Children's HIV and AIDS Reporting System (CHARS)

Annual Report 2022-23

Contents

1. Introduction

1.1 Aims

The Children's HIV and AIDS Reporting System (CHARS) collects clinical and other health data on all children and young people living with HIV seen by paediatric services in England until transition to adult care.

The purpose of CHARS is to monitor health outcomes and quality of services and to contribute to national epidemiological surveillance. The main objectives of the CHARS paediatric HIV surveillance are to:

- provide data for public health surveillance of HIV infections among children and young people
- monitor the quality of care of children living with HIV until transition to adult services, including producing quality of care indicators
- support NHS commissioning services
- provide data on NHS paediatric service specification metrics

NHS England commissioned paediatric HIV service providers are contractually required to submit a complete dataset to CHARS as defined in the paediatric HIV service specification.

1.2 Background

CHARS launched in January 2021 and continues the surveillance activities of the Collaborative HIV Paediatric Study (CHIPS), which was based at the Medical Research Council Clinical Trials Unit at University College London (UCL) and conducted surveillance and research from 2000-2020. CHARS is commissioned by NHS England and is run by the Infections team at UCL Great Ormond Street Institute of Child Health, alongside the Integrated Screening Outcomes Surveillance Service (ISOSS), commissioned by the NHS Infectious Diseases in Pregnancy Screening Programme. CHIPS conducted surveillance of all children living with HIV seen for paediatric HIV care in the UK and Ireland, while CHARS conducts surveillance only for those in England.

CHARS is also designed to complement the UK Health Security Agency's HIV & AIDS Reporting System (HARS) used for monitoring adult infections. CHARS directly supports work of the UK Health Security Agency (UKHSA).

The CHARS paediatric surveillance system is separate to HARS for several reasons including:

- Key differences in the clinical care of children and young people living with HIV compared to adults; for example, paediatric stage C diagnoses (i.e., serious HIV-related or AIDS conditions) differ from those in adults, antiretroviral dosing in children is based on weight/surface area rather than fixed dose tablets, with under- and over-dosing being an ongoing issue, and the antiretroviral drugs used in paediatrics vary considerably
- Paediatric infectious diseases (ID) clinicians largely operating in a network separate to adult ID networks
- Complexities arising from transition between paediatric and adult services requiring careful monitoring to ensure adequate understanding of these processes

CHARS works closely with Chiva, supporting Chiva's standards of care and clinical guidelines, alongside strong links with the British HIV Association and paediatric ID clinical networks across England. CHARS also contributes to the HIV Clinical Reference Group, providing key metrics to support patient outcomes.

1.3 Governance

All Providers delivering services to pregnant women, infants and children who are living with HIV have a mandated contractual obligation under Schedule 6 of their NHS Standard Contract (Specialised Services, Acute), for the recording and submitting of the required data to ISOSS and CHARS.

NHS England's legal basis for CHARS data collection is Section 7A of the National Health Service Act 2006 for NHS Public Health Functions and Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002.

1.4. Reporting to CHARS

All children and young people diagnosed with HIV at <16 years of age are initially reported to ISOSS with subsequent ongoing reporting to CHARS on a quarterly basis. All children and young people living with HIV accessing paediatric care in England, regardless of country of birth, are followed up in CHARS until transition out of paediatric care and into adolescent or adult services. The data flow is illustrated in Figure 1. Data are collected through a secure online portal accessed by clinical staff at approximately 40 paediatric clinics in England, including all key hubs providing paediatric services for children and young people living with HIV. Data collected include demographics, treatment, test results and clinical outcomes.

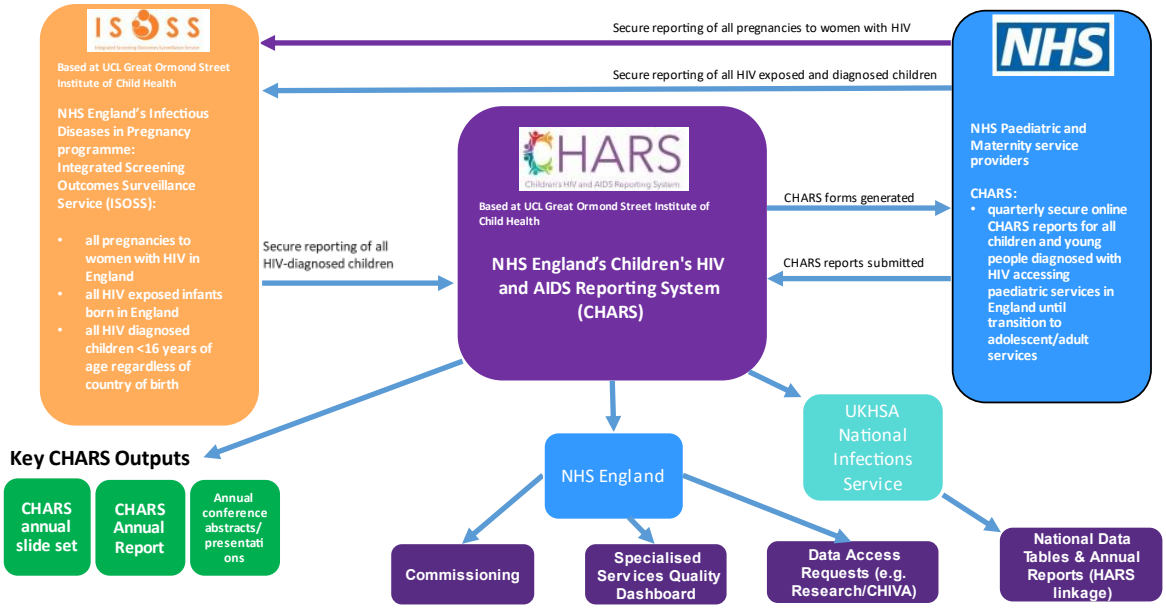

Figure 1. Data flow for CHARS and ISOSS

*Specialised Services Quality Dashboard available at https://www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/

ISOSS ceased reporting newly diagnosed children to CHIPS at the start of 2020, and all CHIPS follow-up stopped by the end of 2020 (some clinics in CHIPS stopped reporting in 2019). Following the launch in 2021, CHARS collected data retrospectively on newly diagnosed children and to bridge the gap in reports for all those in paediatric care following closure of CHIPS. This report focuses on children and young people accessing paediatric services in England since the cessation of CHIPS and reported to CHARS by June 2023. Future reports will focus on the last year of follow-up.

