recommendations, these included: alleviating HIV-stigma through public awareness campaigns, having certain care delivered by nurses (e.g. Pap test, contraceptive counselling), creating women's health booklets, and addressing the cost of HIV medications. Involving patients and providers in discussing research results and co-creating care recommendations is a valuable endeavour for engaging those with lived experience in the later stages of the research process, and may facilitate the transfer of research into action.

## INTRODUCTION

For four decades, healthcare systems and practices have continuously evolved in an effort to respond to the shifting realities of the HIV epidemic (1-3). In the 1980's, HIV care was largely focused on treating opportunistic infections and palliative care. In the mid 1990's, it transitioned to HIV-specialized care as complex antiretroviral therapy (ART) was introduced (1). Today, HIV is considered a manageable chronic disease (4), treatment and care now involves as few as one pill a day, bi-annual care appointments, and a life expectancy nearing that of the general Canadian population (5). Affected populations have also changed over time; in the early days of the epidemic, HIV cases were primarily among men having sex with men, but HIV rates among women doubled between 1999 and 2012 (6, 7), resulting in women making up 23.3% of the current HIV-positive population in Canada (8). Current evidence indicates that care delivery has not sufficiently adapted to meet women's comprehensive HIV care needs. A Canadian cohort study of women living with HIV found that 56.4% of women experienced at least one gap in comprehensive care (i.e. viral suppression, Pap test, reproductive discussion or mammograms) (9). Furthermore, reproductive discussions with providers remain scarce (10, 11), despite the importance of adopting strategies to prevent HIV transmission to sexual partners or infants (12), potential toxicity of ART on the fetus (13), and given evidence that 61% of pregnancies amongst this population are unplanned (14). Women also experience challenges engaging consistently in HIV care (15-17), from HIV testing (18), to ART adherence (19), and sustained viral suppression (20). Finally, women characterize their experience of healthcare, both for HIV and other women's care needs, as fragmented, given care providers' lack of HIV knowledge and persistent HIV-related stigma in healthcare settings (21).

To ensure that future healthcare modifications adequately respond to these care gaps, patients and providers should be engaged in examining existing evidence and producing care recommendations. The potential contributions of patient and public engagement in health research and healthcare decision-making are now well recognized: for instance, in shaping patient and family-centred approaches for chronic care, in tailoring services for marginalized populations, and identifying implementable solutions that are sustained over time (22-25). A recent Lancet article identified public engagement as *crucial* to enabling the Canadian healthcare system to reach its ideals of delivering effective and equitable care (26). Our study objective was to engage patients

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3 and providers in co-designing appropriate recommendations to improve comprehensive care for  
4 women living with HIV in Québec.  
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## 8 **METHODS**

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### 10 **Design – Deliberative Dialogue**

11 We conducted a deliberative dialogue workshop as the final phase of a mixed methods study  
12 investigating comprehensive care for women living with HIV. The project drew on data from the  
13 Canadian HIV Women’s Sexual and Reproductive Health Cohort (CHIWOS) (27), a study  
14 anchored in participatory research approaches (28, 29). Deliberative dialogue is distinguished from  
15 other methods by these key principles: i) the use of evidence for critical examination; ii) the mix  
16 of diverse participants; iii) the valuing of experiential knowledge; and, iv) the skilled facilitation  
17 of discussions aimed at producing statements of the group’s considered views (30-35).  
18 Deliberative dialogue aims to foster thoughtful exchanges with engagement of convergent and  
19 divergent views, rather than promoting consensus (36). Deliberations also differ from focus groups  
20 in that the “research is used not so much to give participants a ‘voice’ . . . but to create a process  
21 in which the participants themselves produce conclusions that can then be relayed to others” (30).  
22 Deliberative dialogue, through the consideration of evidence and the exchange of ideas, values,  
23 and priorities, contributes to the notion of a shared cognitive space or mutual understanding of an  
24 issue, and may thus facilitate the translation of evidence into action (33). This approach is also  
25 coherent with participatory research and may be leveraged to further engage those impacted *by* the  
26 research *in* the knowledge translation and decision-making phases of the research (34, 37-39).  
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### 41 **Participant Recruitment**

