# Creating the Conditions for Shared Decision-Making: Perspectives of People Living With HIV and HIV Support Organisations Across 29 Countries

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## Key Takeaways

- **Not all were asked:** 63.1% (2,051 of 3,251) reported that their provider asked for their opinion before prescribing their current medication; 36.9% did not. Being asked was reported less often soon after diagnosis (58.0% within a year versus 69.0% after more than 10 years) and by trans and non-binary people (50.3%) (Figure 3).
- **Being asked differed by region:** 42.2% in Latin America versus 77.1% in Asia; 60.2% in Europe, 73.5% in North America and 61.2% in other regions (Figure 2).
- **Greater involvement was associated with better reported outcomes:** high versus low shared decision-making, aOR 2.78 (95% CI 2.24–3.44; n=2,058) for good mental health. Being asked was associated with higher odds of viral suppression (aOR 1.41; 1.09–1.82; n=2,807), but not after adjustment for feeling unheard, regardless of trust in the provider (aOR 1.16; 0.89–1.52).
- **Staff perceive barriers:** only 29.2–39.2% of responding staff reported that the average person they support is comfortable discussing the five listed topics with their HIV provider (Table 4).

## Plain Language Summary

- We asked people living with HIV in 29 countries whether their provider asked their opinion before prescribing their medication, and whether they were satisfied with their involvement.
- About 2 in 3 said they were asked. Being asked was reported less often in Latin America, soon after diagnosis, and by trans and non-binary people.
- People with greater involvement more often reported satisfaction with their medication, good mental health and taking doses as prescribed.
- We also asked staff of HIV and community organisations how comfortable they perceive the people they support to be discussing key topics with their provider.
- These results are associations and do not show cause and effect.

## Introduction

- Shared decision-making (SDM) means patients and providers making treatment decisions together. It is a stated goal of HIV care, but little is known about how reported experience of it varies across countries.[1,2]
- It is also unclear whether involvement in treatment decisions is associated with outcomes beyond satisfaction, such as enjoyment of life, emotional and social burden and viral suppression.
- **Objective:** to examine variation in reported treatment involvement and its associations with health and psychosocial outcomes, alongside staff perceptions of communication barriers.

## Methods

- **Design:** Positive Perspectives Wave 3 (PP3) is a cross-sectional survey in 29 countries (August 2024–August 2026; analyses on the final dataset) with two adult parts: people living with HIV on treatment (Adult HIV survey, N=3,888) and staff of HIV and community organisations (staff survey, N=622).
- **Sample:** online or paper questionnaires; recruitment was coordinated through community organisations in 20 of the 29 countries. Participants were not randomly selected and results are not weighted, so findings may not generalise to all people living with HIV.
- **Measures (Adult HIV survey):** "Asked my opinion" = "My healthcare provider asked for my opinion before prescribing my current HIV medication"; "satisfied with involvement" = "I am satisfied with my involvement in HIV treatment decisions" (somewhat or strongly agree). SDM level (study-defined): high = both, moderate = one, low = neither (n=3,056 answering both).
- **Outcomes** (self-reported): satisfaction with current medication; optimal adherence (no missed, non-prescribed or extra doses reported at least "sometimes" in the last 12 months; frequency-based proxy); viral suppression (provider describes viral load as undetectable); good mental health (rated good or excellent, past four weeks); enjoying life; ongoing difficulty coping with anxiety and low mood or with the lifelong commitment of treatment; feeling ashamed of having HIV; confidence explaining undetectable = untransmittable (U=U).
- **Trust** = "I trust my main HIV care provider to meet my health needs"; **feeling unheard** = "Sometimes I feel unheard by my main HIV care provider" (somewhat or strongly agree).
- **Analysis:** adjusted odds ratios (aOR; 95% confidence interval, CI) from logistic regression adjusted for age group, gender, region and time since diagnosis. Trust and feeling unheard were then added together, so feeling unheard is assessed regardless of trust.
- **Staff survey:** Up to 445 staff rated how comfortable the average person they support would be discussing each topic with their HIV provider (perceptions only; not linked to adult respondents).