1.5 Methods

This report includes data on children and young people living with HIV accessing paediatric services to the end of June 2023. Due to reporting delays, some children and young people may have been seen for care prior to June 2023 but those most recent data are not included in this analysis if respondents did not submit reports on time. All children and young people in CHARS are included within this report.

Following a summary of all children and young people living with HIV in England followed up through CHIPS or CHARS since 2000, demographic characteristics are initially described for all children currently in active paediatric care (i.e., reported by CHARS respondent as 'still in follow-up at this unit' or 'transferred to other paediatric clinic' at last reported follow-up) (n=301). Description of ART use and clinical outcomes were limited to those in active paediatric care with a CHARS report submitted since January 2022 (n=270). Children and young people newly diagnosed since 1 January 2020 (n=36) and those who have transitioned out of paediatric care and into adolescent or adult care since the start of CHARS (n=171) are also described. Throughout this report, those 171 children and young people that have transferred to adolescent or adult services will be referred to as "transferred out of paediatric care".

Key metrics on immune status, viral load, ART status, and mortality are presented for children and young people newly diagnosed in England in 2021 (n=6) (and therefore have 12 complete months of follow-up data to the data cut-off), as well as all children in active paediatric care with a CHARS report submitted since January 2022 (n=270).

An undetectable viral load (HIV RNA) was defined as less than or equal to 200 copies/mL as per BHIVA guidelines. Viral load data are also presented as less than or equal to 50 copies/mL and less than or equal to 400 copies/mL.

Immunological status was classified as Stage 1, Stage 2, or Stage 3, based on the CDC paediatric HIV CD4 cell count infection categorisation.

- For children less than 1 year of age:
  - Stage 1 = CD4 cell count ≥ 1,500 cells per mm^3
  - Stage 2 = CD4 cell count < 1500 and ≥ 750 cells per mm^3
  - Stage 3 = CD4 cell count < 750 cells per mm^3
- For children aged 1 year to less than 6 years:
  - Stage 1 = CD4 cell count ≥ 1,000 cells per mm^3
  - Stage 2 = CD4 cell count < 1000 and ≥ 500 cells per mm^3

    - Stage 3 = CD4 cell count < 500 cells per mm^3
- For children and young people older than 6 years of age:
    - Stage 1 = CD4 cell count ≥ 500 cells per mm^3
    - Stage 2 = CD4 cell count < 500 and ≥ 200 cells per mm^3
    - Stage 3 = CD4 cell count < 200 cells per mm^3.

BMI status is determined using a child's most recent height and weight to calculate z-scores with WHO Growth Reference data. The following cut-offs were used.

- Overweight: >+1 to ≤2 SD (standard deviation) (equivalent to BMI 25 kg/m2 at 19 years)
- Obesity: >+2 SD (equivalent to BMI 30 kg/m2 at 19 years)
- Normal: ≤+1 SD and ≥-2 SD
- Thinness: <-2 SD

CHARS largely collects the same data that was routinely collected by CHIPS. CHARS also requests data to support work on inequalities, including issues identified by clinicians with ART adherence and engagement with clinical services, as well as whether there are safeguarding concerns/social services involvement. Forms which show data collected by CHARS (baseline and follow up) and CHIPS (baseline and follow up) are available online.

2. Children and young people living with HIV reported to CHIPS and/or CHARS since 2000: overview

Overall, 1,532 children and young people living with HIV in England have been monitored by CHIPS and/or CHARS since 2000 (when CHIPS was established).

The number of those in active paediatric care increased until around 2009 and has decreased subsequently (Figure 2). Figure 3 shows the age distribution of all people ever reported to CHIPS or CHARS, by year; over 80% are now thought to be 20 years of age or older.

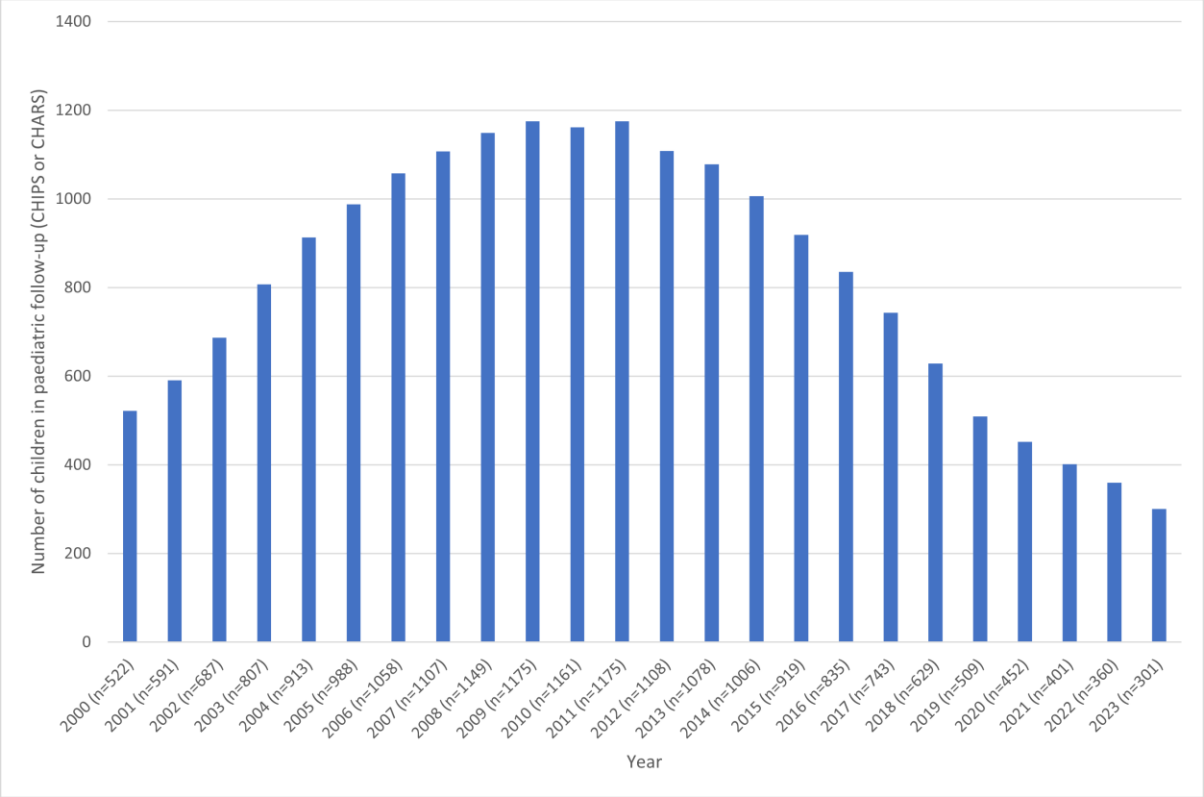

Figure 2. Numbers of children and young people in England with HIV diagnosed in childhood in active paediatric care by year, 2000-2023