42 Recruitment was guided by a purposive maximum variation sampling strategy to ensure an  
43 appropriate mix of participants (33, 40). We recruited eight patients (women living with HIV), and  
44 eight HIV care providers for a total of 16 French speaking participants. Recruitment was facilitated  
45 by our existing CHIWOS networks, including peer researcher associates (women living with HIV  
46 with research training). We included women of different ages and ethnicities, along with different  
47 types of care providers (i.e. doctors, nurses, pharmacists). All participants were offered a \$100  
48 honorarium.  
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## Data Collection & Patient and Provider Engagement

Our deliberation was conducted over one afternoon (five hours) in April 2019, in a non-profit conference facility in Montréal, Québec. One week before the event, participants were sent a lay summary of the evidence to be reviewed (see Table 1) (33, 41); an overview was presented at the beginning of the workshop, with time allotted for clarifying questions. The Québec CHIWOS principal investigator was in attendance to provide clarification of the data as needed.

[TABLE 1]

The workshop was professionally moderated by an independent francophone woman, with expertise in deliberative dialogue. Rules of engagement were established, including the importance of confidentiality (Chatham House Rule) and of ensuring that different perspectives were heard (33, 34). The deliberation was conducted in two phases, one focused on care priorities and the other on promising care improvements. Each phase had two steps starting with separate small group discussions (two groups of four patients and two groups of four providers), followed by a plenary discussion with all participants. Guiding questions were provided for each phase (see Table 2). Small group discussions included moments of individual reflection, group discussion, and group prioritization. Each small group elected a rapporteur. As small groups were composed of only four participants facilitators were not assigned, though rapporteurs or organic leaders often took on this role. A timekeeper (researcher or moderator) was present to answer any clarifying questions and keep time. Rapporteurs relayed a summary of their group's discussions to the plenary sessions for further deliberation. To conclude the deliberation each participant voted on their top three rapid and top three longer-term care improvements using stickers on flip-chart paper posted around the room. All discussions were audio recorded for subsequent transcription and analysis.

[TABLE 2]

## Analysis

The recordings were transcribed verbatim and translated from French to English by a member of the team who is fluently bilingual (N.O.). The included quotes were then validated for accuracy by additional investigators who were present during the deliberation (L.S., K.P.B., A.D.P.). A thematic analysis approach was used, as described by Braun and Clarke, since it allowed us to

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3 “report the experiences, meanings and reality of participants,” rather than reinterpret participants’  
4 contributions (30, 44). The themes identified are driven by the priorities and care improvements  
5 put forth by the deliberants.  
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### 8 9 10 **Ethical Considerations**

11 We recruited providers first and communicated their names to patients so they could better assess  
12 whether they felt comfortable participating. At the beginning of the deliberation, we reminded  
13 patients and providers that they could end their participation at any time, without explanation or  
14 consequence to their care, or change in their honorarium. We also asked all workshop participants,  
15 moderators, and researchers to sign a confidentiality agreement that included both the content of  
16 the discussions and the identity of fellow participants to avoid any inadvertent HIV disclosures.  
17 This study was reviewed and approved by the Research Ethics Board of the McGill University  
18 Health Centre Research Institute.  
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### 28 **RESULTS**

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30 Eight patients and eight care providers participated in the deliberative dialogue. The patients,  
31 women living with HIV (cis gendered) were between 40 and 60 years of age and identified as  
32 African/Caribbean/Black (n=4) and white (n=4). Women accessed HIV care from six different  
33 care sites for an average of 13 years [Interquartile range (IQR): 5–19]. Care providers identified  
34 as men (n=2) and women (n=6) and had trained as medical specialists (n=2), family physicians  
35 (n=2), nurses (n=2), and pharmacists (n=2), and provided HIV care mainly within university  
36 hospitals (n=6), and private clinics (n=2). Care providers had been providing care for women  
37 living with HIV for an average of 12.5 years [IQR: 5–18].  
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### 46 **Care Priorities**

