

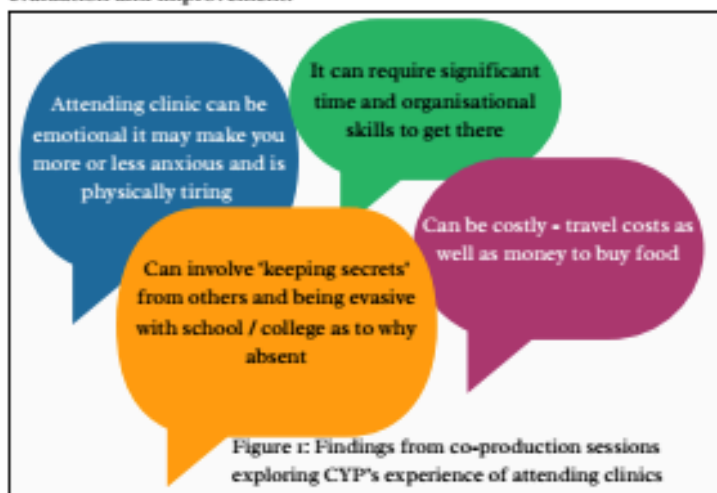
Development of a Patient Reported Experience Measure (PREM) with children & young people living with HIV in the UK to improve healthcare experience

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Introduction

Patient-centred care must reflect the voices of children and young people (CYP) to respond effectively to their needs. This is especially important for CYP living with HIV, who engage with clinical care regularly throughout their lives. Despite their expertise from lived experience, opportunities for CYP to provide structured feedback were limited. Meaningful, accessible feedback tools are essential to improve quality, address barriers, and ensure care reflects young people's priorities. Using co-production, a Patient Reported Experience Measure (PREM) was developed with CYP living with HIV, embedding their voices into service evaluation and improvement.



Methodology

Using co-production methods we held two sessions at residential meetings with CYP living with HIV. Group storytelling captured shared clinic experiences enabling analysis of common experiences. An oversight group of CYP, clinicians, academics, and Chiva staff drafted a questionnaire using these insights along with reference to national standards, including "You're Welcome Criteria"⁰⁴ and NICE guidelines.⁰¹ CYP then refined the draft questions focusing on clarity, simplicity, and relevance. A pilot phase tested the PREM in clinics and evaluated clinic experiences of implementation. Questions were refined and an implementation guide for clinics developed (See Figure 2).

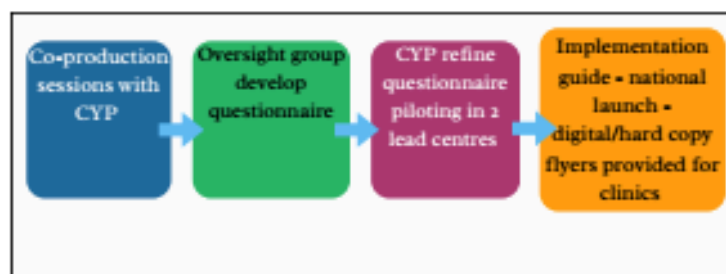


Figure 2. Process of development of PREM and implementing nationally in HIV clinic teams

Results

The development and implementation of the Chiva PREM enabled systematic capture of clinic experience directly from CYP living with HIV across multiple services (see Figure 1). From 56 fully completed surveys from 14 clinics, findings demonstrated overwhelmingly positive experiences, with the majority of CYP reporting feeling in control of how they access appointments and describing positive interactions with clinic teams. Despite this, the PREM identified key barriers to engagement, most commonly travel cost and time, as well as disruption to education. It also generated actionable suggestions for improvement (see Figure 3). These findings illustrate how PREMs provide both reach across services and nuanced patient-led insights that support targeted quality improvement and better alignment of care with the lived experiences of CYP with HIV.



Conclusion

This project demonstrates that co-producing PREMs can successfully capture the voices of CYP living with health conditions in ways that are accessible, acceptable, and relevant to them. Showing that CYP value trust, confidentiality, and involvement in decision-making, while highlighting barriers to accessing care. Reports are shared with clinic teams ongoing via Chiva newsletters. The PREM can support local service improvements and contribute national insights. It is of critical importance to effectively engage CYP living with lifelong health conditions in the care they receive, for early identification of issues and barriers to attendance to improve their experience of care, supporting long term engagement.

References

1. Department of Health (2023) "You're Welcome": Establishing Youth Friendly Health & Care Services.
2. National Institute for Health and Care Excellence (NICE) (2021) Babies, Children and Young Peoples Experiences of Healthcare
3. For further info see [Chiva.org.uk](https://www.chiva.org.uk)