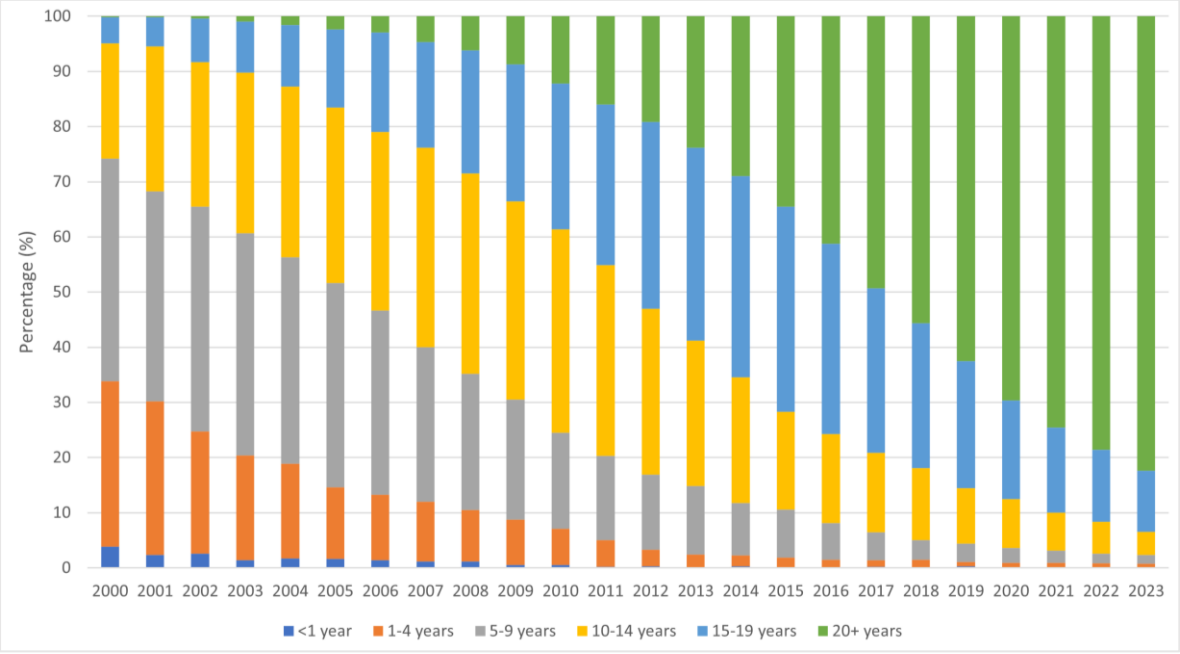

Figure 3. Age distribution of people in England with HIV diagnosed in childhood (n=1,532), 2000-2023

Data are for all children and young people who ever presented to medical services in the England, including children who have since transferred to adult care. CHARS does not collect outcome data (e.g. deaths or lost to follow-up) for those who have transferred to adult care. All paediatric patients are included, from date of first presentation to paediatric HIV services in the UK, regardless of mode of HIV acquisition. Those who died or

moved abroad while in paediatric care are included up until the year of death or year they left the country. Data for 2022/23 are incomplete as subject to reporting delay.

3. Follow up status of all children and young people living with HIV reported since the launch of CHARS

Since its launch, CHARS has collected data on 481 children and young people living with HIV in England, 436 were from CHIPS (representing all still in paediatric care when CHIPS ended) and 45 were newly reported to CHARS since CHIPS ended. Of these 481 children and young people, 301 remain in active paediatric care (as described in previous sections). Of the remaining 180, 171 transferred out of paediatric care, 8 were known to have left the country, and 1 was lost to follow up (Figure 4). No deaths have been reported among children and young people living with HIV in paediatric follow-up in England since the start of CHARS. Follow-up status by age group is shown in Figure 5.

