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# Response Patterns to a Patient-Reported Outcomes Assessment (MyPRO) Among Racialized Women Living With and Without HIV in a Community Health Clinic in Toronto, Canada

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## Key Takeaways

- By completing a pre-clinical visit electronic patient-reported outcomes assessment (MyPRO), participants living with and without HIV were prompted to reflect on a diverse array of health-related needs and priorities
- Notable levels of loneliness and difficulty paying for essentials were observed among all participants.
- There were high levels of internalized HIV stigma (45.6%) and disclosure concerns (80.8%) among participants living with HIV.
- Participants living with HIV wanted to discuss other treatment options with their providers, and sexually active participants wanted more information about PrEP.
- MyPRO provides patient-specific insights across general and social influences of health, sexual health, and HIV-specific topics to healthcare providers.

## Purpose

- Pre-visit patient-reported outcomes (PRO) assessments highlight participant needs, priorities, and preferences to providers, including HIV-specific concerns like stigma or treatment satisfaction.<sup>1-3</sup>
- An electronic PRO platform was designed and implemented in a clinic caring for both people living with and without HIV.
- We explored patterns in participant responses to a PRO screener piloted at a Toronto community health clinic serving primarily racialized women with immigrant or refugee status.

## Methods

- Participants self-administered an electronic PRO assessment (MyPRO) addressing general and social influences of health, sexual behaviours, and HIV-related topics (**Table 1**).
- Response summaries were available to providers ahead of appointments.
- We describe aggregated de-identified PRO data from participants living with HIV (PLHIV) and participants without HIV or of unknown HIV status (PLWOH).
- Descriptive statistics were calculated excluding missing responses; data are presented overall and stratified by HIV status.

**Table 1. PRO Domains & Components**

Derived from validated scale	
General health & wellbeing	General health screener
	Depression (PHQ-9) <sup>4</sup>
	Anxiety (GAD-7) <sup>5</sup>
	Loneliness (3-item) <sup>6</sup>
	Social support (MAPSS-SF) <sup>7</sup>
	Weight change
Sexual health	Intimate partner violence (IPV-4) <sup>8</sup>
	Sexual Risk Behavior Questionnaire
HIV-related health	HIV screener
	HIV understanding
	Internalized HIV stigma (4-item) <sup>9</sup>
HIV medications	HIV disclosure (partial HAT-QoL) <sup>10</sup>
	Adherence visual analogue scale
	Medication burden (partial HAT-QoL) <sup>10</sup>
	Medication concerns
	Alternative treatment discussion
Social influences of health	Housing status <sup>11</sup>
	Financial security
	Alcohol (AUDIT-C) <sup>12</sup>
	Drug use (modified ASSIST) <sup>13</sup>
Smoking behaviors	

## Results

- Overall, 280 participant profiles were registered on the MyPRO platform, and 252 assessment were completed, including 106 (42.1%) from PLHIV.
  - 25 participants did not provide their HIV status.
- Among registered participants, most (78.9%, n=221) profiles used email-only communication; 10.0% (n=28) used SMS text-only and 10.7% (n=30) used both email and SMS text communication.

## Social Influences of Health & Health Behaviours

- Participant housing context at the time of PRO completion and within the prior 12 months is displayed in **Table 2**.
- A descriptive summary of general and social health-related PRO items is provided in **Table 3**.
- N=103 participants fully completed the AUDIT-C, with 86.4% (n=89) of those in the low-risk category (score 0-4).
  - 11.7% (n=12) of responses indicated moderate risk (score 5-7) and 4.9% (n=5) high risk (score 8-9).
- 20.6% (n=52) of participants reported ever using substances.
  - Among all participants, the most common substance reported was cannabis (17.9%, n=45), followed by cocaine (4.0%, n=10) and hallucinogens (4.0%, n=10).
- 9.1% (n=23) had ever used tobacco.

57.1% (n=128) of participants were having difficulty paying for essentials.



**Table 2. Housing Context Among All Participants**

	N=252	Within past 12 months, n (%)	Currently, n (%)
Room in a house, hotel, or similar		49 (19.4)	48 (19.0)
House, apartment, or similar		123 (48.8)	139 (55.2)
Housing facility with support for physical/mental health		26 (10.3)	28 (11.1)
Halfway house / transition house		26 (10.3)	19 (7.5)
Temporary sheltered housing		26 (10.3)	26 (10.3)
Another person's home on a temporary basis		25 (9.9)	19 (7.5)
Outdoors (e.g. street, park, car)		13 (5.2)	20 (7.9)
Other		16 (6.3)	16 (6.3)

Note: participants could select more than one housing option.

