

Survey on the Experiences of People With HIV Around the World

Xavier Guillaume¹, Robin Barkins², Marcel Dams³, Nomfundo Eland⁴, Maureen Owino⁵, Carlos Saucedo⁶, Yun-Chung Lu⁷, Amina Omri¹, Alissar Moussallem¹, Larkin Callaghan⁸, Michael Bogart⁸, Connie Kim⁸, Megan Dunbar⁸

¹Oracle Life Sciences, Paris, France; ²To Restore, Unite, Support, and Transform, Los Angeles, CA, USA; ³Aidshilfe NRW e.V., Cologne, Germany; ⁴Emthonjeni Counselling & Training, Cape Town, South Africa; ⁵York University, Toronto, ON, Canada; ⁶Agenda LGBT, A.C., Mexico City, Mexico; ⁷We As One Association, Taiwan; ⁸Gilead Sciences, Inc., Foster City, CA, USA

Copies of this poster obtained through QR (Quick Response) code are for personal use only and may not be reproduced without written permission of the authors.



Conclusions

- Among all participants in this global survey, 38% reported that they started HIV treatment >30 days after their diagnosis, which highlights opportunities to support or improve rapid initiation of antiretroviral therapy
- The majority of participants (93%) were on antiretroviral therapy at the time of the survey, and most did not report challenges with treatment adherence, with 87% and 83% reporting no difficulty in taking an oral medication or injectable medication, respectively
- Participants identified treatment effectiveness, reduced side effects, and long-term safety as the most important HIV medication considerations. The most common reason for switching was that the participant's doctor had suggested they switch treatment. Findings were similar across subpopulation analyses
- Overall, participants reported high levels of satisfaction with their HIV treatment; the highest treatment satisfaction score among daily oral medications was reported for bicitgravir/emtricitabine/tenofovir alafenamide

Plain Language Summary

- People with HIV can live long, healthy lives if they take medicine to treat the virus, but some people may face stigma (feeling ashamed or judged), experience discrimination, or have trouble getting to a doctor
- It is important to understand how satisfied people with HIV are with their treatment so they can get the support they need for long-term health
- In this study, 2532 people with HIV from 11 countries answered a survey about their experiences with HIV medications
- Most people said they had no problems taking their medicine and were satisfied with their treatment
- However, some people started treatment later than current health guidelines recommend
- The most important things that people with HIV said would help them to take HIV medicine were that the medicine worked well over a long period of time and had few side effects

Introduction

- Improvements in antiretroviral therapy (ART) have made HIV treatment more effective and convenient, enabling people with HIV (PWH) to achieve a normal life expectancy and a high quality of life¹⁻⁴
- PWH may face challenges in receiving care due to various socioeconomic factors and barriers within medical facilities, which result in delayed diagnosis and/or delayed initiation of ART and suboptimal support to adhere to their treatment⁵⁻⁷
- Understanding the treatment experiences of PWH is crucial for improving engagement in care and ensuring long-term treatment success⁸
- In this study, a global population of PWH was surveyed to explore perspectives on the barriers and facilitators of HIV care, focusing on treatment initiation, adherence, and preferences for and satisfaction with HIV treatment options

Methods

- In this multinational, observational, cross-sectional study, a quantitative, 45-minute survey was conducted online from May 2024 to May 2025 using a multimodal approach involving HIV communities/databases; referrals from HIV advocacy groups, physicians, and other PWH; and social media targeting
 - Target recruitment was 2500 PWH
 - Certain subpopulations of interest were recruited 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 survey countries (Canada, France, Germany, Italy, Japan, Mexico, South Africa, Spain, Taiwan, the United Kingdom, and the United States)
- Participating PWH were ≥18 years of age, had a self-reported diagnosis of HIV, resided in one of the survey countries, and could complete the survey in one of the local languages
- Survey questions assessed the experiences of PWH across the HIV care cascade and included sociodemographic information, sociobehavioural 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,^{9,10} which is used to assess treatment satisfaction at the start of treatment or following treatment switch. The HIVTSQ is scored on a 6-point ordinal scale, with a total score between 0 (lowest satisfaction) and 60 (highest satisfaction)
- Descriptive statistics were used to summarise the data, with continuous/discrete variables presented as counts, means, and SDs (or medians, minima, and maxima) and categorical variables presented as frequencies and percentages