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48 Deliberants identified a number of priorities based on the evidence presented and their experiences  
49 of care (Table 3). Patient and provider groups both highlighted the importance of integrating HIV  
50 care with other care needs as a means to address current gaps in comprehensive care. Participants  
51 also prioritized the need to address HIV knowledge gaps and HIV-related stigma within healthcare  
52 settings to reduce needless referrals to HIV specialist for depression care or routine immunization.  
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3 Another priority was the need to provide public coverage for costs related to ART, and care  
4 services not currently included within RAMQ (Québec's provincial health insurance plan), such  
5 as for psychologists or physiotherapists. Participants argued that the lack of complete financial  
6 ART coverage (unlike in British Columbia or France) was a fundamental issue that jeopardized  
7 women's ability to access their medication and achieve the individual and societal benefits of a  
8 suppressed viral load. Patients and providers highlighted that poverty is a common experience in  
9 this population, resulting in patients forgoing ART in order to pay for food for their families or  
10 formula for their infants.  
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18 [TABLE 3]  
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### 21 **Care Improvements**

22 Participants identified four rapid care improvements and three longer-term improvements,  
23 distinguishing between those modifications or interventions that could be implemented relatively  
24 quickly and those requiring more time and wider stakeholder involvement (e.g. Ministry of Health)  
25 (Table 4). All top-ranked care improvements were identified separately in the patient and provider  
26 group discussions and were further defined, and voted upon, in the full plenary discussion (see  
27 Figure 1).  
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34 [FIGURE 1]  
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37 The top-ranked rapid improvement was the delegation of medical acts as appropriate from  
38 physicians to members of multidisciplinary care teams, such as nurses or nurse-practitioners, to  
39 enable the routine provision of Pap tests and reproductive and contraceptive counselling (10 votes).  
40 Certain HIV clinics in Montréal have begun delegating the provision of Pap tests, but further  
41 efforts were required to routinize and expand this practice. Two care improvements tied for second.  
42 This included the greater involvement of HIV community members within healthcare settings and  
43 healthcare decision-making (eight votes). Patients advocated for women living with HIV to sit on  
44 decision-making committees, while clinicians put forth that community organizations should have  
45 a standing presence within HIV clinics to provide onsite patient support. Similarly ranked was the  
46 proposition that a women's health information booklet be created, modeled after existing  
47 vaccination or diabetes booklets (eight votes). Patients and providers stated that this would help  
48 women self-advocate for their required screenings, keep track of their appointments, and enhance  
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3 self-management, in line with chronic disease care models. The third-ranked rapid care  
4 improvement involved educational and training strategies to improve care provider's knowledge,  
5 starting with improving the basic HIV knowledge of all care providers in the healthcare system,  
6 followed by raising awareness of women's care needs beyond HIV-specific care (e.g. ART, viral  
7 load) amongst HIV care providers (seven votes).  
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13 The three longer-term improvements addressed the priorities identified in the first phase of the  
14 deliberation. The top-rated longer-term improvement was to support current initiatives that  
15 advocate for the financial coverage of ART (11 votes). Participants highlighted the appropriateness  
16 of this response given the societal benefits of an undetectable viral load and the parallels between  
17 ART and other medications available at no cost to patients for the treatment of other infectious  
18 diseases. The second strategy was to facilitate access to healthcare providers not fully covered by  
19 RAMQ, especially for conditions resulting directly from HIV infection or from ART side effects  
20 (10 votes). The third strategy was a population-wide campaign led by Public Health Departments  
21 to increase awareness of U=U and other HIV advances (eight votes). This would increase the  
22 knowledge of citizens and clinicians, helping to reduce discrimination and enable better care  
23 within the broader healthcare system.  
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34 [TABLE 4]  
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### 37 **INTERPRETATION**