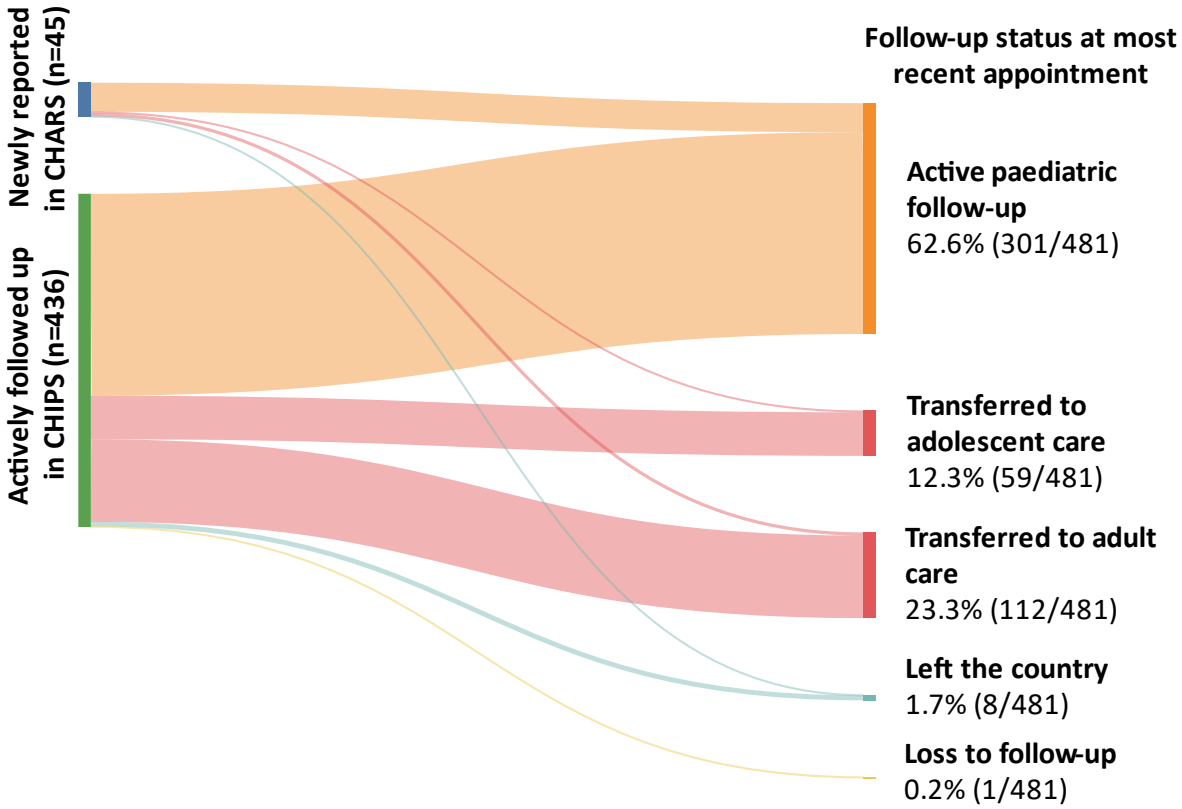

Figure 4 Most recent follow up status of all children and young people reported to CHARS

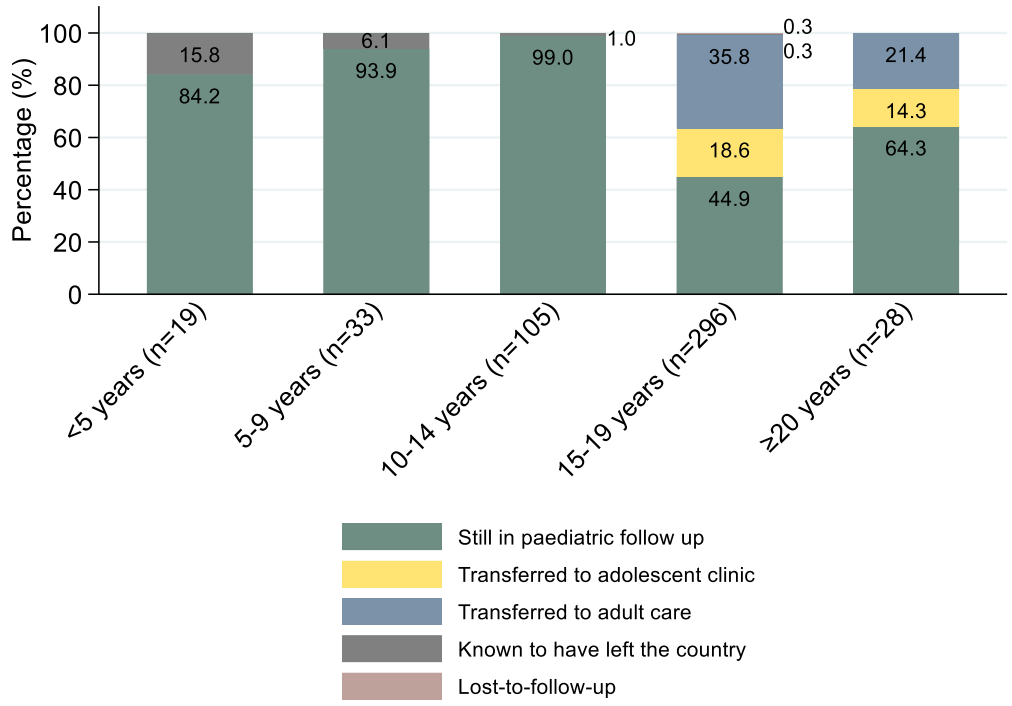

Figure 5. Most recent follow-up status by age group (age at most recent follow-up)

4. Children and young people living with HIV in active paediatric care

There were 301 children and young people in active paediatric care at last report to CHARS (i.e., excluding those who have died, been lost to follow-up, left England or transferred to adult care). Of these, 270 (89.7%) were last followed up and reported to CHARS in the period since January 2022, with the remainder seen in 2021 (mainly last quarter 2021) at last report to CHARS. Most (94.6%, 281/301) had a face-to-face appointment at their most recent reported follow-up, while 12 had a telephone appointment, 1 a virtual appointment and 3 had another appointment type (including home visit).

4.1 Regional distribution

The majority of the 301 children and young people were receiving HIV care in London (144/301, 47.8%), followed by the Midlands (81/301, 26.9%), and the North West (32/301, 10.6%) (Figure 6). There were some differences in the age group for each region, although in all regions apart from the South West the majority were aged 10-19 years (Figure 7).

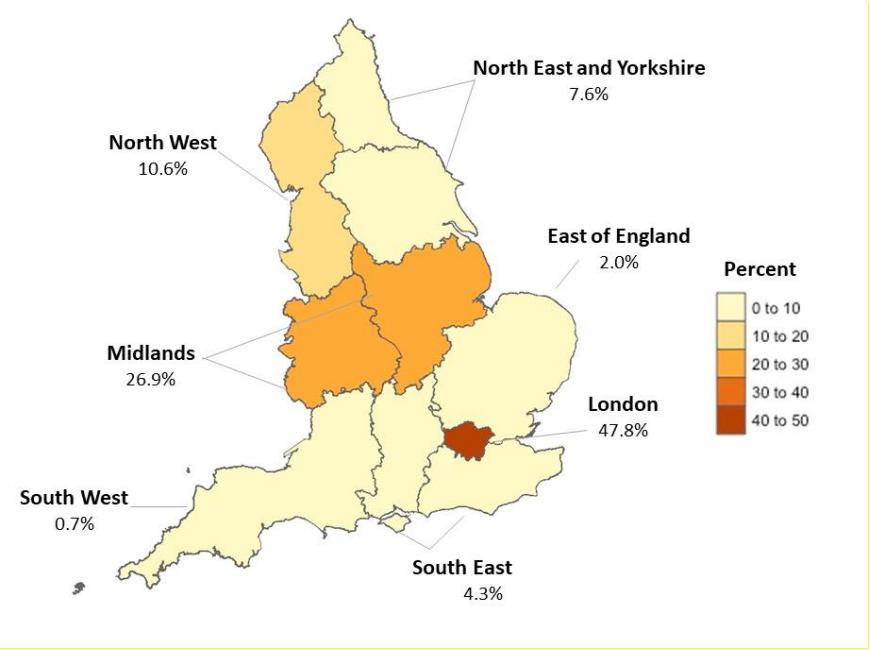

Figure 6. Distribution of main follow-up clinic for 301 children and young people in active paediatric care, by NHS England region

