Queen Mary University of London

SHARE RESEARCH FOR HEALTH EQUITY

Perspectives of people living with HIV in Europe on their clinical consultations: an equity analysis

THPEE 490

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Plain Language Summary

- Long-acting HIV treatments (which don't need to be taken every day) are being developed.
- Cabotegravir and rilpivirine (CAB+RPV) injections given every 2-months are available in many European countries.
- Although people living with HIV have shown strong interest in long-acting options, relatively few people across Europe are taking CAB+RPV, suggesting a gap between what people want and what is happening in clinics.
- **This study asks people living with HIV across Europe about their experiences discussing new treatments with their healthcare providers through an online survey.**
- Most participants (81%) said they had previously discussed whether their current treatment is the best for them with their healthcare provider, but only 41% recalled having this discussion within the last year.
- When these discussions did take place, less than half said they had discussed CAB+RPV in the discussion (45%). Many of the people who did not discuss CAB+RPV (45%) were eligible and interested in taking it. People aged 55+ were less likely to have treatment discussions and less likely to have discussed CAB+RPV with their healthcare provider.
- This research shows that not everyone has equal access to discussions about new treatments options like CAB+RPV. This raises concern that some groups may be left behind as new drugs are developed.

Background

- Despite significant interest in long-acting modalities, long-acting injectable cabotegravir + rilpivirine (CAB+RPV) usage is low across Europe.
- This suggests a **gap between studies assessing the interest of people living with HIV and what is happening in practice**.
- We aim to understand this by exploring if and how novel treatments are being discussed and offered by healthcare providers (HCPs) through an equity analysis of the 'Ask Us Europe' survey.

Methods

- Ask Us Europe is an **equity-focused, multi-country, cross-sectional online survey**, **co-produced** with 18 community members, in partnership with the European AIDS Treatment Group and the UK Community Advisory Board.
- Eligible participants: people living with HIV, aged ≥18, living in a European country where CAB+RPV treatment is currently licensed, available and reimbursed.
- Dissemination of the survey was via social media and community and clinical networks between July 22 2025- May 20 2026.
- We performed an equity-focused analysis on prespecified endpoints: whether participants 1) ever had a treatment review discussion, 2) had a treatment review discussion in the past year, 3) ever discussed CAB+RPV with their HCP. In addition to age, gender, ethnicity and time since HIV diagnosis, we incorporated multiple under-reported dimensions: neurodivergence, physical disability, financial stability, employment and housing status, and need for specialist support. We report adjusted odds ratios (OR) and profile likelihood confidence intervals (CI).

Results

- 1935 participants: 18% cis women, 8% transgender/gender diverse, 75% White, 39% ≥55 years; 10% were recent migrants (<5 years) (Table 1).
- 80% were clinically eligible for CAB+RPV and 16% had ever received it.

Table 1. Demographic characteristics of participants

	Overall* (N=1935)
Age	
<55	1180 (61%)
≥55	755 (39%)
Gender	
Cis man	1369 (71%)
Cis woman	355 (18%)
Trans, non-binary, gender diverse	162 (8%)
Ethnicity	
White	1432 (75%)
Black	131 (7%)
Latinx	169 (9%)
Education	
No higher education	
Higher education	
Recent immigration status (<5 years)	167 (10%)
Neurodivergence	138 (8%)
Physical disability	151 (9%)
Financial instability	483 (29%)
Shared/insecure housing	373 (19%)
Need for tailored specialist support**	823 (43%)
Diagnosis (more than 7 years ago)	1424 (82%)
Years on HIV treatment	
Mean (SD)	16.4 (9.63)
Taking other medication	1023 (61%)

	Overall* (N=1935)
Missed a dose (past 12 months)	
Mistakenly	349 (61%)
Intentionally	108 (7%)
HIV consultations twice a year	975 (57%)
Current HIV medication	
One pill taken once daily	1376 (71%)
Two or more pills, taken once daily	188 (10%)
Two or more pills taken twice daily	94 (5%)
Other	12 (0.6%)
Clinically eligible for CAB+RPV * **	
Yes	1549 (80%)
CAB+RPV	
Ever on CAB+RPV	300 (16%)

** Other/Missing data not indicated*
*** Needing support with substance use, food or housing insecurity, domestic violence, claiming benefits, immigration or mental health.*
**** Clinical eligibility for CAB+RPV was determined according to the licensed indication. Participants were ineligible if their HCP had described their HIV viral load as detectable, indicated that their HIV medication was ineffective or had developed resistance, or if they were being treated for Hepatitis B infection.*

Figure 2. Adjusted odds ratios and 95% confidence intervals (CI) for recalling ever having a treatment optimisation discussion