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39 The deliberative dialogue workshop garnered patients and providers' priorities and  
40 recommendations to improve the comprehensive care of women living with HIV in Québec. Our  
41 findings offer stakeholder insights regarding patient-centred health service modifications, ranging  
42 from direct patient care to policy initiatives. The deliberative outputs provide compelling  
43 endorsement for care improvement efforts already underway in Québec. These include campaigns  
44 to fully cover ART costs (45, 46), awareness campaigns for U=U (47, 48), education for providers  
45 (49), and the delegation of care acts within multidisciplinary teams (50). Our findings also provide  
46 new avenues for care improvements, such as women's health booklets to support self-management  
47 and health literacy, as well as policies to encourage family physicians to provide HIV care, thereby  
48 facilitating a comprehensive care delivery approach for women living with HIV.  
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## Limitations

Despite a range of participants in attendance, younger women (<40 years of age) were not represented, despite efforts to recruit them and may have provided differing perspectives. The deliberation was conducted in Montréal, Québec, and so priorities and recommendations may vary in other provinces with different health policies and practices, or rural settings with more limited resources.

## Lessons Learned from Patient and Care Provider Engagement

As Abelson et al. acknowledge, the centrality of power differentials cannot be excluded from the public sphere of deliberative dialogue (40), though certain strategies may be adopted to enable productive conversations to occur. In our deliberation, where power gradients were particularly steep between care providers and patients, strategies such as setting rules of engagement, planning separate patient and provider small groups as well as large group deliberations, and recruiting patients with previous experience in AIDS Service Organizations (ASO) and participatory research projects, appeared to be successful strategies. Three of the eight patients present had extensive ASO and participatory research experience. These experienced patients provided an essential communication bridge during the workshop, relaying information between small patient groups and large mixed group deliberations. Though the current patient engagement literature contains some reticence regarding the role of “professional patients” or “super patients” (51-53), our case suggests that this expertise may be essential for ensuring that the full range of patient perspectives are heard. Since HIV patients and affected communities have been a central part of the HIV response since the onset of the epidemic, providers also had previous experience engaging with patients beyond individual clinical care. This familiarity with community-academic partnerships in the field of HIV undoubtedly facilitated productive discussions.

The results of the workshop also demonstrated the first intended effect of a deliberation, which is to promote mutual understanding of an issue (33). For instance, a U=U public information campaign was brought forward as a priority area by one patient group in the first phase of the deliberation and was then recommended as a care improvement by all four small groups in the

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3 second phase. This suggests that agreement on priorities and recommendations can occur across  
4 stakeholder groups, and within the limitations of a single workshop.  
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## 8 **Conclusion**

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10 Our deliberative dialogue workshop provided a productive mechanism for validating research  
11 findings within lived experience, and for the creation of evidence-informed stakeholder  
12 recommendations. Further investigation of the implementation and impact of such approaches is  
13 required to understand the extent to which deliberative outputs are used to enact change, and to  
14 identify if further required action is required to transform recommendations into actual care  
15 improvements.  
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**Table 1: Sources and types of evidence provided to deliberative workshop participants**

Source of Evidence	Participants	Main Results	Reference
Focus groups (Qualitative)	77 women living with HIV (BC, ON, QC)	Women's perspectives and experiences of care in Canada summarized in an envisioned model of women-centred HIV care	O'Brien et al. 2017 (42)
Cohort surveys (Quantitative)	1164 women living with HIV (BC, ON, QC)	Comprehensive care gaps experienced. HIV related outcomes (e.g. adherence, viral load), and women's health (e.g. reproductive discussion, Pap test)	O'Brien et al. 2019 (9)
Systematic review (Mixed methods)	44 peer reviewed articles, n=17,659 women living with HIV	Features of care at the provider, clinic and social structural level found to improve access to care for women living with HIV	O'Brien et al. 2018 (43)