Results

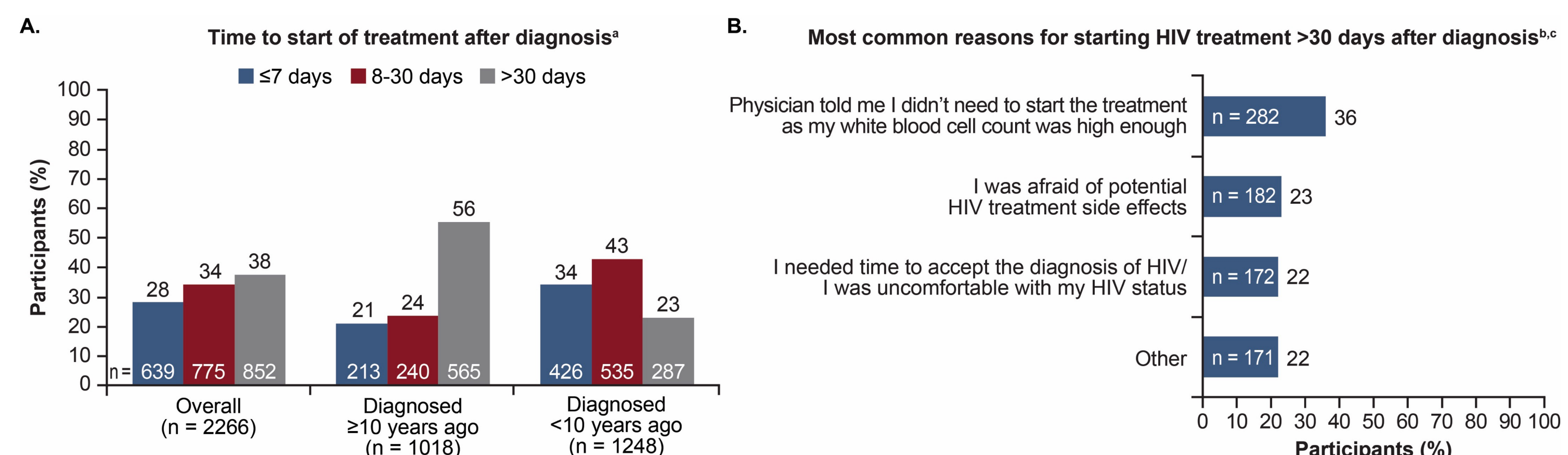
Table 1. Demographic and Clinical Characteristics

Characteristic	Participants (N = 2532)
Gender, n (%)^a	
Male	1831 (72)
Female	603 (24)
Other	98 (4)
Age, years, mean (SD)	42.1 (12.0)
Country, n (%)	
United States	402 (16)
Japan	250 (10)
Mexico	250 (10)
United Kingdom	213 (8)
Taiwan	208 (8)
South Africa	205 (8)
Italy	203 (8)
Spain	201 (8)
Canada	200 (8)
France	200 (8)
Germany	200 (8)
Subpopulation, n (%)^b	
Men who have sex with men	1416 (56)
Older adults (≥50 years of age)	706 (28)
People who use drugs	616 (24)
Cisgender women	561 (22)
Migrants	268 (11)
Transgender and nonbinary individuals	138 (5)
Young adults (18-24 years of age)	128 (5)
Time since initiation of first ART, years, mean (SD)^c	11.0 (9.4)
Treatment status, n (%)	
Currently receiving ART	2355 (93)
Previously treated	79 (3)
Never treated	98 (4)
Type of ART taken at the time of survey completion, n (%)^d	
1 daily oral pill	1731 (74)
Multitablen regimen	414 (18)
Injections only	122 (5)
Injections and oral pills	78 (3)

^aGender was identified by participants; n = 11 selected "prefer not to answer."
^bSubpopulations overlap, and participants could be in multiple subgroups; thus, percentages may not sum to 100%.
^cn = 2424.
^dn = 2345; 10 participants did not answer this part of the survey.
ART, antiretroviral therapy.

