

APPENDIX 1: Guidance on CHIPS annual feedback

Background to the annual feedback

CHIPS produces the following sets of annual feedback slides in May of each year, based on data reported to CHIPS to the end of March of that year:

- an overall slide set, showing data for the whole of the UK and Ireland together
- national slide sets, separately for: England and Wales; Scotland; and Northern Ireland (Belfast) and Eire (Dublin) combined
- regional (CHINN network) slide sets, separately for: London only; London and direct linking clinics; direct linking clinics only; outside London; Midlands; North-East; North-West; South-West
- clinic slide sets (for clinics with ≥ 25 patients; those with fewer patients receive the same data but in text format rather than as slides)

These slides are intended to be used for commissioning purposes, as well as on a regional and local level for clinicians to review their clinic population and for presentations. Each clinic is sent its own set of slides, plus regional slides for the regions it falls under, and the overall slide set. The London HIV Consortium Specialised Commissioning Group has previously been sent the overall slide set, national slide sets, and regional slide sets, plus a breakdown of the number of patients seen in each of the London clinics.

Data presented in the annual feedback

All slide sets include data on the following aspects of clinical care in paediatric HIV:

- the follow-up status of children, including the number lost to follow-up, deaths, and transfers to adult care
- the age distribution of children by year of follow-up
- the proportion of children suppressing viral load 12 months after starting combination ART naive, and also after switching to second line, by year; and of those suppressing virus on first line, time to rebound
- the number of ART drugs taken, by age of the child
- the drug classes taken at last follow-up
- the most recent CD4 count, percent, and HIV-1 RNA by type of ART

Some of these measures can be used as outcomes for commissioning, and are similar to adult outcome measures, for example:

- % of patients on ART who have an undetectable viral load < 50 c/ml in the last year
- % of patients who died in the last year
- % of patients with ≤ 2 weeks between diagnosis and first CD4 count

However it should be noted that the number of new diagnoses in CHIPS each year, as well as the number of deaths, is relatively small compared to adult services, and some clinics have a small patient caseload. Therefore it is more appropriate to compare paediatric data on a network rather than clinic level.

Also as the median age of the cohort is now 12 years, and a quarter are aged 15 years or above, issues concerning adolescence and transition to adulthood are becoming prominent. Therefore the five year projections work and increased focus on second line in CHIPS helps address this. However the changing characteristics of the cohort, and few incident cases, also complicate the identification and production of simple outcome measures.