**Table 2: Guiding questions for the small group and plenary discussions at the deliberative dialogue workshop**

Phase 1: Care priorities	What is your response to the research presented? Is there information that resonates with your knowledge or experience?  Of the care gaps identified, which five should be prioritized?
Phase 2: Care improvements	If you could bring 2-3 modifications to the healthcare system that would bring about rapid change, what would they be? (no set time was provided)  If you could bring 2-3 modifications to the healthcare system that might take more time but would have a lasting impact what would they be? (no set time was provided)

Table 3: Priority areas identified by patients and providers (as translated from French to English).

COMMON PRIORITIES: PATIENTS & PROVIDERS	
Priorities	Illustrative quotes
<b>Integrating HIV care with comprehensive healthcare needs.</b>	<p><i>I would lump all that together with comprehensive care for women. Because that would address almost everything. Sure, we see a specialist for HIV, but there isn't just that in the lives of women living with HIV. If we go to a medical clinic, even one specialized in HIV, then well, "viral load is undetectable, CD4 is 1,000, all is good, goodbye!" Then we are promoting the idea that this is women's sole identity. . . I think care must—and I'm daring to say MUST, because it's imperative that care be in line with the evolution of the HIV epidemic. Because we are often told that things have advanced, but could we also advance in the care? It's really to consider women as a whole-person. There isn't just HIV in her life. . . it is not her identity, she is a WOMAN. – Patient</i></p> <p><i>The integration of HIV care with other healthcare needs is related to this idea of comprehensive women's care. HIV is but one of the health concerns that she may have, but there can also be menopause, diabetes, being pregnant, needing contraceptive care, depression—and that all needs to be coordinated and integrated in her care. – Provider</i></p>
<b>Increasing HIV-related knowledge of all care providers to prevent HIV-related stigma.</b>	<p><i>How do we train providers so that there is less discrimination, so women don't fall on a gynecologist that doesn't know what a CD4 count is—and I mean training as much for social workers, as doctors, as pharmacists. – Provider</i></p> <p><i>I needed to have vaccines, so I went to the CLSC [community clinic] near my house. I said the truth, you know maybe the doctors need to know what medication I am on. And they were all ready to give me the vaccine, but when I told them that [I was HIV-positive], they wrapped everything up, put everything away and said: "Oh no, we can't do that. Go see your doctor at the HIV clinic and they will give you your vaccines." – Patient</i></p>
<b>Covering the full costs of ART and care services (not currently covered by RAMQ).</b>	<p><i>Especially with age, there are certain situations that we did not see ten years ago—for example joint pains, back pains—so we talk to the doctor and they refer you to a physiotherapist, etc., but often those are professionals that you have to pay out of pocket for. If you don't have private health insurance, then you get stuck paying for it, or stuck with the pain. – Patient</i></p> <p><i>I have seen many women living with HIV who are working minimum wage, two young children, single mom, the kids don't have anything to eat, and so she prefers to say: "I will not take my ART, I can't pay for them, I will feed my kids". . . Poverty among women living with HIV is glaring. It's a top priority. What can we do? – Patient</i></p> <p><i>Access to medication, because here in Québec we still pay for medication, and it's very expensive. We still have systems of co-payment. Poverty is the biggest reason why patients need support programs. – Provider</i></p>
PATIENT PRIORITIES	
Priorities	Illustrative quotes
<b>Diffusing the U=U Message</b>	<i>People who don't read these articles, who don't go to conferences, well, they are not well-informed. We have to find other ways, like undetectable = untransmissible, people have to know this, because people have stayed with this old idea that HIV means death. – Patient</i>
<b>Addressing aging and menopause</b>	<i>Do follow-up care for women who are in menopause, because they find themselves abandoned, because they are no longer of reproductive age. – Patient (previously followed by gynecologist for contraceptives)</i>
<b>Fostering continuity of care</b> Same providers, and across interdisciplinary providers.	<p><i>I also really like what we call continuity of care. It's been 15 years that I'm with the same doctor. We talk about everything and he knows me, he doesn't even need to ask questions because when there is a change, he knows, he sees it, and I find this very important. – Patient</i></p> <p><i>I think communication between your HIV doctor and your family doctor should be done too. They should make a team. – Patient</i></p>