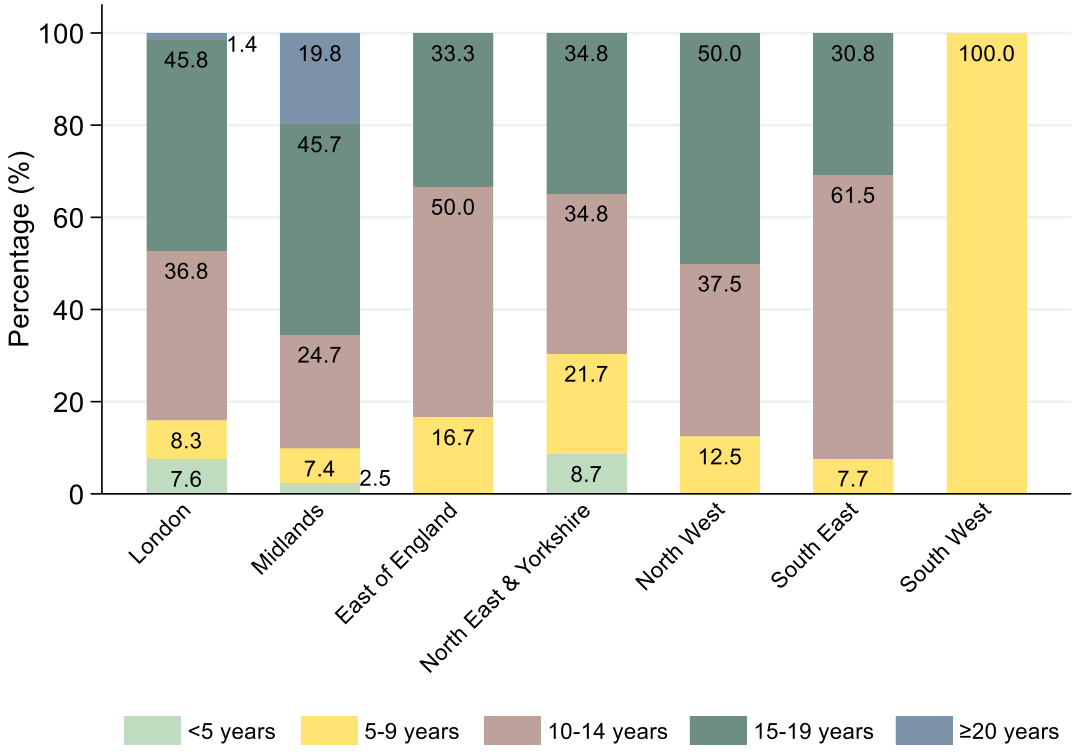

Figure 7. Regional distribution of 301 children and young people in active paediatric HIV care by age at last reported follow-up

4.1.1 Shared care

Of the 301 children and young people in paediatric care, 13.0% (39/301) were in shared care, meaning that they received care at more than one clinic, one of which is a main reporting clinic to CHARS. Most of these were attending shared care clinics based in London (46.2%, 18/39), followed by the South East (20.5%, 8/301), and the East of England (12.8%, 5/301) (Table 1).

Table 1. Region of shared care

Region of shared care		
	Number	%
Denominator	39	100.0%
London	18	46.2%
South East	8	20.5%
East of England	5	12.8%
North East and Yorkshire	3	7.7%
Midlands	3	7.7%
North West	1	2.6%
Scotland	1	2.6%
Wales	0	0%

4.2 Demographics and circumstances around diagnosis

Of the 301 children and young people, 159 (52.8%) were female and 175 (58.1%) were born in the UK or Ireland (Table 2). Many of those still in paediatric care were in their late teens, aged 15 to 19 years (44.2%), and the age distribution was similar between UK/Ireland-born and those born abroad. Of 126 born abroad, 93 (73.8%) were from Africa; 19 (15.2%) were born in Zimbabwe, 15 (12.1%) in Nigeria, and 8 (6.5%) in Uganda. Five (4.0%) were from Eastern Europe. Most were of Black African ethnicity (74.8%). Fifty-one per cent (53/104) of those born abroad were known to be diagnosed before arrival in the UK.

The majority (93.7%, 282/301) of children and young people were reported as having acquired HIV vertically, with only two (0.7%) having known non-vertical acquisition and a further 17 (5.7%) having unknown mode of acquisition. Sixty-nine (22.9%) were identified through their mothers' maternal screening in pregnancy and 94 (31.2%) were identified due to the child being symptomatic, though how HIV was identified in the child was unknown for 123 (40.9%) children and young people.

Table 2. Demographics and circumstances around diagnosis among 301 children and young people in active HIV care, by place of birth

	Total	**Born in UK or Ireland**	**Born abroad**
Denominator	301	175	126
Median age at diagnosis (years) [IQR]	1 [0-4]	0 [0-1]	4 [2-8]
Median age at diagnosis in the UK (years) [IQR]	2.1 [0.3-6.5]	0.5 [0.2-1.8]	6.6 [3.5-10.6]

Median age at last reported follow-up (years)	15 (11-16)	14 (11-16)	15 (11-16)
Age at last reported follow-up (years)			
<5	15 (5.0%)	12 (6.9%)	3 (2.4%)
5-9	31 (10.3%)	16 (9.1%)	15 (11.9%)
10-14	104 (34.6%)	61 (34.9%)	43 (34.1%)
15-19	133 (44.2%)	78 (44.6%)	55 (43.7%)
≥20	18 (6.0%)	8 (4.6%)	10 (7.9%)
Sex			
Male	142 (47.2%)	80 (45.7%)	62 (49.2%)
Female	159 (52.8%)	95 (54.3%)	64 (50.8%)
Ethnicity (n=298)			
White	21 (7.0%)	16 (9.1%)	5 (4.1%)
Asian	7 (2.3%)	1 (0.6%)	6 (4.9%)
Black African	223 (74.8%)	127 (72.6%)	96 (78.0%)
Any other Black background	7 (2.3%)	5 (2.9%)	2 (1.6%)
Mixed	37 (12.4%)	25 (14.3%)	12 (9.8%)
Other	3 (1.0%)	1 (0.6%)	2 (1.6%)
Mode of HIV acquisition			
Other	2 (0.7%)	0 (0.0%)	2 (1.6%)
Vertical	282 (93.7%%)	175 (100.0%)	107 (84.9%)
Unknown	17 (5.7%	0 (0.0%)	17 (13.5%)
Timing of maternal HIV diagnosis			
Before pregnancy	32 (10.6%)	27 (15.4%)	5 (4.0%)
During pregnancy	35 (11.6%)	31 (17.7%)	4 (3.2%)
Postnatal	195 (64.8%)	114 (65.1%)	81 (64.3%)
Unknown	39 (13.0%)	3 (1.7%)	36 (28.6%)

4.3 Antiretroviral treatment of children and young people in active paediatric care reported to be followed up since January 2022

The next sections on ART, viral load, immune status, and other clinical outcomes focus on children in active paediatric care, where a CHARS report has been submitted recently (i.e. since January 2022). Of 301 children and young people in active paediatric care at last reported visit, 270 had a report since January 2022.