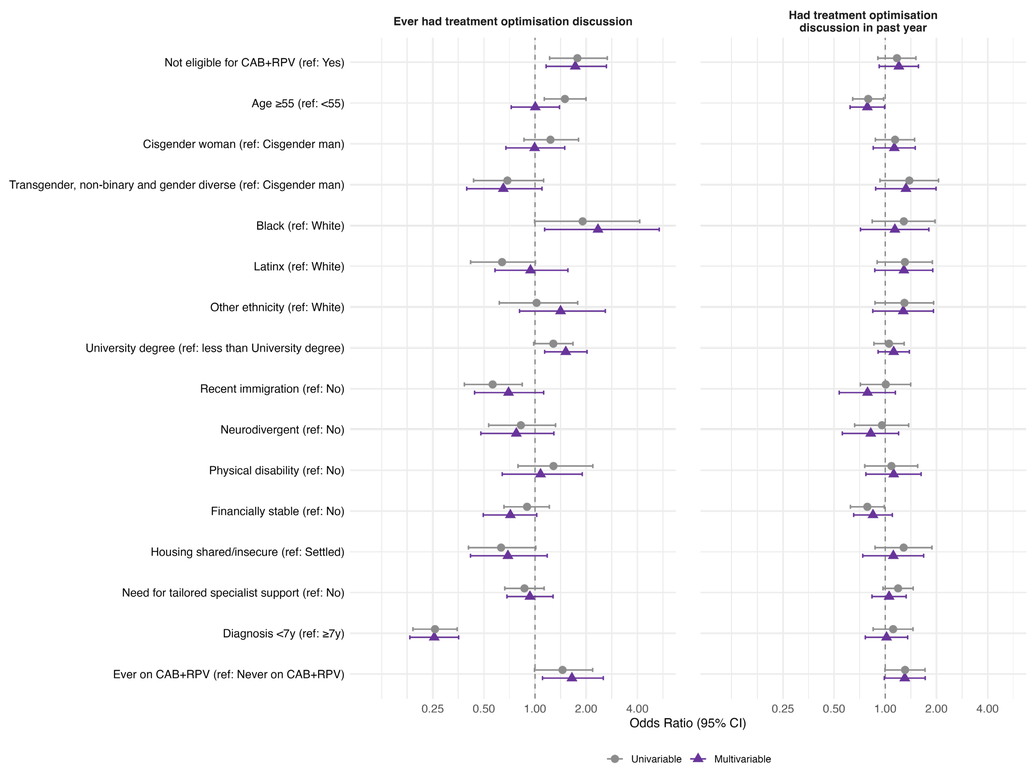
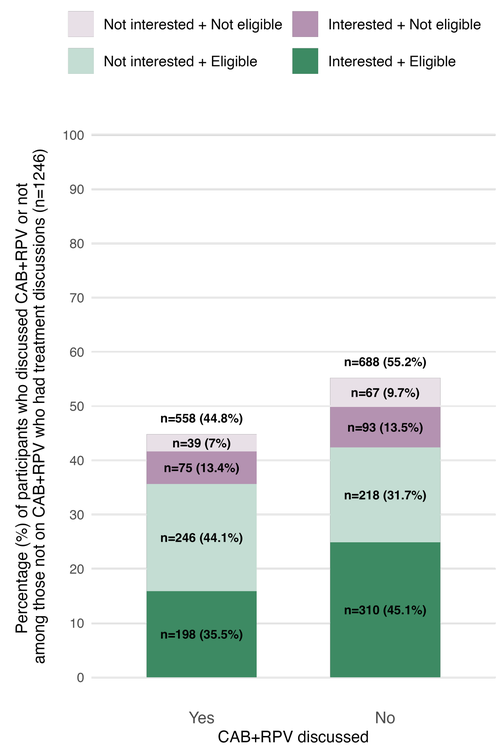
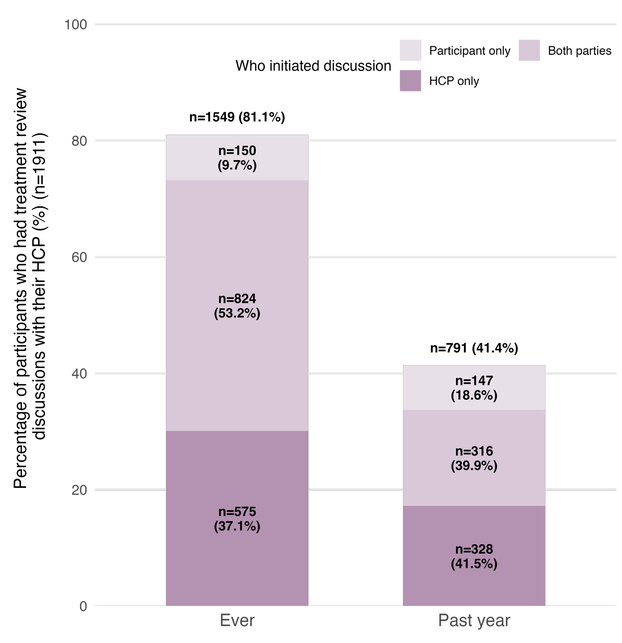


