

A qualitative study of health information-seeking among adults living with HIV enrolled in the REMAIN national digital cohort

Daryl Mangosing DrPH, MPH¹, Carissa Crews MPH¹, Stacy Castellanos MA², Aimee Rochelle MPH¹, Valerie El-Alfi MA², Sean D. Young PhD³, Henna Patani, MPH, MSITM, BDS⁴, Yancy Granados⁴, Jacob B. Stocks, MSc¹, Pamina M. Gorbach DrPH², Lisa B. Hightow-Weidman MD, MPH¹, Kathryn E. Muessig PhD¹



Objectives

- HIV raises a unique set of questions for patients when managing health concerns. Patients who are out-of-care or between appointments need reliable, easily-accessible health information.
- The EPI-LoVE Study comprises a national virtual cohort of people with HIV (PWH) who are provided digital health resources.
- We characterized the cohort's health information priorities by analyzing participants' questions from the Ask the Expert forum (AtE).

Methods

- Participants are recruited via online platforms and referrals from a national HIV clinic network (AIDS Healthcare Foundation).
- Eligible PWH are age 18+, English or Spanish speaking, with smartphone access, and at-risk for or virally unsuppressed.
- All participants enroll in a smartphone application (app): REMAIN [Retain, Maintain, Sustain] to complete study activities.
- In AtE, participants post anonymous questions to staff who respond or triage questions to medical and public health providers.
- Experts' responses include text, images, and resource links.
- We thematically analyzed AtE content from 2/9/2024 to 2/18/2025.

Results

- Among 992 participants, 84 (8.5%) contributed a total of 307 posts in AtE (205 submitted questions, 102 commented).
- This sub-sample was mean age 40.1, range 24 to 58 years, 4.8% female, 9.5% Latinx, 79.8% Black/AA and 36.9% virally suppressed.
- 67% of posts covered HIV topics including care, cure, diagnosis, prevention, STIs, HIV/STI testing, sexual practices, and disease progression.
- 43% of posts focused on personal and social well-being encompassing dating and romantic relationships, mental health, managing stress, fitness/nutrition, substance use, and socioeconomic needs.
- Despite AtE being an expert-led forum, some participants offered their own advice and shared personal experiences.

Conclusions

- Offering PWH in a virtual cohort a space to ask questions on a digital platform like an app provides a way to get information and reach experts confidentially and efficiently.
- Participants' broad range of HIV and non-HIV health questions will guide priorities for developing future digital resources and health information.
- Findings underscore the importance of expert-led online spaces, and the modest volume of questions suggests AtE is a scalable resource.

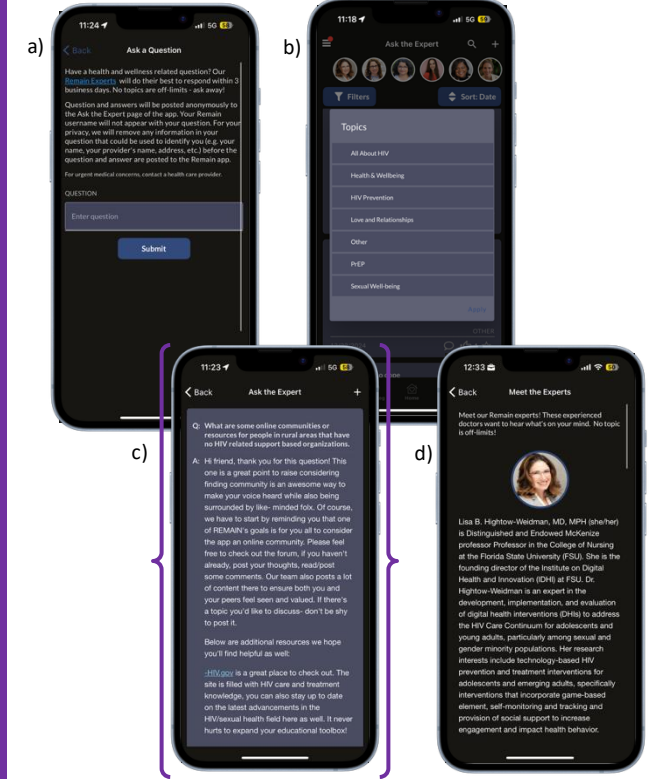
Results (continued)



Example questions:

- "Do you help with housing for at risk people facing homelessness?"* [socioeconomic assistance]
- "What are some ways an introvert can improve their mental health?"* [mental health]
- "What are some online communities or resources for people in rural areas that have no HIV related support-based organizations?"* [HIV care]

REMAIN Ask the Expert screenshots



Top: a) Ask a question, b) Topics search filter. Bottom: c) Participant question and expert answer, d) Meet the experts.

Acknowledgements

NIH-NIAID (UG3AI176592; PIs: Gorbach, Hightow-Weidman, & Young)
 Florida State University, Tallahassee, FL¹; University of California Los Angeles, Los Angeles, CA²; University of California Irvine, Irvine, CA³;
 AIDS Healthcare Foundation, Los Angeles, CA⁴

