# Exploring young people's perspectives on using unconsented health data for HIV research: follow-up insights from the Chiva Youth Committee.

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**Background:** Linking England's HIV surveillance data enables exploration of health outcomes across the lifecourse. Ethical use of unconsented routine care health data requires meaningful involvement with people with lived experience, so UCL partnered with Chiva's Youth Committee (CYC) to explore research acceptability, priorities, and preferences for future involvement.

**Methods**: In October 2025, we held an interactive workshop with 15 CYC members (aged 13–17). Participants received age-appropriate information and provided written consent. The workshop included presentations on use of unconsented data for research, risks and safeguards, and our proposed project assessing health outcomes of adults born with HIV. We asked participants to rank research priority questions and discussed data privacy and acceptability. Data were analysed descriptively and thematically.

**Results:** Participants were generally supportive of using their routine health data for research, believing it could provide insights into long-term health. Four themes emerged:

1. **Support for data use and broader priorities:** Participants wanted research beyond HIV focused-outcomes, prioritising mental health, other health conditions, and educational outcomes (Figure 1) and fed back: *"My data might as well be used – why waste it!"*
2. **Data safety:** Most (11/15) felt reassured about the safeguards for use of health data in research, 2/15 felt it was safe but had some questions, and the remainder (2/15) were unsure or had concerns about use of unconsented data, potential data breaches, and risk of HIV status disclosure.
3. **Clear communication:** Participants called for jargon-free explanations: *"Language is so important, I get confused by what the doctor is talking about. I don't have the same degree as them."* They agreed clinicians should explain the potential use of routine care data for research: *"[I want to know] what data are being collected, how it's being used and the benefits."*
4. **Meaningful project & involvement:** Most (13/15) felt the project was meaningful for people growing up with childhood HIV. Suggested involvement strategies included reviewing materials, presenting at conferences, and

outreach. Participants highlighted the need for clear, ongoing communication and structured feedback mechanisms in research using their data.

**Conclusion:** CYC members were broadly supportive of use of routine health data for research and stressed the importance of data safeguards and transparent communication.

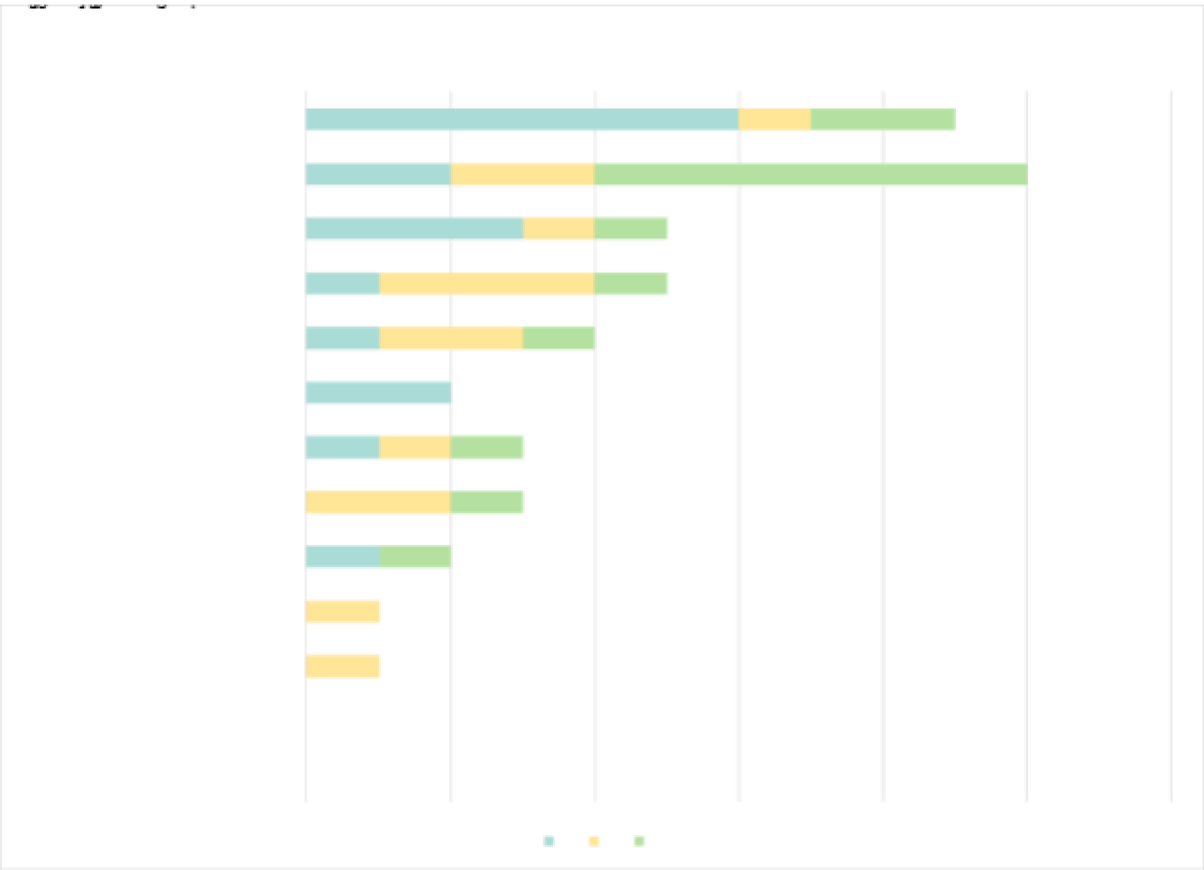

Figure 1. Topic rankings. Horizontal stacked bars show the number of participants who ranked each topic as their 1st, 2nd, or 3rd priority.