### Figure 1. Study Population and Shared Decision-Making Levels




Staff survey: N=622 staff of HIV and community organisations; up to 445 rated comfort of the people they support.

High = asked my opinion and satisfied with involvement; moderate = one of the two; low = neither. Percentages are of those answering both items.

### Table 1. Characteristics of Adult HIV Survey Participants

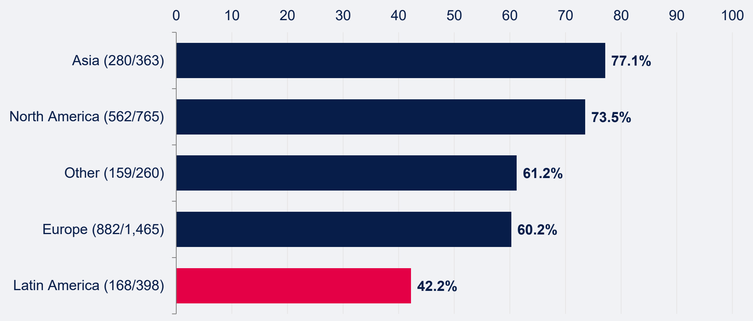
| Age, years | | Region | | Time since diagnosis | |
|---|---|---|---|---|---|
| 18–34 | 23.7 | Europe | 46.5 | Under 1 year | 15.7 |
| 35–44 | 23.1 | North America | 22.4 | 1–5 years | 26.1 |
| 45–64 | 43.6 | Latin America | 12.3 | 6–10 years | 16.3 |
| 65 and over | 9.5 | Asia | 10.5 | Over 10 years | 41.9 |
| | | Other† | 8.3 | | |
| **Gender** | | **Social profile** | | **Sexual orientation** | |
| Men | 58.1 | Has health insurance | 84.7 | Heterosexual | 46.5 |
| Women | 36.3 | Employed | 64.1 | Gay or lesbian | 42.0 |
| Trans or non-binary | 4.7 | | | Bi-, pan- or asexual | 9.3 |
| Other or not stated | 0.9 | | | Other or not stated | 2.2 |

% of those answering each item (n: age 3,887; gender 3,850; region 3,888; health insurance 3,019; employed 3,099; time since diagnosis 3,747; sexual orientation 3,851). Median age 46 years. †Australia and South Africa.

### Being Asked Before Prescribing Differed by Region

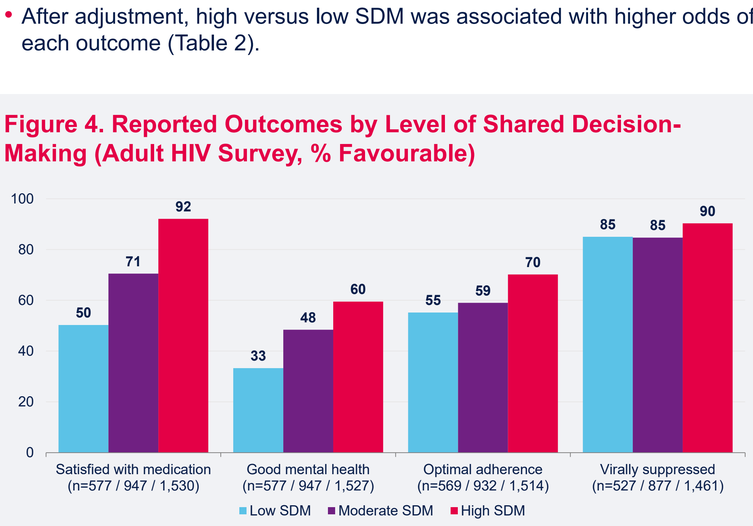
- **42.2%** of people in Latin America and **77.1%** in Asia reported that their provider asked for their opinion before prescribing their current medication (Europe 60.2%, North America 73.5%, other regions 61.2%).
- Being asked was also reported less often soon after diagnosis and by trans and non-binary people, and more often by people on injectable regimens (Figure 3).