<b>PROVIDER PRIORITIES</b>	
<b>Priorities</b>	<b>Illustrative quotes</b>
<b>Situating health among women's other life priorities</b>	<i>You see, for women that we have difficulty retaining in care. You know she had the choice between going for a job interview and going to the clinic. Or she has to go get children at school at 3 p.m., because the daycare service is too expensive, and then her doctor is not available outside those times. In these circumstances, you tell yourself, it's not easy. What a battle just to get her care. – Provider</i>
<b>Initiating reproductive discussions</b>	<i>The biggest gap for women less than 50 years old is the reproductive health discussion. In each of our offices we have a list of all screening to be done by age group, for example Pap and mammograms are always there, but reproductive health discussion is not, I find that interesting and it's really important for HIV now. – Provider</i>
<b>Adapting to the population of people living with HIV</b>	<i>Well, if I can speak from my experience . . . it has historically been more of a male population, so that means that the specific care for women is really, really forgotten. – Provider</i>
<b>Delegating care acts within a multidisciplinary team</b>	<i>The idea is to open up these medical acts, not just doctors but to the whole team, the whole interdisciplinary team. The delegation of these medical acts is not very well established. – Provider</i>
<b>Providing patient education</b>	<i>It's in line with HIV as a chronic disease. Chronic disease models are always models focused on the patients, focused on self-care, and so that is a part of that: awareness, education. –Provider</i>

**Table 4: Co-designed care recommendations by patients and providers**

<b>TOP FOUR RAPID CARE IMPROVEMENTS</b>	
<b>Care Improvement</b>	<b>Illustrative quotes</b>
<b>Delegate care to nurses and nurse practitioners</b>  Votes: 10	<i>In our group, we were talking about interdisciplinary teams. It's up to each clinic to decide how to delegate different medical acts, certain prevention activities, women's health. -Provider</i>  <i>To delegate certain professional acts, for example, to nurse practitioners: as much for you [doctors] as for us [patients]! (Laughter). It could be a solution that is relatively quick. -Patient</i>
<b>Make space for community within HIV clinics and at different levels of decision-making.</b>  Votes: 8	<i>To open the doors so women living with HIV could sit on decision-making committees, at the Ministry of Health, at the governmental level . . . it's possible, it's possible. - Patient</i>  <i>Get the community within the clinic. . . For sure, this is delicate, but I know that when we add a new service to a team, at first everyone is quite uncertain, but after some time it finds its place, and those people then become essential. -Provider</i>
<b>Women's booklet</b>  Votes: 8	<i>The second thing is a booklet or information package on comprehensive care for women, and it would have information on HIV appointments for tests (Pap, mammo. etc.). And the frequencies, because sometimes we forget, or we don't know. - Patient</i>  <i>So women gain responsibility for, or raise awareness among women, because it is also up to me to take charge of my health. - Patient</i>  <i>There's a lot of emphasis on care guidelines for doctors and nurses. But what about a little care passport for women that they have themselves? Like a vaccination booklet. Women could say, "Listen, I'm due for my Pap test." - Provider</i>
<b>Training and education for all care providers</b>  Votes: 7	<i>There should be awareness building and knowledge transfer workshops for care providers, nurses, doctors, etc. who are not in the HIV sector. . . Because if they know how it gets transmitted, then they will be less afraid. - Patient</i>  <i>There's [a provincial initiative] trying to do a provincial training so that a person in [rural Québec] can go online and get the training on HIV 101. Outside of Montréal, there are so few [people living with HIV], so it's not so much a lack of interest as misconceptions, and then it's scary: "I don't really want to get too close because I don't understand." So what we are doing is having designated persons in each family medicine unit who are [trained] in substance use, hepatitis and HIV, to increase the confidence levels with these pathologies. - Provider</i>  <i>We have to remind ourselves that for many women, their HIV doctor is the only doctor they see . . . the HIV care providers should also be women's providers for their comprehensive care needs. - Provider</i>
<b>ADDITIONAL RAPID CARE IMPROVEMENTS</b>	
<b>CHIWOS researcher should present research results</b>	<i>The CHIWOS researchers should present results to each multidisciplinary team so that they can then make concrete tools to improve their care practice. . . Just having this discussion this afternoon wakes us up to what we could all do in our clinics, but I think it could be broadened by going to each clinic. -Provider</i>
<b>Resources booklet to facilitate communication amongst providers</b>	<i>Like a list of resources . . . for providers to be able to orient the patients adequately within the healthcare system and avoid instances where they feel discriminated, while we wait for education to be done. - Provider</i>
<b>TOP THREE LONGER-TERM CARE IMPROVEMENTS</b>	
<b>Care Improvements</b>	<b>Illustrative quotes</b>
<b>Full financial coverage of ART in context of U=U</b>  Votes: 11	<i>I agree that it would take a lot of political will and a lot of work, but the moment it is implemented it changes the entire landscape. - Provider</i>  <i>Full coverage of other health services and most importantly ART. - Patient</i>