Figure 3. Percentage of participants who recall discussing CAB+RPV with their HCP



- Participants more likely to have had a treatment optimisation were on CAB+RPV (OR=1.65, 95%CI=1.11-2.52), **clinically ineligible for CAB+RPV** (OR=1.72, 95%CI=1.16-2.63), of **Black heritage** (OR=2.35, 95%CI=1.14-5.38) or had a **university degree** (OR=1.52, 95% CI=1.14-2.02) **(Figure 2).**
- Participants **over the age of 55** were less likely to have discussed optimising their treatment **in the past year** (OR=0.79, 95%CI=0.62-0.99).

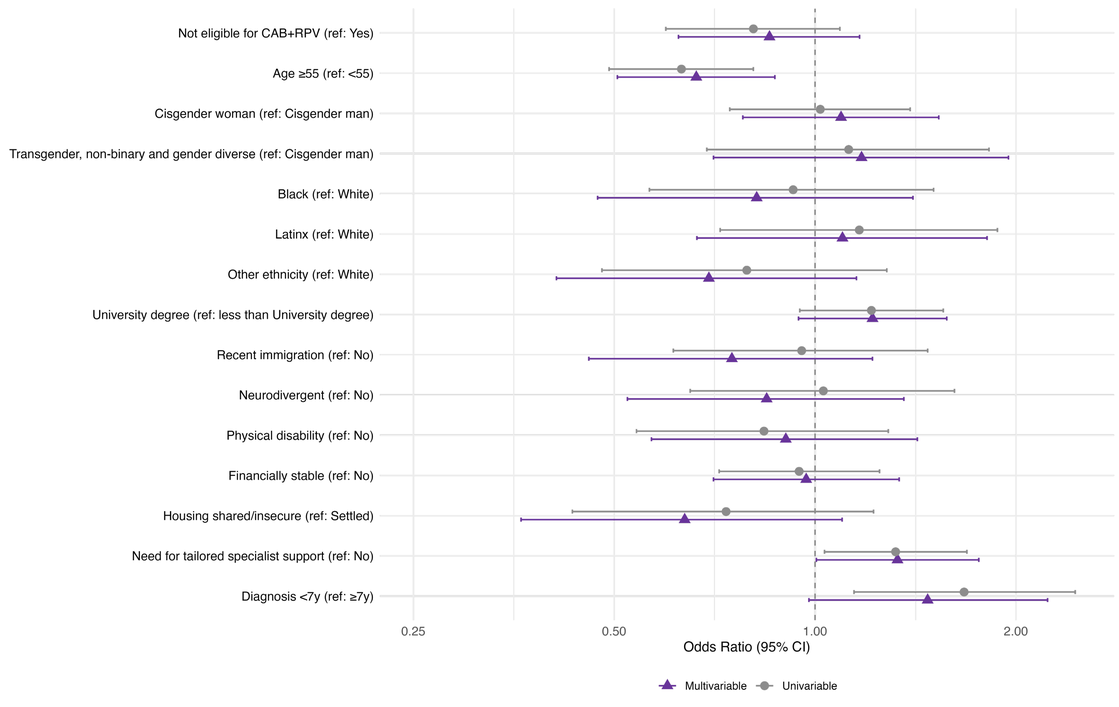
Figure 1. Percentage of participants who recall having a treatment review discussions with their HCP



- 81% of participants reported having a treatment review but only 41% recalled having one in the past year **(Figure 1).**

- Among participants who had treatment optimisation discussion/s with their HCP and who had never received CAB+RPV, 45% indicated that CAB+RPV was discussed **(Figure 3).**
- Among those who did not discuss CAB+RPV, **45% were both eligible and interested.**
- **People over 55 years** old (OR=0.66, 95%CI=0.51-0.87) were **less likely to report discussing CAB+RPV**, while those with tailored specialist support needs were more likely (OR=1.33, 95%CI= 1.00-1.76) **(Figure 4).**
- Some groups (e.g Latinx ethnicity) reported the lowest awareness of CAB+RPV but had the highest interest.

Figure 4: Adjusted odds ratios and 95% confidence intervals (CI) for having discussed CAB+RPV



Discussion and Conclusions

- Most participants did not have treatment optimisation discussions annually and almost 20% did not ever recall having one. Even when treatment optimisation discussions occurred, less than half discussed CAB+RPV. Almost half of those that did not discuss CAB+RPV were both interested and eligible, highlighting that many people who could benefit from CAB+RPV are not discussing it with their HCP.
- The equity analysis highlighted that opportunities to discuss treatment innovation remain socially patterned which risks some populations being left behind in the delivery of personalised HIV care.

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