HIV Viewpoints: Survey on the Treatment Experiences of People Living With HIV in Europe

eP350

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Conclusions

- In this survey of 1017 people with HIV, most agreed that starting antiretroviral therapy immediately was important; however, 75% 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 (92%) were on antiretroviral therapy and most did not report challenges with treatment adherence, with 87% and 80% 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 medicines are now more effective and easier to take. They help people with HIV live long, healthy lives
- We need to understand how satisfied people with HIV are with their treatment so they can get the support they need to stay healthy over time
- In this study, 1017 people with HIV from France, Germany, Italy, Spain, and the United Kingdom filled out a survey about their experiences with HIV medicines
- Most people said they had no trouble taking their medicine and felt satisfied with their treatment
- Some people, however, started treatment later than current health guidelines recommend
- People with HIV said the most important things that help them take their HIV medicine are that it works well over time and causes few side effects

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Introduction

- Advances in antiretroviral therapy (ART) have enhanced 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 supression[1-5]
- PWH may face challenges in receiving care due to various socioeconomic factors and health care system barriers, which can lead to delays in diagnosis and initiation of ART and suboptimal support for adhering to treatment[6-8]
- Individuals who were diagnosed relatively recently (ie, within the past ~5 years) may be more likely than those diagnosed a longer time ago to benefit from changes in guidelines for rapid initiation, "undetectable = untransmittable" messaging, and simplified regimens
  - Recognising the diverse identities and lived experiences of PWH, including experiences related to taking ART, can empower individuals to engage in care, improve long-term treatment outcomes, and increase health equity[9]
- This study surveyed PWH from France, Germany, Italy, Spain, and the United Kingdom and represents a European subanalysis of the global survey, which encompassed 11 countries/regions[10]

Objective

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

Methods

- This was a multinational, observational, cross-sectional study. From May 2024 to May 2025, a quantitative, 45-minute survey was conducted online using a multimodal approach involving HIV communities and databases; referrals from HIV advocacy groups, physicians, and other PWH; and social media targeting
  - To ensure broad representation, people from certain backgrounds were included; 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
  - This subanalysis includes data from France, Germany, Italy, Spain, and the United Kingdom
- 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 encompassed 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,[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
- Descriptive statistics were used to summarise the data, 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 low. For continuous or ordinal variables, the Wilcoxon rank sum test was used to compare distributions between independent groups

Results

- Overall, 1017 PWH who participated in the survey were included in this subanalysis (**Table 1**)

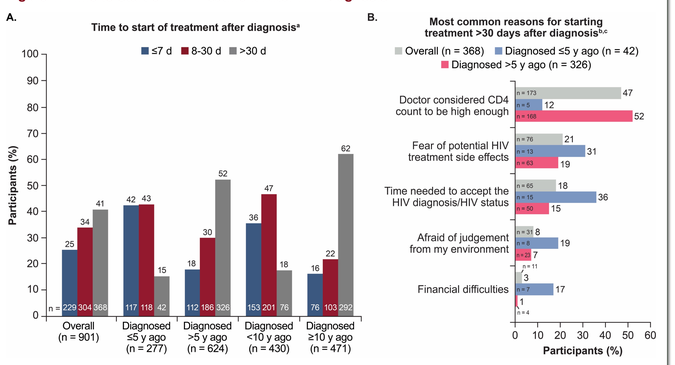
Table 1. Demographic and Clinical Characteristics

Characteristic	Participants (N = 1017)
Sex assigned at birth, n (%)	
Male	776 (76)
Female	238 (23)
Prefer not to answer	3 (<1)
Mean (SD) age, y	44.7 (12.5)
Country, n (%)	
France	200 (20)
Germany	200 (20)
Italy	203 (20)
Spain	201 (20)
United Kingdom	213 (21)
HIV treatment status, n (%)	
Currently treated	934 (92)
Previously treated	35 (3)
Never treated	48 (5)
Time since initiation of first ART, y	n = 964[a]
Mean (SD)	12.8 (10.4)
Median (IQR)	10.0 (4.0-20.0)
Subpopulation, n (%)[b]	
Men who have sex with men	572 (56)
Older adults (≥50 y of age)	386 (38)
People who used drugs	257 (25)
Cisgender women	220 (22)
Un-/underinsured individuals	97 (10)
Migrants	138 (14)
Transgender and nonbinary individuals	59 (6)
Young adults (18-24 y of age)	47 (5)
Type of ART taken at the time of survey completion, n (%)	n = 929[c]
1 daily oral pill	632 (68)
MTR	188 (20)
Injections only	81 (9)
Injections and oral pills	28 (3)
Time since HIV diagnosis, n (%)	
≤5 y ago	301 (30)
>5 y ago	716 (70)
<10 y ago	474 (47)
≥10 y ago	543 (53)
HIV treatment switch status, n (%)	n = 964[a]
Switched treatment at least once	837 (87)
Never switched treatment	127 (13)

[a]Of 969 participants who were currently or had been on treatment, 5 did not answer this part of the survey.
[b]Subpopulations are not mutually exclusive; thus, percentages may not sum to 100%.
[c]Of 934 participants who were currently on treatment, 5 did not answer this part of the survey.
ART, antiretroviral therapy; MTR, multi-tablet regimen.