Overall, 98.5% (266/270) of children and young people were on ART at their last appointment. Of the four not on treatment, two were ART naive and two were reported to have interrupted their treatment. Of the two ART naïve children, one was diagnosed in 2022; the other was diagnosed in 2010 and was not on ART due to patient choice (elite controller reviewed with regional hub annually).

Of those on ART, the majority (96.3%, 256/266) were on a ≥3 drug regimen, with ten on a 2 drug regimen (Figure 8). INSTI-based regimens were the most common, with Triumeq (ABC+3TC+DTG) accounting for 31.6% (81/256) of the ≥3 drug regimens. ART adverse events were reported for 0.8% (2/266) of children and young people between their most recent follow-up and the previous follow-up (one event in 2020 and the other in 2022).

Patterns of ART by drug class varied by age, with a higher proportion on PI-based regimens in the older age groups (Figure 9).

Since 2023 CHARS have been collecting data on ART resistance and treatment failure and will include insights from this in future reports.

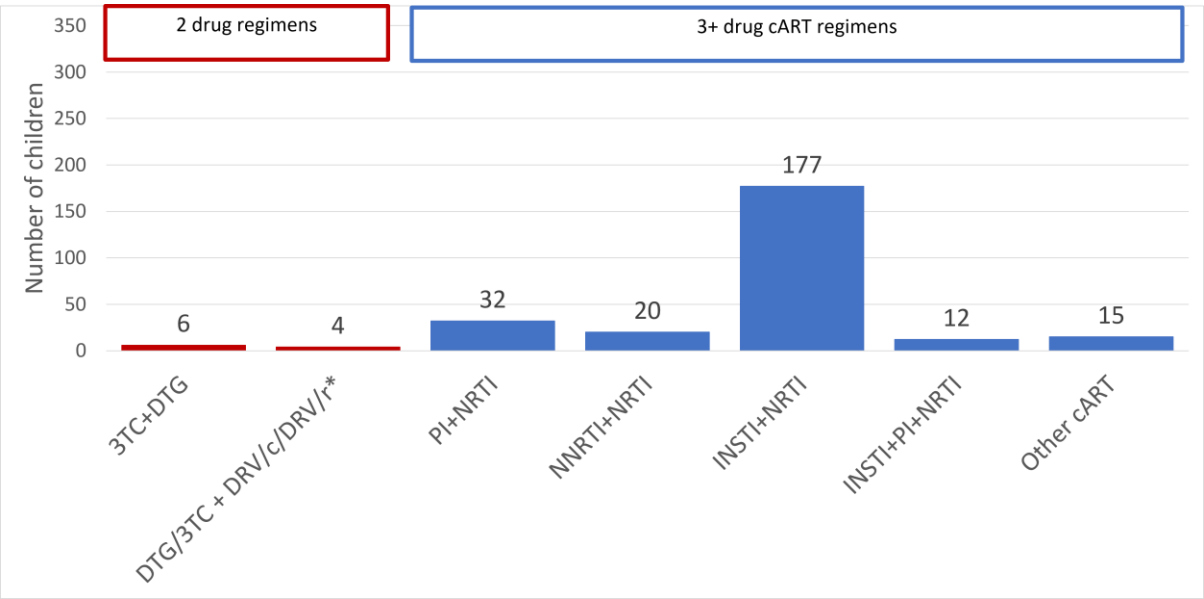

Figure 8. ART regimen at last reported follow-up (Jan 2022 – June 2023) among 266 children and young people on ART

*Ritonavir and Cobicistat, included as booster drugs as part of a combination with DTG or 3TC and DRV, were not counted as individual drugs.

"Other cART" regimens include NRTI+NtRTI+INSTI, NRTI+NNRTI+NtRTI, NRTI+PI+NtRTI+INSTI, NRTI+NNRTI+PI+NtRTI, and NRTI+NNRTI+PI+NtRTI