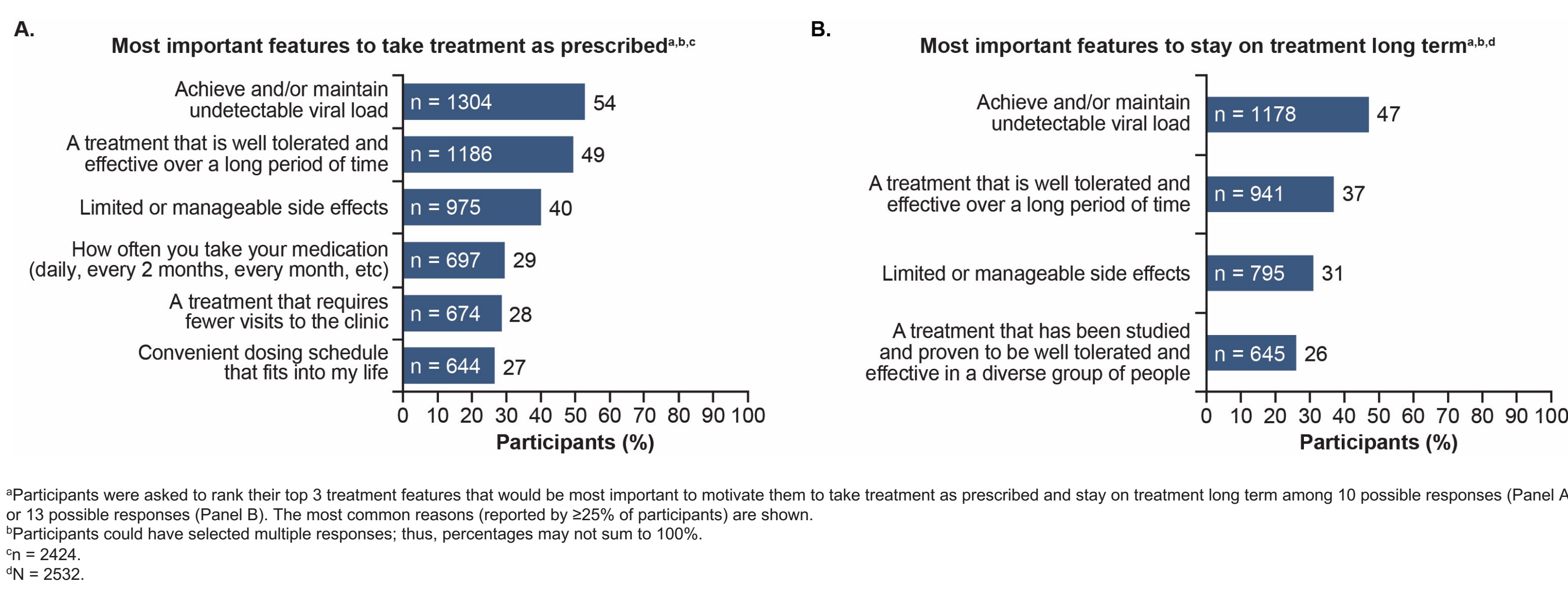
- Overall, 72% of participants did not start treatment within 7 days of diagnosis, including two-thirds of participants who were diagnosed <10 years ago (**Figure 1A**). The most common reason for starting treatment >30 days after diagnosis was physician recommendation based on white blood cell count (**Figure 1B**)
- Of the total survey participants, 88 (3%) never discussed treatment with a physician. The most common reasons for not discussing treatment were fear of potential HIV treatment side effects (19%), difficulties paying for travel to the hospital/clinic or paying for the visit (17%), insurance not covering the expenses or not having insurance (16%), and a lack of information around the HIV care process (15%)