### Figure 2. Provider Asked for My Opinion Before Prescribing Current Medication, by Region (Adult HIV Survey)




% of people answering the item (n=3,251; n/N in labels). "Other" = Australia and South Africa. Recruitment mode (online or paper) and setting varied by country, so regional differences may partly reflect who took part and how; they do not show that providers in a region are less engaging. Satisfaction with involvement was reported by 60.0% (234/390) in Latin America, 65.1% (902/1,385) in Europe, 67.0% (233/348) in Asia and 75.5% (550/728) in North America.

### Figure 3. Asked for My Opinion Before Prescribing, by Participant Characteristic (Adult HIV Survey)




% of people answering the item, by group (n/N in labels; unadjusted). Red = groups reporting being asked less often; purple = more often. Trans and non-binary respondents were also less often satisfied with their involvement in treatment decisions: 52.4% (75/143) versus 67.2% (771/1,148) of women and 69.1% (1,231/1,782) of men.

### Involvement Was Associated With Better Reported Outcomes

- Higher shared decision-making was associated with a higher proportion reporting satisfaction, good mental health, optimal adherence and viral suppression (Figure 4).
- After adjustment, high versus low SDM was associated with higher odds of each outcome (Table 2).

### Figure 4. Reported Outcomes by Level of Shared Decision-Making (Adult HIV Survey, % Favourable)




% of those answering each outcome; self-reported; unadjusted. n shown under each outcome as low / moderate / high SDM.

### Table 2. High Versus Low Shared Decision-Making: Percentages and Adjusted Odds Ratios

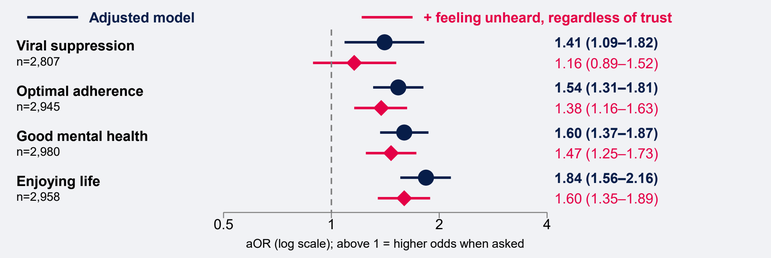
| Outcome | Low SDM, % | High SDM, % | aOR (95% CI) | n (low / high) |
|---|---|---|---|---|
| Satisfied with current medication | 50.3 | 92.1 | 10.67 (8.19–13.91) | 549 / 1,512 |
| Good mental health | 33.3 | 59.5 | 2.78 (2.24–3.44) | 549 / 1,509 |
| Optimal adherence | 55.2 | 70.2 | 1.94 (1.57–2.41) | 543 / 1,496 |
| Virally suppressed | 85.0 | 90.3 | 1.46 (1.04–2.04) | 506 / 1,443 |

Percentages as in Figure 4. aOR and n (low / high SDM) are from models adjusted for age group, gender, region and time since diagnosis (complete cases). aOR above 1 = higher odds with high SDM.

### Feeling Unheard, Regardless of Trust: Viral Suppression

- Trust and feeling unheard are separate: 77.1% (n=3,110) reported trusting their HIV provider; 25.4% (n=3,104) sometimes feeling unheard.
- Being asked was associated with higher odds of every outcome. After additional adjustment for feeling unheard regardless of trust, associations were attenuated and, for viral suppression, no longer statistically significant (CI includes 1). This is consistent with a relational pathway; it does not show that trust or feeling unheard explains them.

### Figure 5. Asked for My Opinion and Outcomes, Before and After Adding Feeling Unheard, Regardless of Trust (aOR, 95% CI)




Adjusted for age group, gender, region and time since diagnosis; both models use the same people per outcome (n shown; those answering both trust items). The second model includes trust and feeling unheard together. Dashed line = no difference (aOR 1).

