

HIV Viewpoints: Survey on the Treatment Experiences of People Living With HIV in Canada, Mexico, and the United States

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Conclusions

- While most of the 852 people with HIV in Canada, Mexico, and the United States who participated in the survey agreed that starting antiretroviral therapy immediately was important, 76% did not start treatment within 7 days of diagnosis, underscoring opportunities to support or improve rapid initiation of antiretroviral therapy
- At the time of the survey, the majority of participants (94%) were on antiretroviral therapy and most did not report challenges with treatment adherence, with 84% and 87% reporting no difficulty in taking oral medication or injectable medication, respectively
- Participants identified treatment effectiveness, long-term safety, and reduced side effects as top considerations for staying on treatment. The most common reason for switching treatment was doctor recommendation
- Overall, participants reported high satisfaction with their HIV treatment; treatment satisfaction was the highest for bictegravir/emtricitabine/tenofovir alafenamide compared with all other regimens
- This study highlights important considerations for supporting people with HIV to remain engaged in care and take medication as prescribed

Plain Language Summary

- HIV treatments are now more effective and convenient. They help people with HIV live long, healthy lives
- It is important to understand how satisfied people with HIV are with their treatment. This helps them get the support they need for long-term health
- In this study, 852 people with HIV from Canada, Mexico, and the United States answered a survey and shared their experiences with HIV medications
- Most people said they had no difficulties taking their medicine and were satisfied with their treatment
- However, some people started treatment later than current health guidelines recommend
- People with HIV said the most important things that help them take their medicine are knowing it works well for a long time and has few side effects

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Introduction

- Advances in antiretroviral therapy (ART) have improved the effectiveness and convenience of HIV treatment, allowing people with HIV (PWH) to achieve a life expectancy similar to that of those without HIV and a high quality of life, provided they maintain viral suppression¹⁻⁵
- PWH may face challenges in receiving care due to a variety of socioeconomic factors and health care system barriers, which can lead to delayed diagnosis and initiation of ART and suboptimal support for adhering to treatment⁶⁻⁸
- Individuals who were diagnosed relatively recently (ie, within the past ~5 years) may be more likely to benefit from rapid initiation, “undetectable = untransmittable” messaging, and simplified regimens than those diagnosed a longer time ago
 - Recognizing the diverse identities and lived experiences of PWH, and understanding treatment experiences, can empower PWH to engage in care, improve long-term outcomes, and increase health equity⁹
- This study surveyed PWH from Canada, Mexico, and the United States and represents a subanalysis of the global survey, which encompassed 11 countries/regions¹⁰

Objective

- To explore the perspectives of PWH on the barriers and facilitators of HIV care, focusing on treatment initiation, adherence, preference, and satisfaction

Methods

- In this multinational, observational, cross-sectional study, a quantitative, 45-minute online survey was conducted from May 2024 to November 2024 using a multimodal approach involving HIV communities and databases; referrals from HIV advocacy groups, physicians, and other PWH; and social media targeting
 - People from certain backgrounds were included to ensure broad representation; quotas were set for men who have sex with men, transgender and nonbinary individuals, young adults (18-24 years of age), older adults (≥50 years of age), cisgender women, people who use drugs, and migrants
- The survey was codeveloped by investigators and community advocates who represented the 11 survey countries/regions
 - This subanalysis includes data from Canada, Mexico, and the United States
- PWH were eligible to participate if they were ≥18 years of age, had a self-reported diagnosis of HIV, resided in 1 of the survey countries, and could complete the survey in 1 of the local languages
- Survey questions assessed the experiences of PWH across the HIV care cascade and included sociodemographic information, sociobehavioral characteristics, clinical characteristics, HIV diagnosis and care, HIV treatment and preferences, and treatment success
 - The survey included the 10-item HIV Treatment Satisfaction Questionnaire (HIVTSQ) status version,^{11,12} which is scored on a 6-point ordinal scale, with a total score between 0 (lowest satisfaction) and 60 (highest satisfaction). The HIVTSQ is used to assess treatment satisfaction at the start of treatment or following treatment switch
- The data were summarized using descriptive statistics, with continuous/discrete variables presented as counts, means, and SDs (or medians and IQRs) and categorical variables presented as frequencies and percentages
- Categorical variables were compared using Pearson’s chi-square test, or Fisher’s exact test if sample sizes were small. For continuous or ordinal variables, the Wilcoxon rank sum test was used to compare distributions between independent groups