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



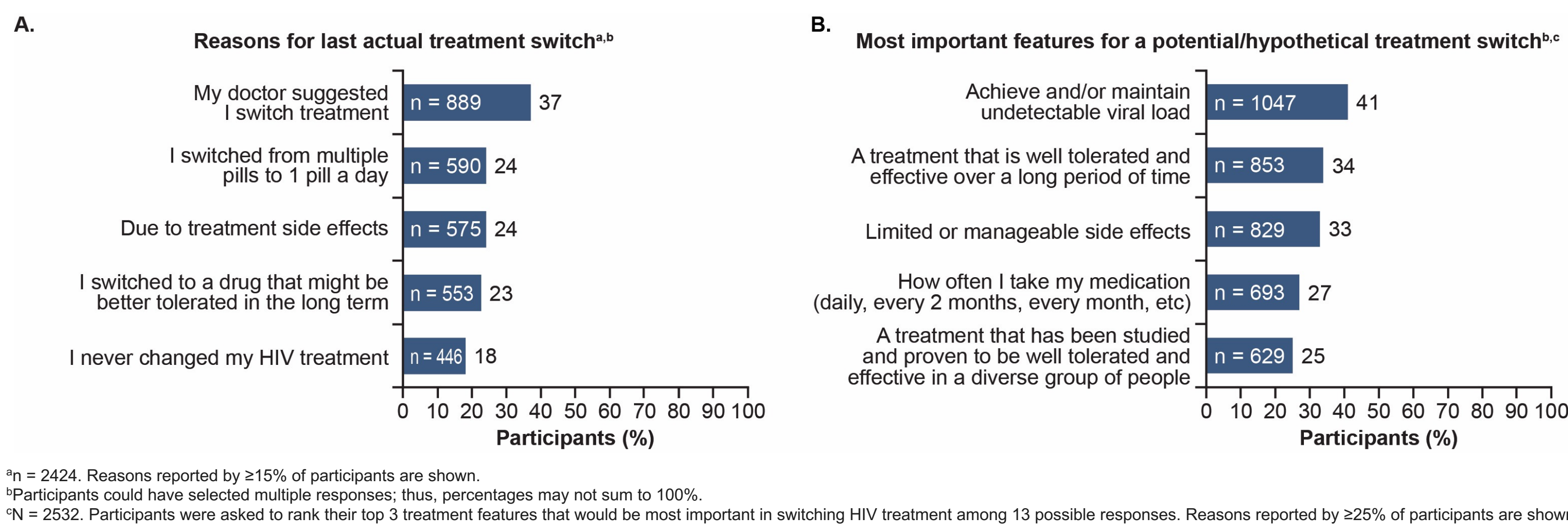
- Most participants did not report adherence challenges with oral ART in the past month (1852/2135 [87%]) or injectable ART in the past 6 months (166/200 [83%]). The most commonly cited barriers to taking HIV treatment as prescribed were the financial cost of treatment and clinics/pharmacies not having the appropriate medications. The most commonly cited facilitators were support or medication counselling from health care providers; support from family, friends, or the community; and other support services
- 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
- The most important treatment features reported in **Figures 2A** and **2B** did not vary substantially by subgroup. The only difference was among people who use drugs, who reported that the most important feature was a treatment that was well tolerated and effective over a long period of time

Figure 2. Most Important Features for Treatment Adherence and Persistence



- The most common reason for switching HIV treatment was clinician suggestion (**Figure 3A**)
- The most important features that participants identified for why they might choose to switch treatments are shown in **Figure 3B**. For all subgroups, the top 4 features were the same, except for people who use drugs and young adults. For people who use drugs, the top reason was to manage treatment side effects; for young adults, the top feature was a treatment that has been studied and proven to be well tolerated and effective in a diverse group of people