### Being Asked, Psychosocial Outcomes and U=U Confidence

### Table 3. Provider Asked for My Opinion Versus Not (Adult HIV Survey)

| Outcome | Asked, % | Not asked, % | aOR (95% CI) | n (asked / not) |
|---|---|---|---|---|
| Ongoing difficulty coping with anxiety and low mood | 28.3 | 36.5 | 0.71 (0.60–0.83) | 1,985 / 1,122 |
| Ongoing difficulty with the lifelong commitment of treatment | 20.9 | 26.2 | 0.80 (0.67–0.96) | 1,984 / 1,122 |
| Feel ashamed that I have HIV | 34.9 | 39.7 | 0.85 (0.73–1.01) | 1,947 / 1,087 |
| Confident explaining U=U to others | 71.5 | 59.1 | 1.95 (1.65–2.31) | 1,950 / 1,089 |

Percentages unadjusted; n (asked / not asked) shown per row. "Not asked" = did not report this. aOR below 1 = lower odds of the difficulty among people who were asked; above 1 = higher odds of the outcome. Adjusted for age group, gender, region and time since diagnosis. For feeling ashamed the CI includes 1 (not statistically significant).

### Staff Perceive Barriers to Discussing Key Topics

### Table 4. Staff Survey: Staff Who Said the Average Person They Support Is Comfortable Discussing the Topic With Their HIV Provider

| Topic | % of staff | n / N |
|---|---|---|
| Adherence challenges | 39.2 | 174 / 444 |
| Impact of HIV on work | 37.8 | 168 / 444 |
| Stigma experiences | 33.1 | 147 / 444 |
| Pills as a constant reminder of HIV | 31.5 | 140 / 445 |
| Mental health (depression, anxiety) | 29.2 | 130 / 445 |

Staff survey, N=622 respondents (not organisations). Organisation type (n=618): hospital or clinic 29.1%, community-based 12.9%, non-profit 12.0%, NGO 9.4%, other 36.6%; 26.2% living with HIV (n=619). Perceptions of the average person supported, not patient reports. Five of 18 topics shown; across all 18, 23.6–50.0% of staff said people would be comfortable.

## Conclusions

- **Observed:** 63.1% reported that their provider asked their opinion before prescribing their current medication. This was least often reported in Latin America (42.2%) and by trans and non-binary people (50.3%).
- **Observed:** higher shared decision-making was associated with higher satisfaction, mental health and adherence. The association between being asked and viral suppression was not statistically significant after adjustment for feeling unheard, regardless of trust.
- **Staff view:** only 29.2–39.2% of responding staff reported that the average person they support is comfortable discussing the listed topics with their HIV provider.
- **Implication:** these results suggest value in supporting provider engagement and in community organisations and peer support that help people prepare for and raise these topics in consultations; this study did not test any intervention.

## Limitations

- Cross-sectional, self-reported, unweighted convenience sample (online or paper, varying by country): associations only. Reverse causation is possible, as people in better health or with more resources may find it easier to take part in decisions.
- Viral suppression was participant-reported (provider's description of viral load) and missing or "not sure" for about 21%. All analyses are exploratory (not confirmatory); small subgroups may give imprecise estimates. Attenuation after adjustment does not establish mediation. Staff perceptions were not linked to adult respondents.

**Acknowledgements:** The authors thank the people living with HIV in 29 countries who took part in Positive Perspectives Wave 3 (PP3) and the staff of HIV and community organisations who completed the staff survey. Recruitment and implementation were supported by community organisations and local partners; Fundación Huésped coordinated recruitment through community organisations in 20 of the 29 countries. The study was sponsored by ViiV Healthcare. Abbreviations: aOR, adjusted odds ratio; CI, confidence interval; SDM, shared decision-making; U=U, undetectable = untransmittable.

**References:** 1. Beach MC, Keruly J, Moore RD. J Gen Intern Med 2006;21:661–5. 2. Flickinger TE, Saha S, Moore RD, Beach MC. J Acquir Immune Defic Syndr 2013;63:362–6.

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