

FROM PARTICIPATION TO LEADERSHIP: A 15 YEAR REVIEW OF THE CHIVA YOUTH COMMITTEE

INTRODUCTION

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Young people living with HIV (YPHIV) are experts in the unique barriers faced during adolescence, and their insight is essential for shaping relevant support and programmes. Meaningful, fully integrated, non-tokenistic youth participation is critical for organisations working in adolescent health as it ensures that services remain grounded in real experiences and support emerging needs. Chiva established the Chiva Youth Committee (CYC) in 2010 to embed youth voice & leadership at the centre of its work. The committee brings together young people aged 13–17 to advise on programme development, identify gaps in support, challenge stigma and influence the wider public/institutions on HIV. This review explores 15 years of the CYC model, examining its impact on young people, its contribution to organisational development, and how the approach is evolving as the cohort of YPHIV ages.

CYC IMPACT WITHIN CHIVA

- **Educational resources** — The CYC co-developed the **Education Toolkit (2021)**, now distributed to schools across the UK and used in PSHE lessons to challenge myths and reduce stigma. This resource was created in direct response to CYC members consistently identifying poor HIV awareness in schools as a source of stigma.
- **Audio resources**— A 5-episode podcast series created and directed by CYC members called **Don't Listen to Me, Listen to My HIV (2023)**, explores YPHIV perspectives on healthcare, mental health, relationships and stigma.
- **Films** — CYC members co directed films **Paris (2021)** (HIV awareness film for the deaf community) and **Safe With Me (2024)**, (a story of a young person coming to terms with their HIV) both films designed to raise awareness and tackle stigma.
- **Books** - The CYC current creative project is **More Than a Label (2026)**, a co-produced book featuring personal stories from 11 CYC members. Launching later in 2026.
- **Programme influence** — The CYC provides yearly input into the theme and direction of Chiva's **annual F2B summer camp**, ensuring each year's programme responds to emerging needs.

New HIV education toolkit

Empower Students: End HIV Stigma



CYC IMPACT ON MEMBERS WELLBEING

Sustained support enables young people to develop the confidence and skills needed to engage in advocacy, leadership and wider HIV sector work.

Young people report that participation has led to:

- **Improved public speaking and confidence** — Professional training delivered every two years builds presentation skills and reduces anxiety around speaking in public or advocacy settings.
- **Community & peer support** — Strong friendships and shared experiences create a sense of belonging, improving wellbeing and resilience. CYC members are also supported throughout their term by the Participation officer and CYC alumni that assist residentials in a pastoral capacity.

"I am proud of the CYC label" - CYC member (2026)

01

Recruitment

- Applications reviewed for diversity.
- Entry interviews capture baseline confidence and expectations.
- Term lasts 2 years

02

Monthly Participation

- Monthly virtual meetings to plan projects, advise on research opportunities and reflect on Chiva's work to establish routine engagement.

The Chiva Youth Committee participation cycle

03

Residential with skill development

- Three residentials per year focussing on project and skill development.
- A safe space for connection.
- Provided professional public speaking training.

04

Co-Production

- The CYC co-produce resources to be used within and beyond Chiva.
- Planning of these resources occurs during residentials and zoom calls.

05

Organisational Influence

- Members highlight any gaps of support and strengthen Chiva's ability to address stigma.
- CYC meet with Chiva Steering Group to raise issues for attention at Chiva.

06

18+ progression

- As the YPHIV cohort ages, Chiva is extending its participation pathway by launching CYC+ for 18-25 year olds in 2027.
- Additionally, CYC Alumni can now support CYC residents in a pastoral capacity.

CYC INFLUENCE ON POLICY / RESEARCH / SERVICES

The CYC plays an active role in shaping research and policy across the HIV sector, ensuring youth perspectives directly influence in national and international forums.

- **Advocacy research:** In 2025, members contributed to HIV Outcomes' Living Well with HIV: Understanding and Addressing Vulnerability toolkit, examining how gaps in health and social systems limit equitable access to care.
- **Clinic service improvement:** The committee led an internal project exploring young people's experiences in HIV clinics, developing the Chiva PREM (Patient Experience Measure) now used as patient feedback tool in clinics across the UK.
- **Policy engagement:** Each year, members meet with the All-Party Parliamentary Group on HIV/AIDS (APPG) to share youth priorities and highlight emerging issues.
- **Recent national & international representation:** NAZ Zero HIV Stigma Day (2026), Royal College of Paediatrics and Child Health annual conference (2026), Bristol Adolescent Health Conference (2025), International AIDS Conferences Munich (2024) and Montreal (2022).
- **Influencing UK HIV healthcare delivery:** Annual CYC symposium at Chiva's national conference. This involvement ensures young people living with HIV influence research agendas, policy discussions, health care service delivery and sector-wide advocacy.

CONCLUSION

- Embedded, fully supported youth participation is essential for ensuring that programmes, research and policy within the HIV sector remain relevant and grounded in lived experience.
- When young people receive structured opportunities to lead, organisations benefit greatly in terms of resource output and more responsive services.
- Public awareness raising is informed by lived experience without any compromise to individuals personal confidentiality.
- Youth members experience increased confidence, improved communication skills and peer support through structured participation opportunities led by the participation officer and CYC alumni pastoral team.