Figure 3. Reasons and Most Important Features for Treatment Switch



- The overall median HIVTSQ score was 52.0/60.0 (**Table 2**)
- In participant subgroups, the median HIVTSQ score was highest for older adults and migrants and lowest for people who use drugs
- The median HIVTSQ score for bicitgravir/emtricitabine/tenofovir alafenamide was numerically higher than the overall median score and higher than the scores for those taking other regimens
- Median HIVTSQ scores were numerically higher for those who had been on treatment for ≥10 years versus <10 years

Table 2. HIV Treatment Satisfaction Questionnaire Scores

Participants	HIVTSQ Score, Median (IQR) ^a
Overall, n = 2345^b	52.0 (46.0-57.0)
Subgroup	
Men who have sex with men, n = 1416	52.0 (46.0-58.0)
Older adults (≥50 years of age), n = 706	54.0 (48.0-59.0)
People who use drugs, n = 616	48.0 (43.0-56.0)
Cisgender women, n = 561	52.0 (45.0-58.0)
Migrants, n = 268	54.0 (48.0-59.0)
Transgender and nonbinary individuals, n = 138	52.0 (46.0-59.0)
Young adults (18-24 years of age), n = 128	50.0 (43.8-56.0)
Treatment type	
B/F/TAF, n = 689	54.0 (48.0-59.0)
All other oral regimens, n = 1456 ^c	50.0 (45.0-57.0)
All other regimens, n = 1656 ^c	51.0 (45.0-57.0)
Duration on treatment	
Participants on treatment for ≥10 years, n = 1014	54.0 (48.0-59.0)
Participants on treatment for <10 years, n = 1331	50.0 (44.0-56.0)
Treatment switch status	
Participants who never switched treatment, n = 443	53.0 (46.0-58.0)
Participants who switched treatment, n = 1902	51.0 (46.0-57.0)

^aThe HIVTSQ is a validated 10-item questionnaire scored on a 6-point ordinal scale, with 6 indicating high favourability and 0 indicating low favourability. Responses to all questions are summed to produce a total score between 0 and 60, with 60 being the highest satisfaction and 0 being the lowest satisfaction.
^bOf 2355 participants currently on treatment, 10 did not answer the HIVTSQ survey.
^cExcluding B/F/TAF.
B/F/TAF, bicitgravir/emtricitabine/tenofovir alafenamide; HIVTSQ, HIV Treatment Satisfaction Questionnaire.

References: 1. World Health Organization. HIV and AIDS. Accessed 9 September 2024. <https://www.who.int/news-room/fact-sheets/detail/hiv-aids>. 2. Cohen MS, et al. *N Engl J Med*. 2011;365:493-505. 3. Rana AI, et al. *Drugs*. 2020;80:535-45. 4. US Department of Health and Human Services. Guidelines for the use of antiretroviral agents in adults and adolescents with HIV. Accessed 10 September 2024. <https://clinicalinfo.hiv.gov/sites/default/files/guidelines/documents/adult-adolescent-arv/guidelines-adult-adolescent-arv.pdf>. 5. Mugavero MJ, et al. *Clin Infect Dis*. 2013;57:1164-71. 6. Katz IT, et al. *J Int AIDS Soc*. 2013;16:18640. 7. Genberg BL, et al. *Soc Sci Med*. 2009;68:2279-87. 8. Lazarus JV, et al. *HIV Med*. 2023;24:8-19. 9. Woodcock A, Bradley C. *Qual Life Res*. 2001;10:517-31. 10. Woodcock A, Bradley C. *Value Health*. 2006;9:320-33.

Acknowledgements: This study was funded by Gilead Sciences, Inc. We extend our thanks to the survey participants. Medical writing and editorial support were provided by Katherine Townsend, PhD, of Humanity Communications Inc., and were funded by Gilead Sciences, Inc.

Correspondence: Megan Dunbar, megan.dunbar2@gilead.com

Disclosures: **XG, AO, and AM** are employees of Oracle Life Sciences and were commissioned by Gilead Sciences, Inc., to conduct this study. **LC, MB, CK, and MDu** are stockholders and employees of Gilead Sciences, Inc. **RB, MDa, NE, MO, CS, and Y-CL** have no disclosures to report.