Results

- Baseline demographic and clinical characteristics of the participants are summarized in **Table 1**
 - In Canada, the most common races/ethnicities were White and Black (72 [36%] participants each); in Mexico, the most common race/ethnicity was Mestizo (137 [55%]); and in the United States, the most common race/ethnicity was White (264 [66%])

Table 1. Demographic and Clinical Characteristics

Characteristic	Participants (N = 852)
Sex assigned at birth, n (%)	
Male	664 (78)
Female	185 (22)
Prefer not to answer	3 (<1)
Mean (SD) age, y	41.9 (12.2)
Country, n (%)	
Canada	200 (23)
Mexico	250 (29)
United States	402 (47)
HIV treatment status, n (%)	
Currently treated	800 (94)
Previously treated	25 (3)
Never treated	27 (3)
Time since initiation of first ART, y	n = 794 ^a
Mean (SD)	10.3 (9.6)
Median (IQR)	7.0 (3.0-15.0)
Subpopulation, n (%)^b	
MSM	482 (57)
People who use drugs	269 (32)
Older adults (≥50 y of age)	220 (26)
Cisgender women	179 (21)
Black, Latinx, and other BIPOC	179 (21)
MSM communities	117 (14)
Migrants	117 (14)
Un-/underinsured individuals	62 (7)
Transgender and nonbinary individuals	44 (5)
Young adults (18-24 y of age)	42 (5)
Type of ART taken at the time of survey completion, n (%)	n = 798 ^c
1 daily oral pill	613 (77)
MTR	122 (15)
Injections only	29 (4)
Injections and oral pills	34 (4)
Time since HIV diagnosis, n (%)	
≤5 y ago	340 (40)
>5 y ago	512 (60)
<10 y ago	506 (59)
≥10 y ago	346 (41)
HIV treatment switch status, n (%)	
Switched treatment at least once	665 (81)
Never switched treatment	158 (19)

^aOf 825 participants who were currently or had been on treatment, 2 did not answer this part of the survey and 29 had missing data.

^bSubpopulations are not mutually exclusive; thus, percentages may not sum to 100%.

^cOf 800 participants who were currently on treatment, 2 did not answer this part of the survey.

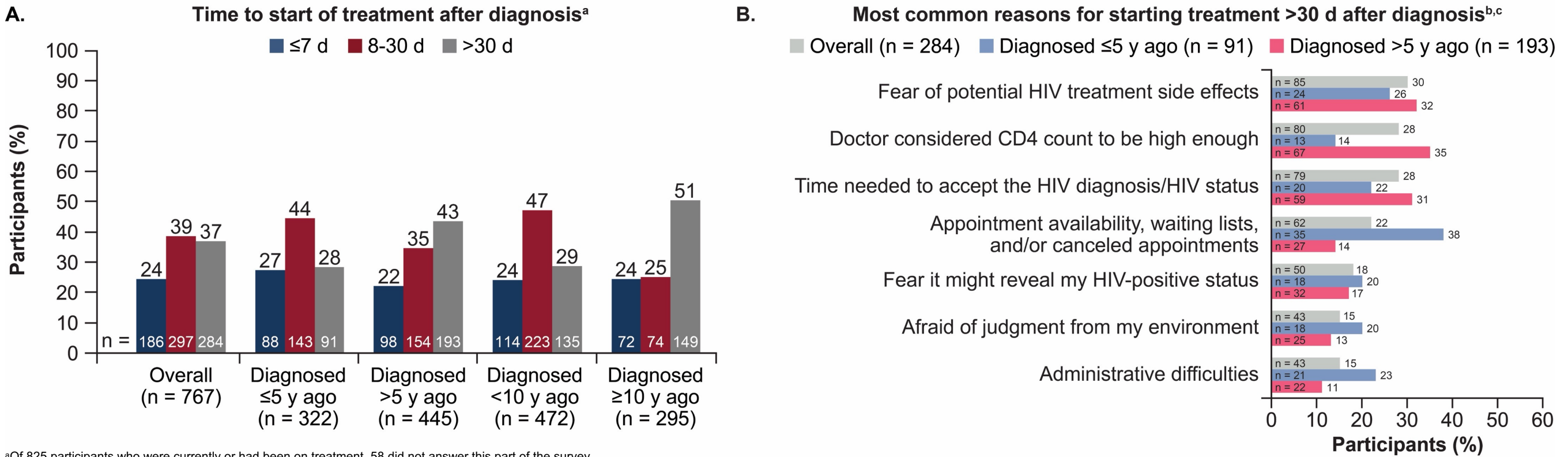
^dOf 825 participants who were currently or had been on treatment, 2 did not answer this part of the survey.