### High Risk Alerts



The MyPRO platform automatically alerts clinic staff if a participant submits PRO responses indicating risk of suicidality or intimate partner violence. The clinic staff created a protocol to address these situations promptly upon identification.

A total of **32** high risk alerts were triggered among **29** participants.

**9.3%** of all responses indicated a potential risk of physical or sexual **intimate partner violence** (n=21)

**4.4%** of all responses indicated a potential risk of **suicidality** (n=11)

**Table 3. General, Social, & Mental Health PRO Responses from Participants**

	PLHIV (n=106)	PLWOH (n=146)	Total (n=252)
General health <sup>1</sup> , median (IQR)	3 (2-4)	3 (3-4)	3 (2-4)
Unexpected weight change, n (%)			
Decrease	20 (20.0)	20 (15.0)	40 (17.2)
No change	51 (51.0)	71 (53.4)	122 (52.4)
Increase	29 (29.0)	42 (31.6)	71 (30.5)
Depression <sup>2</sup> [moderate to severe], n (%)	35 (33.0)	58 (39.7)	93 (36.9)
Anxiety <sup>3</sup> [moderate to severe], n (%)	28 (26.4)	38 (26.0)	66 (26.2)
Social support <sup>4</sup> [low], n (%)	19 (19.4)	31 (24.6)	50 (22.3)
Loneliness <sup>5</sup> [often, sometimes], n (%)	54 (51.9)	58 (43.6)	112 (47.3)
Difficulty paying for essentials, n (%)	58 (59.8)	70 (55.1)	128 (57.1)

<sup>1</sup>Likert scale 1-5 where 5 indicates better perceived general health; <sup>2</sup>Patient health questionnaire, 9-item (PHQ-9); <sup>3</sup>Generalized anxiety disorder scale, 7-item (GAD-7); <sup>4</sup>Multifactorial assessment of perceived social support (MAPSS-SF); <sup>5</sup>UCLA Loneliness, 3-item scale. Missing responses removed (range 12-28). PLHIV, People living with HIV; PLWOH, People living without HIV or of unknown HIV status; IQR, interquartile range

## Sexual Health & HIV-Related Domains

- 40.4% (n=95) of all participants were sexually active.
- Ten sexually active participants were having sex with PLHIV, and 90% of those participants said their partners were currently taking HIV medication.
- Among sexually active PLHIV, only 6.1% (n=2) reported that some or all of their HIV-negative partners were taking PrEP.
- Among PLHIV, most felt they had high understanding of HIV, and many experience disclosure concerns or internalized HIV stigma (**Figure 1**).

