

Implementation Guide to using the Chiva PREM in Clinics

Version: 0.1

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1. Background, purpose and rationale

This PREM (Patient Reported Experience Measure) has been developed to provide young people with a safe and meaningful way to share their experiences of care, enabling clinics to celebrate good practice as well as identify and address service improvements quickly while protecting anonymity. The approach balances timely feedback with robust data governance; no individual patient identifying information is included.

This project was initiated in response to concerns raised by the Chiva Youth Committee - despite raising concerns related to clinical care at several of the annual Chiva meetings, the young people felt frustrated that some of their suggestions for improvement had not been implemented. This PREM was developed with input from members of the Chiva Youth Committee, to enable consistent collection of young people's feedback following clinic appointments. Priorities identified by the Chiva Youth Committee as well as key aspects of Standards of Care pertaining to young people's health services are included in the questionnaire.

1.1 Summary

The PREM is intended for service improvement rather than research, and the design and implementation takes into account practical, ethical, and governance considerations. Reviewed against formal research ethics criteria set out by the Health Research Authority, ethical approval is not required, as no patient identifiers are collected, and the aim of the project is service improvement. Informal review from an NHS Trust Caldicott Guardian and an NHS Ethics Committee Chair confirmed this opinion.

Clinic staff will distribute information leaflets on the PREM to young people attending clinic. Young people will be able to complete the electronic questionnaire after their appointment, either at clinic or elsewhere, and there is no expectation to complete it if they do not wish to.

Clinics will be provided with aggregated data summaries on a six-monthly basis, allowing them to respond to feedback without compromising patient confidentiality. Regular provision of these summary data will support monitoring of trends over time, both within and across clinic settings.

Clinics can request ad hoc summaries of their own data at other times if required.

A core set of PREM questions will be maintained for consistency, with any updates clearly communicated to participating centres.

It is hoped that through national implementation of the tool, with regular review of feedback, changes will be made to improve clinical care experiences for young people.

2. Scope

This guidance applies to all staff involved in the distribution of information leaflets about the PREM at participating hospitals.

Inclusion criteria:

Young people can be approached to complete the questionnaire if they are aged 12- 25 and living with HIV. They can complete one questionnaire per clinic visit.

3. Responsibilities

3.1 Clinic Staff

Provide support to young people to understand the purpose of the PREM and assistance as required to help them to access the questionnaire, including free WIFI if available.

After the clinic appointment, hand out the PREM information leaflet (which includes the QR code to link to the electronic questionnaire). Please ensure an adequate supply of PREM information leaflets is available at all times and contact Chiva to obtain further copies as required.

Explain to young people why they are being asked to complete the questionnaire by providing the information below and reassure them that their responses are confidential and will not affect their care.

- **Your feedback matters to us, we want to know what it's really like for you when you come here**
- **Your answers can help us make things better for you and for other young people**
- **The data (information collected) is anonymous**
- **We will use what we learn from your responses to improve care at this clinic. We will fix things quickly where we can, but sometimes we will look at results over time to spot bigger changes we might need to make**
- **If you have a worry or concern about your experience at clinic, please do tell us now, as well as writing it in the PREM, as information in the PREM is anonymised and it may not be read immediately**

In addition, please display the **'Thank You' poster** (provided by Chiva) in the clinic to demonstrate appreciation to young people for having taken the time to complete the survey.

Contact Chiva if you require translation services or accessible formats (e.g., large print, digital version).

3.2 Project Management

Chiva holds responsibility for the PREM Project. A working group comprising Chiva staff members and Trustees with clinical and research experience and an additional external academic expert guided the development of the PREM and are providing ongoing oversight.

The Chiva project manager will collate the feedback from questionnaire data and share this with clinic teams on a 6 monthly basis.

4. Data management and confidentiality

Compliance with Data protection law is assured as no personal data are collected. Chiva has robust data security in place with data protection policies followed for how data are held across the organisation. Chiva also holds Cyber Essentials accreditation which ensures robust planning has taken place around Data protection with mitigations against Cyber security incidents in place.

The questionnaire is anonymous; no personal data are recorded in the questionnaire. However, in smaller clinics or centres, even aggregated feedback can make individuals identifiable. This risk will be addressed through:

- Minimum response thresholds before feedback is shared. Clinics will receive aggregate summaries when their completion number is ≥ 5
- Collective sharing of responses from several smaller centres in reports (those reporting numbers < 5) to ensure participant confidentiality
- Identifying information is limited to age groups and gender
- Ensuring free text question responses contain no personal identifying information before sharing with clinics
- Individual reports for clinics will not be shared in the public domain, only overview reports which do not name individual clinics will be shared more widely

5. Reporting, feedback and review

A six-monthly report summarizing key findings will be shared with participating clinic teams. Reports will provide an overview of feedback from different clinics and highlight particular insights without naming individual clinics.

These will be shared via email bulletins to clinic teams with key findings provided via the Chiva Newsletter.

Additionally, individual clinics will receive their own report on their data, this will be via a slide deck to support sharing with teams.

Insights will be shared at the annual Chiva conference which will pick up trends more broadly across clinic teams and over time.

Clinic teams may request feedback in between the reporting period if they would like data to be shared more quickly for example following a busy clinic. To request this, they should email Chiva Project Manager, Kate Lobley – kate.lobley@chiva.org.uk

To allow meaningful trend analysis, the core set of PREM questions will remain consistent. Any changes to the question set will follow a documented review process.

The project working group will review and update this guidance annually or as needed based on feedback or process changes.

Chiva will issue a clinic survey annually to assess what impact the PREM is having on services and to identify any issues around implementation.

CONTACT DETAILS FOR FURTHER INFO

Chiva Project Manager: kate.lobley@chiva.org.uk

Document History

Version	Date	Changes Made	Approved by
Version 0.1	27th October 2025		