- Starting ART immediately was considered "very important" or "important" by ~90% of all survey participants
- Overall, 75% of participants did not start treatment within 7 days of diagnosis, including 64% of those diagnosed <10 years ago and 58% of those diagnosed ≤5 years ago (**Figure 1A**). While time to start treatment has improved, there has not been a drastic uptake of rapid initiation
  - The most common reason for the overall population for starting treatment >30 days after diagnosis was doctor considered CD4 count to be high enough, and for PWH diagnosed ≤5 years ago, was time needed to accept the HIV diagnosis/HIV status (**Figure 1B**). 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, 43 (4%) never discussed treatment with a physician. The most common reasons for not discussing treatment were fear of potential HIV treatment side effects (26%), thinking I do not need HIV treatment yet (21%), and lack of information around the HIV care process (16%)

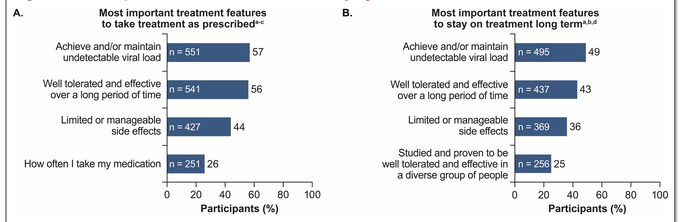
Figure 1. Time to Start of HIV Treatment After HIV Diagnosis



[a]Of 969 participants who were currently on or had been on treatment, 68 did not answer this part of the survey.
[b]Participants could have selected multiple responses; thus, percentages may not sum to 100%. Out of 18 possible responses, the most common reasons (reported by ≥15% of participants overall or in either subgroup) are shown.
[c]Participants who started treatment >30 days after diagnosis.

- Most participants did not report adherence challenges with oral ART in the past month (716/820 [87%]) or injectable ART in the past 6 months (87/109 [80%])
- 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 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
  - More PWH diagnosed >5 years ago versus ≤5 years ago selected achieve and/or maintain undetectable viral load (53% vs 38%, respectively) and limited or manageable side effects (40% vs 28%) as reasons to say on treatment long term

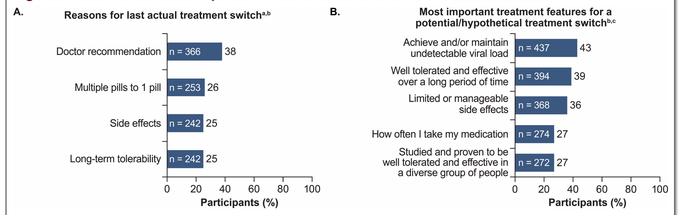
Figure 2. Most Important Treatment Features for Staying on HIV Treatment



[a]Participants 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.
[b]Participants could have selected multiple responses; thus, percentages may not sum to 100%.
[c]n = 964; 5 participants who were currently on or had been on treatment did not answer this part of the survey.
[d]N = 1017.

- The most common reason for switching HIV treatment was doctor recommendation (**Figure 3A**)
- The most important feature that participants identified for why they might choose to switch treatment was achieving and/or maintaining an undetectable viral load (**Figure 3B**)
  - More PWH diagnosed >5 years ago versus ≤5 years ago selected achieve and/or maintain undetectable viral load (47% vs 34%, respectively) and limited or manageable side effects (40% vs 27%) as reasons to potentially switch treatment, while fewer selected studied and proven to be well tolerated and effective in a diverse group of people (24% vs 32%)

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



[a]n = 964; 5 participants who were currently on or had been on treatment did not answer this part of the survey. The most common reasons (reported by ≥25% of participants) are shown.
[b]Participants could have selected multiple responses; thus, percentages may not sum to 100%.
[c]N = 1017. 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.

- The overall median HIVTSQ score was 52.0 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 and were numerically higher for those who never switched treatment versus those who had switched

Table 2. HIV Treatment Satisfaction Questionnaire Scores

Participants	HIVTSQ Score, Median (IQR)[a]	*P* Value
Overall, n = 929[b]	52.0 (45.0-58.0)	–
HIV treatment type		
B/F/TAF, n = 214	55.0 (48.0-60.0)	
All other STRs, n = 418[c]	51.0 (47.0-58.0)	0.002[d]
MTRs, n = 188	46.0 (37.0-54.0)	<0.001[e]
All other regimens, n = 715[c]	51.0 (44.0-57.0)	<0.001[f]
Time since HIV diagnosis		
≤5 y ago, n = 257	50.0 (42.0-56.0)	<0.001
>5 y ago, n = 672	52.0 (47.0-58.0)	
<10 y ago, n = 419	49.0 (43.0-56.0)	<0.001
≥10 y ago, n = 510	54.0 (48.0-58.0)	
HIV treatment switch status		
Switched treatment at least once, n = 803	51.0 (45.0-57.5)	0.07
Never switched treatment, n = 126	54.0 (47.0-58.0)	

[a]The HIVTSQ is a validated 10-item questionnaire scored on a 6-point ordinal scale, with 0 indicating low favourability and 6 indicating high favourability. Responses to all questions are summed to produce a total score between 0 (lowest satisfaction) and 60 (highest satisfaction).
[b]Of 934 participants currently on treatment, 5 were missing HIVTSQ data.
[c]Excluding B/F/TAF.
[d]*P* = 0.002 for B/F/TAF versus all other STRs (excluding B/F/TAF).
[e]*P* <0.001 for B/F/TAF versus MTRs.
[f]*P* <0.001 for 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.