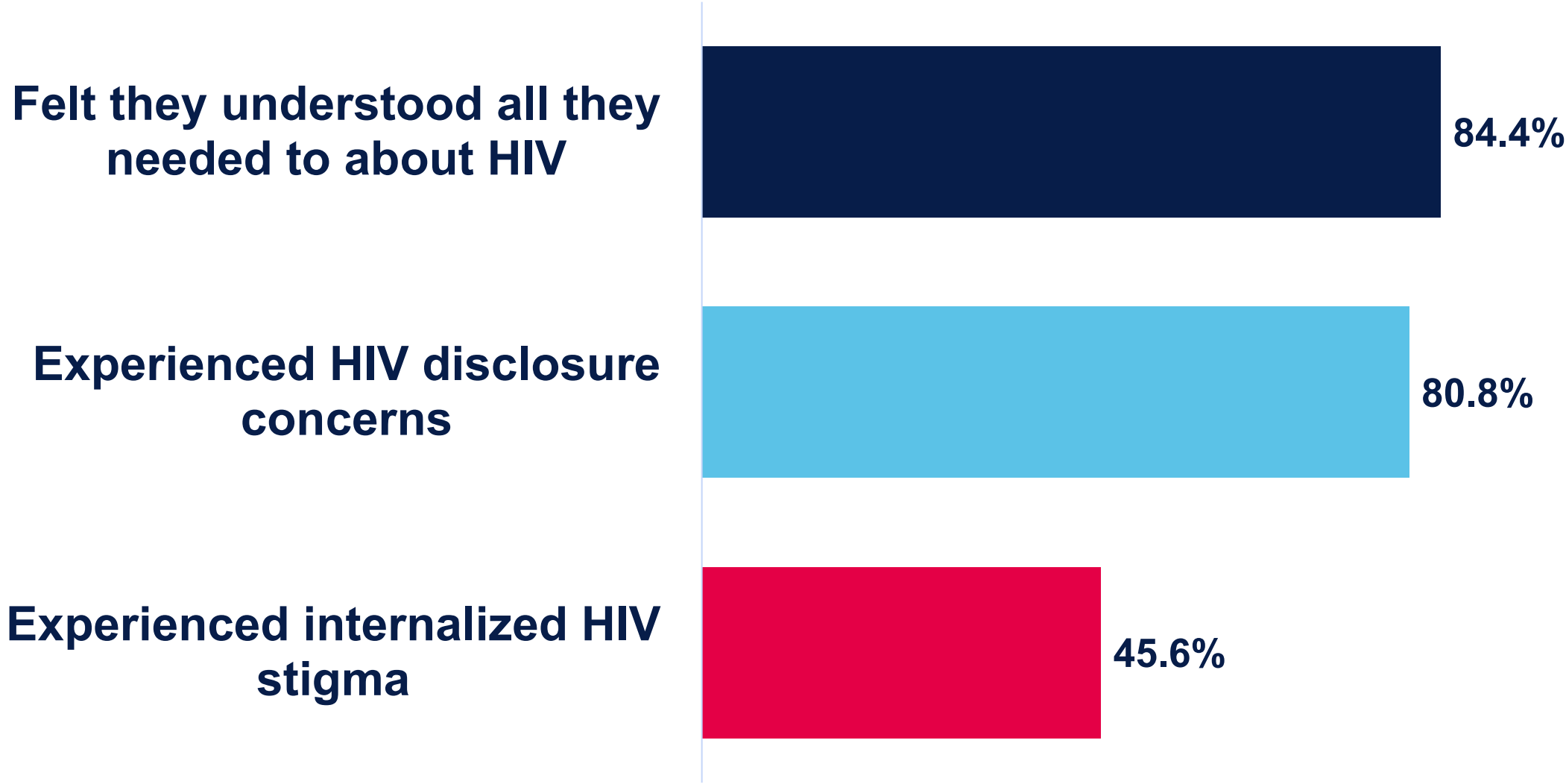


Half (49.4%, n=42) of all sexually active participants wanted more information about PrEP, for themselves or for their partners.

**Table 4. Experiences with HIV Medication among PLHIV**

HAT-QoL <sup>10</sup> : Medication burdens (Past 4 weeks)	N (%)
Taking my medicine has been a burden	27 (27.3)
Taking my medicine has made it hard to live a normal life	29 (29.0)
Taking my medicine has caused unpleasant side effects	12 (12.1)
I've been worried about the effects medicine may have on my body	32 (32.0)
Medication concerns	N (%)
My medicines remind me of my HIV status.	49 (46.2)
Taking my medicines every day causes me problems.	9 (8.5)
I am concerned that my different medicines affect each other and mean they will not work properly.	11 (10.4)
I'm worried about the number of medicines that I'm taking.	14 (13.2)
I am not sure that my HIV medicines are the best for me	12 (11.3)

**Figure 1. HIV understanding, disclosure, & stigma among PLHIV**



- Median self-reported adherence to HIV medication was high (100% [IQR: 95-100%])
- Participants ranked their happiness with their HIV medication on a scale of 0 ("very unhappy") to 6 ("very happy"); 21.0% (n=21) reported happiness below the upper range of the scale (score <5) for their current medication.
- Participants were also asked to provide responses about their experiences taking HIV medication (**Table 4**).
  - Common medication concerns included being reminded of their HIV status (46.2%, n=49) and being worried about the number of medications they were taking (13.2%, n=14).
- Nearly one third of PLHIV were worried about HIV medication side effects (32.0%, n=32) or felt that taking medicine made it hard to live a normal life (29.0%, n=29).

Over half (58.9%, n=56) of PLHIV wanted to discuss other HIV treatment options with their provider.



## Conclusions

- A variety of health-related priorities that may otherwise not have been raised were communicated to providers through MyPRO.
- Clinic staff notifications for high risk alerts were crucial for identifying patients in sensitive situations that may need more immediate attention.
- PLHIV demonstrated a desire to discuss alternative treatment options.
- Nearly half of sexually active participants showed interest in PrEP.



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