<p><b>Health service coverage</b></p> <p>Votes: 10</p>	<p><i>Another suggestion: free access to mental health services for people living with HIV. –Provider.</i></p> <p><i>People should have access to care like physiotherapy, or kinesiology or something like that, if it's following side effects of the medication or is due to the HIV itself –Patient</i></p>
<p><b>U=U public campaign</b></p> <p>Votes: 8</p>	<p><i>We would really appreciate if public health– so, starting from the top instead of from the ground up–if they'd continue to inform the population on HIV, but to do so around U=U, and that it be widely diffused to the whole population, so that the message is received more effectively. – Patient</i></p> <p><i>There are challenges regarding HIV knowledge, the lack of overall HIV knowledge of care providers in the healthcare system. And it's true that at the ministry level, there is not a lot of efforts being made for U=U. Sure it's new, but still, there is a lack of knowledge. Even just HIV is a chronic disease now. We need to be doing whole-person care. – Provider</i></p>
<p><b>ADDITIONAL LONGER-TERM CARE IMPROVEMENTS</b></p>	
<p><b>Facilitate family doctors as care providers.</b></p>	<p><i>I'm a huge advocate for family doctors to continue to do routine HIV follow up, because it brings a comprehensive care approach, and it's a specificity that we have here in Québec that isn't everywhere . . . HIV clinics, in my opinion, should really have an approach that is much more a chronic disease approach, like diabetes, like hypertensions. – Provider</i></p>
<p><b>Outreach nursing care</b></p>	<p><i>This might not be required for everyone, but for outreach nursing care or follow up care by phone. For people to not always have to be the ones travelling, sometimes there are things that can be done by phone, or some blood draws that don't need an appointment. –Provider</i></p> <p><i>It is already offered for active drug users, but for the woman who is a single mom, working, well her, she needs to come in for an appointment. – Provider</i></p>
<p><b>Mandatory health days within labour codes</b></p>	<p><i>Employees are quite hesitant to ask for time off on a pretty regular basis. They don't want to make their employer think that they have something. – Provider</i></p>