ART, antiretroviral therapy; BIPOC, Black, Indigenous, and people of color; MSM, men who have sex with men; MTR, multi-tablet regimen.

- Starting ART immediately after HIV diagnosis was considered “very important” or “important” by 92% of all survey participants
- Overall, 76% of participants did not start treatment within 7 days of diagnosis, including 73% of those diagnosed ≤5 years ago and 76% of those diagnosed <10 years ago (**Figure 1A**). While time to start treatment has improved among those diagnosed more recently, rapid initiation within 7 days remains a treatment gap
 - The most common reason for starting treatment >30 days after diagnosis for the overall population was fear of potential HIV treatment side effects (**Figure 1B**)
 - The most common reasons for those diagnosed ≤5 or >5 years ago were appointment availability, waiting lists, and/or canceled appointments; and physician recommendation based on white blood cell count, respectively. Data were similar for those diagnosed <10 or ≥10 years ago compared with those diagnosed ≤5 or >5 years ago
- Of the total survey participants, 22 (3%) never discussed treatment with a physician. The most common reasons for not discussing treatment were insurance not covering the expenses/not having insurance (32%), difficulties paying for travel to the hospital/clinic or paying for the visit (27%), and difficulties getting to the hospital/clinic (27%)
- Most participants did not report adherence challenges with oral ART in the past month (620/735 [84%]) or injectable ART in the past 6 months (55/63 [87%])
- The most commonly cited barriers to taking HIV treatment as prescribed were the financial cost of treatment and clinics/pharmacies not having the appropriate medications. The most commonly cited facilitators were support from family, friends, or community; support or medication counseling from health care providers; and digital tools
- The most important treatment features that motivated participants to take treatment as prescribed (**Figure 2A**) and to stay on treatment long term (**Figure 2B**) were that the treatment allowed people to achieve and/or maintain an undetectable viral load, was well tolerated and effective over a long period of time, and had limited or manageable side effects
 - A greater proportion of PWH diagnosed >5 years ago versus ≤5 years ago selected achieve and/or maintain undetectable viral load as a top 3 reason to stay on treatment long term (51% vs 36%)

- The most common reason for switching HIV treatment was doctor recommendation (**Figure 3A**)
- The most important treatment feature that participants identified for why they might choose to switch treatment was achieving and/or maintaining an undetectable viral load (**Figure 3B**)
 - A greater proportion of PWH diagnosed >5 years ago versus ≤5 years ago selected well tolerated and effective over a long period of time as a top 3 reason to potentially switch treatment (37% vs 30%)
- The overall median HIVTSQ score was 51.5 out of 60.0 (**Table 2**)
- The median score for bictegravir/emtricitabine/tenofovir alafenamide was significantly higher than the scores for those taking other regimens
- Median HIVTSQ scores were significantly higher for those diagnosed >5 years ago versus ≤5 years ago and those diagnosed ≥10 years ago versus <10 years ago

Figure 1. Time to Start of HIV Treatment After HIV Diagnosis

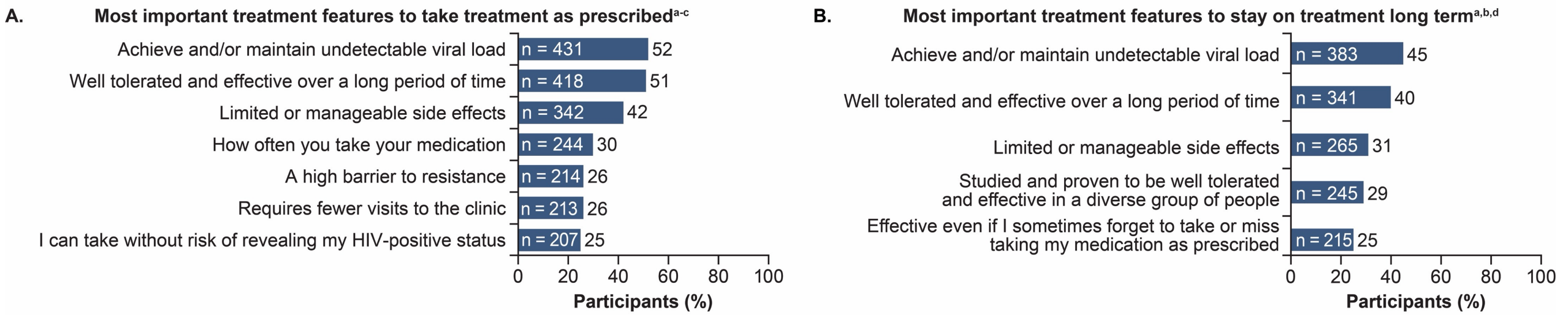


^aOf 825 participants who were currently or had been on treatment, 58 did not answer this part of the survey.