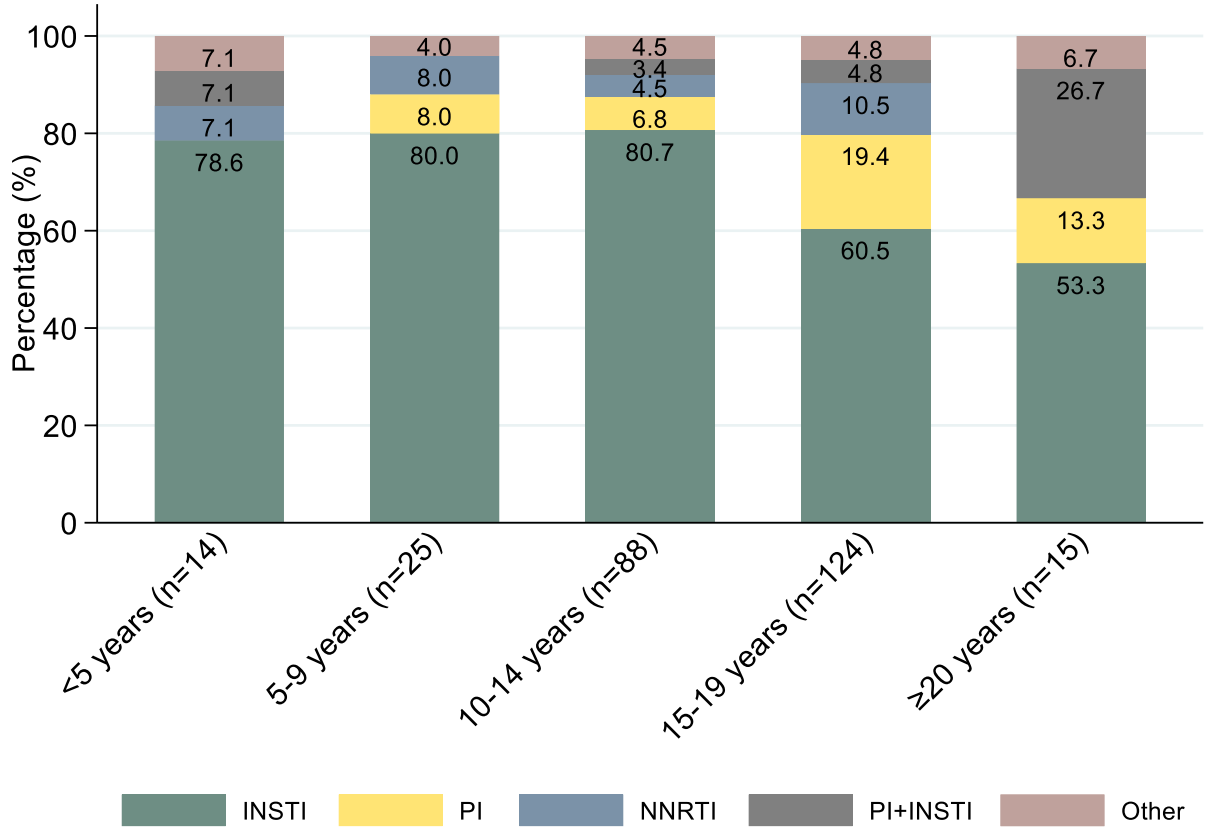

Figure 9. Current anchor drug class reported since January 2022 among 266 children and young people on ART, by age group

"Other" group includes INSTI+NtRTI, NNRTI+NtRTI, INSTI+NtRTI+PI, INSTI+NtRTI+NNRTI, and NtRTI+PI+NNRTI

4.4. Viral suppression among children and young people in active paediatric care reported to be followed up since January 2022

Of 270 children and young people, 97.8% (264/270) had a viral load result available. For the majority of these children, viral load had been measured since January 2022, but for five of these individuals, most recent results in the second half of 2021 were used. Of four children not on ART, the two on a treatment interruption had an undetectable viral load at their most recent clinic visit, while the two ART naïve children had detectable viral loads (greater than 400 copies/ml, but less than 1000 copies/ml).

Overall 93.5% (243/260) of children and young people on ART with viral load data had an undetectable viral load ≤200 copies/mL, 1.2% of children (3/260) had a low detectable viremia (viral load between >200-≤400 copies/ml), 1.2% (3/260) had a viremia between >400-≤1000 copies/ml, and 4.2% (11/260) had viral loads greater than 1000 copies/ml. Patterns of viral suppression by age group are presented in Figure 10. Suppression ≤200 copies/mL was around 95% across those aged 5 to 14 years, and lower (93%, 93%, 83%) in those aged <5, 15-19, and≥20 years respectively.

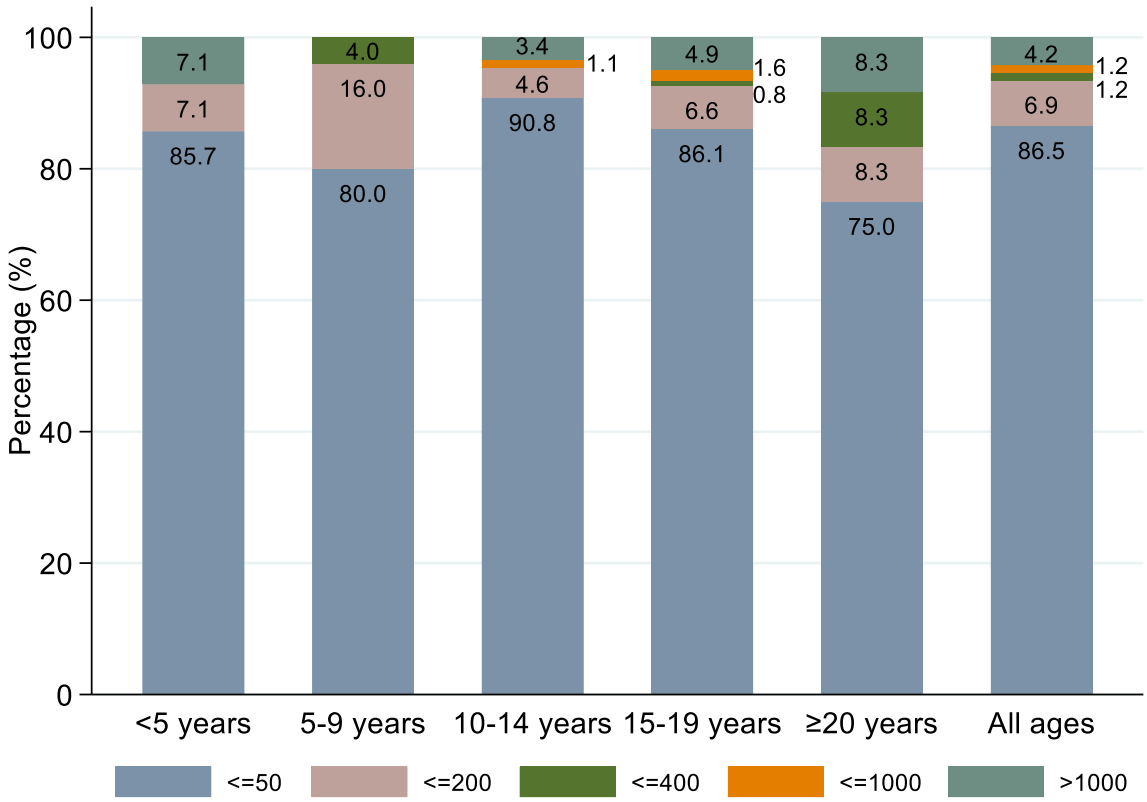

Figure 10. Most recent viral load among 260 children and young people on ART, by age group

4.5 Clinical and immune status among children and young people in active paediatric care reported to be followed up since January 2022

Of 270 children and young people, 95.9% (259/270) had a CD4 count measurement recorded since January 2022. In terms of immune status classification at most recent measurement, 81.9% (212/259) were in Stage 1 based on age-specific CD4 counts, 16.2% (42/259) were in Stage 2, and 1.9% (5/259) were in Stage 3. All of those in Stage 3 were aged 15 years or older (Figure 11). The 259 children and young people included one on an ART interruption and two who were naive, all of whom had a Stage 1 immune classification.