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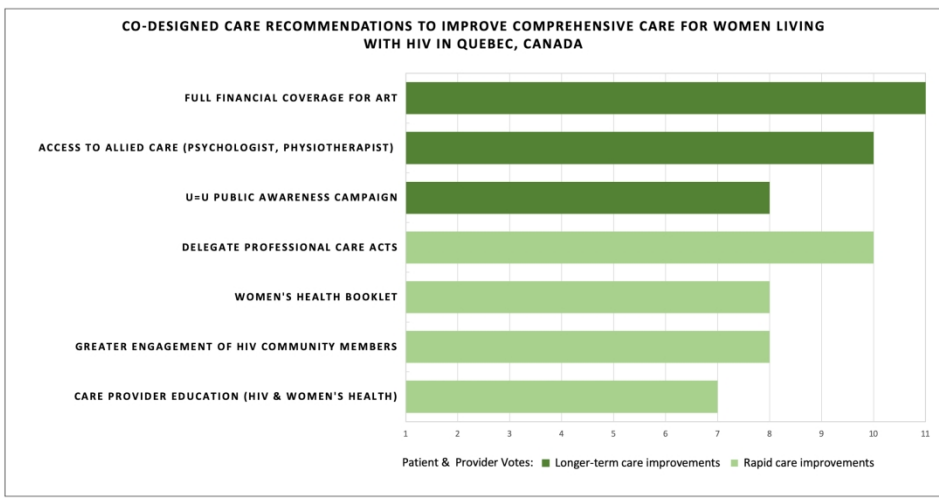


Figure 1: Evidence-informed, stakeholder-driven care improvement recommendations co-designed with patients (women living with HIV) and care providers during a deliberative dialogue in Montréal, Québec.



## GRIPP2 short form

**Manuscript:** Co-designing care improvements for women living with HIV: a patient-oriented deliberative dialogue workshop in Montréal, Québec

and topic	Item	Reported on page No
1: Aim	<p>Report the aim of PPI in the study</p> <p><i>Our study objective was to engage patients and providers in co-designing appropriate recommendations to improve comprehensive care for women living with HIV in Québec.</i></p>	4-5
2: Methods	<p>Provide a clear description of the methods used for PPI in the study</p> <p><i>We conducted a deliberative dialogue workshop as the final phase of a mixed methods study investigating comprehensive care for women living with HIV . . . Deliberative dialogue is distinguished from other methods by these key principles: i) the use of evidence for critical examination; ii) the mix of diverse participants; iii) the valuing of experiential knowledge; and, iv) the skilled facilitation of discussions aimed at producing statements of the group's considered views.</i></p>	5
3: Study results	<p>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</p> <p><i>Eight patients and eight care providers participated in the deliberative dialogue . . . Deliberants identified a number of priorities based on the evidence presented and their experiences of care . . . Participants identified four rapid care improvements and three longer-term improvements, distinguishing between those modifications or interventions that could be implemented relatively quickly and those requiring more time and wider stakeholder involvement.</i></p>	7-9
4: Discussion and conclusions	<p>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects</p> <p><i>Our deliberative dialogue workshop provided a productive mechanism for validating research findings within lived experience, and for the creation of evidence-informed stakeholder recommendations. Further investigation of the implementation and impact of such approaches is required to understand the extent to which deliberative outputs are used to enact change, and to identify if further required action is required to transform recommendations into actual care improvements.</i></p>	10-11
5: Reflections/ Critical perspective	<p>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience</p> <p><i>As Abelson et al. acknowledge, the centrality of power differentials cannot be excluded from the public sphere of deliberative dialogue, though certain strategies may be adopted to enable productive conversations to occur. In our deliberation, where power gradients were particularly steep between care providers and patients, strategies such as setting rules of engagement, planning separate patient and provider small groups as well as large group deliberations, and recruiting patients with previous experience in AIDS Service Organizations (ASO) and participatory research projects, appeared to be successful strategies.</i></p>	10