^bParticipants could have selected multiple responses; thus, percentages may not sum to 100%.

^cParticipants who started treatment >30 days after diagnosis.

Figure 2. Most Important Treatment Features for Staying on HIV Treatment



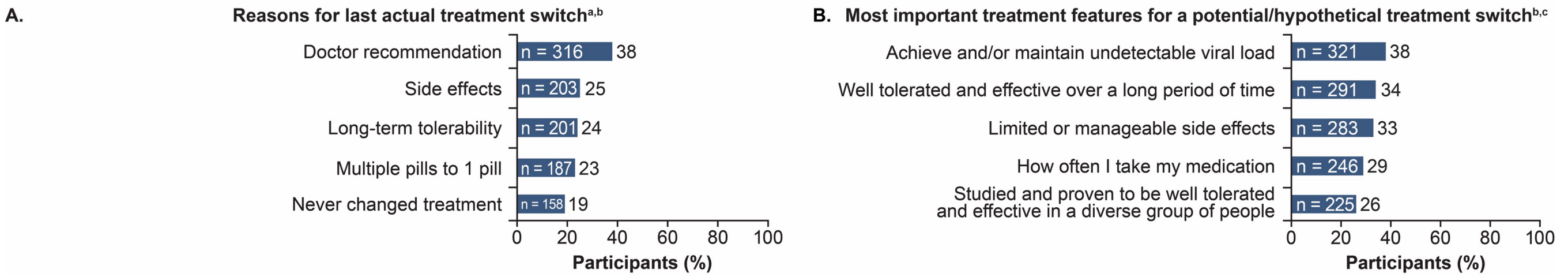
^aParticipants were asked to rank their top 3 treatment features that would be most important to motivate them to take their treatment as prescribed and stay on treatment long term among 10 possible responses (Panel A) or 13 possible responses (Panel B). The most common reasons (reported by ≥25% of participants) are shown.

^bParticipants could have selected multiple responses; thus, percentages may not sum to 100%.

^cn = 823; 2 participants who were currently or had been on treatment did not answer this part of the survey.

^dN = 852.

Figure 3. Reasons and Most Important Treatment Features for HIV Treatment Switch



^an = 823; 2 participants who were currently or had been on treatment did not answer this part of the survey. The most common reasons (reported by ≥15% of participants) are shown.

^bParticipants could have selected multiple responses; thus, percentages may not sum to 100%.

^cN = 852. Participants were asked to rank their top 3 treatment features that would be most important in switching HIV treatment among 13 possible responses. The most common reasons (reported by ≥25% of participants) are shown.

Table 2. HIV Treatment Satisfaction Questionnaire Scores

Participants	HIVTSQ Score, Median (IQR) ^a	P Value
Overall, n = 798 ^b	51.5 (46.0-58.0)	—
HIV treatment type		
B/F/TAF, n = 329	55.0 (48.0-59.0)	<0.001 ^d
All other STRs, n = 284 ^c	49.0 (46.0-56.0)	
MTRs, n = 122	49.0 (43.0-54.8)	
All other regimens, n = 469 ^e	49.0 (45.0-56.0)	
Time since HIV diagnosis		
≤5 y ago, n = 314	49.0 (44.0-55.0)	<0.001
>5 y ago, n = 484	54.0 (47.8-59.0)	
<10 y ago, n = 476	49.0 (46.0-55.0)	<0.001
≥10 y ago, n = 322	56.0 (48.0-60.0)	
HIV treatment switch status		
Switched treatment at least once, n = 642	51.0 (46.0-58.0)	0.2
Never switched treatment, n = 156	52.0 (48.0-58.0)	

^aThe HIVTSQ is a validated 10-item questionnaire scored on a 6-point ordinal scale, with 0 indicating low favorability and 6 indicating high favorability. Responses to all questions are summed to produce a total score between 0 (lowest satisfaction) and 60 (highest satisfaction).

^bOf 800 participants currently on treatment, 2 were missing HIVTSQ data.

^cExcluding B/F/TAF.

^dP < 0.001 for B/F/TAF versus all other STRs (excluding B/F/TAF), B/F/TAF versus MTRs, and B/F/TAF versus all other regimens (excluding B/F/TAF).

B/F/TAF, bictegravir/emtricitabine/tenofovir alafenamide; HIVTSQ, HIV Treatment Satisfaction Questionnaire; MTR, multi-tablet regimen; STR, single-tablet regimen.