New CDC Clinical Stage B/C events were reported for 4.9% (13/267) at their most recent reported follow-up (i.e., diagnosed since the previous reported follow-up visit).

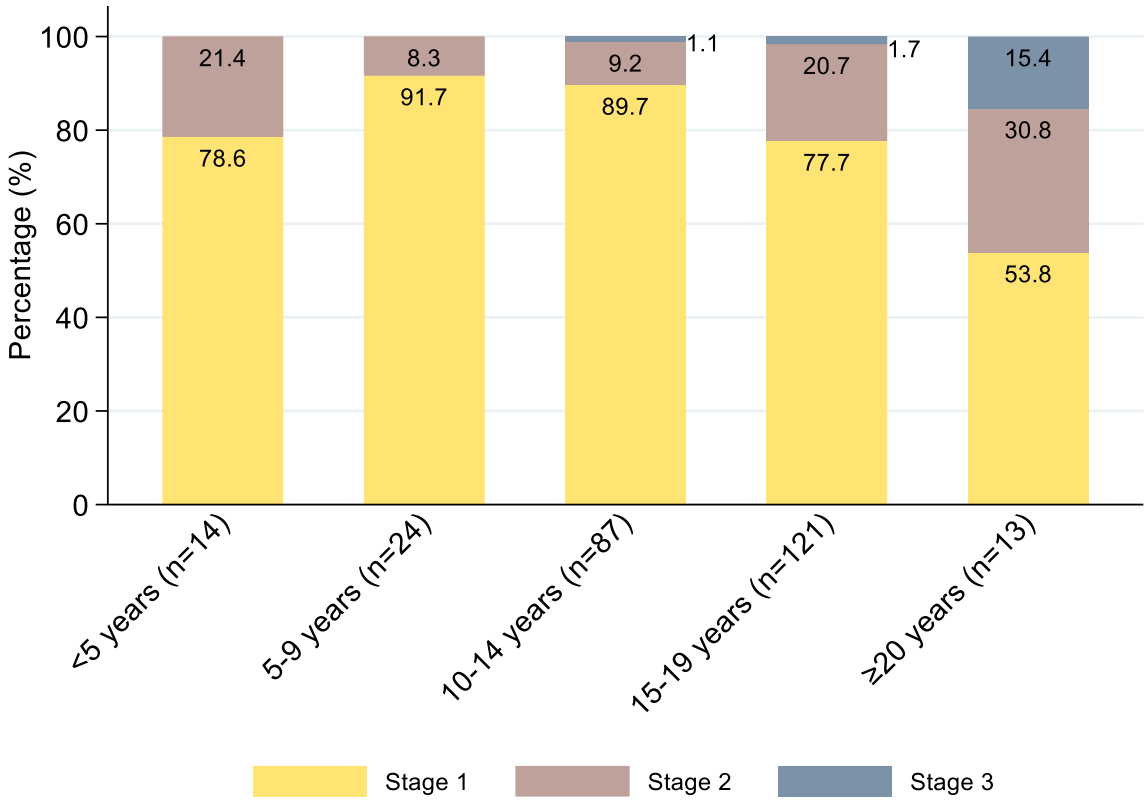

Figure 11. Immune status among 259 children and young people in paediatric HIV care by age group, based on most recent age-specific CD4 cell count

4.6. Other routine health measurements among children and young people in active paediatric care reported to be followed up since January 2022

BMI information was available for 83.0% (224/270) children and young people. Of these, at most recent measurement, 55.4% (124/224) were classified as having a normal BMI, 21.9% (49/224) had an overweight BMI, and 21.9% (49/224) were obese based on WHO reference groups. Two (0.9%) were classified as having thinness.

Where information was available, 15.5% (41/265) of children and young people were tested for hepatitis C, and all tests were negative (100%). 28.6% (76/266) were tested for hepatitis B (exact markers not collected), and among these, 1.3% (1/76) tested positive, and one child had an equivocal result. The remainder (74/76, 97.4%) tested negative.

Of 108 children and young people with known COVID-19 vaccination status, 46.3% (50/108) were vaccinated against COVID-19. Of 138 with known COVID diagnosis status, 42.0% (58/138) reported a current or previous COVID-19 diagnosis.

4.7. Hospital admissions among children and young people in active paediatric care reported to be followed up since January 2022

Overall, 9.4% (25/267) of children and young people were known to have one or more hospital admissions between their most recent reported follow-up and the reported follow-up prior to that, representing a rate of 6.7 per 100 person-years. Of these admissions, one (4.0%) admission was related to HIV seroconversion illness in a newly diagnosed child, three (12.0%) were related to support with ART adherence, and the rest were other causes, including injuries, mental health, and other infections.

5. Children and young people living with HIV newly diagnosed since 1 January 2020

Thirty-six children and young people were newly diagnosed in England with HIV between 1 January 2020 and 30 June 2023. Median age at last reported follow up of these newly diagnosed children was 10 [IQR: 3-15] years. Of the 36, 10 (27.8%) were diagnosed in 2020, 14 (38.9%) in 2021, 11 (30.6%) in 2022, and 1 (2.8%) in 2023. Twenty-seven of 36 were born abroad, of whom 19 (70.4%) were also diagnosed abroad prior to arrival in England and all 19 started ART while abroad.

The majority of new diagnoses (33/36, 91.6%) were still in active paediatric care, two transferred out of paediatric care and one was known to have left England. Just over a quarter (27.8%) of the newly diagnosed children and young people were aged less than 5 years at diagnosis in the UK, 22.2% were 5 to 9 years, 33.3% were 10 to 14 years, and the remainder (16.7%) were 15 or 16 years old.

All 36 newly diagnosed children and young people had a viral load result available, and 86.1% (31/36) were undetectable (less than 200 copies per mL) at their most recent reported follow-up visit. Among 34 newly diagnosed children and young people with known immunological status, 73.5% (25/34) were classified as having Stage 1 HIV infection, based on age-specific CD4 count, while 26.5% (9/34) were classified as having Stage 2. None of the newly diagnosed children were classified as having Stage 3 infection. At the time of last reported follow-up visit 35/36 (97.2%) were on ART. Information was not available about why one child was not on ART.

Of the 17 children and young people who were reported to have not been previously diagnosed with HIV prior to their first diagnosis in England, 76.5% (13/17) were undetectable (viral load less than 200 copies/mL) and 75.0% (12/16) were classified as having Stage 1 immune status at their most recent reported follow-up.

6. Transition out of paediatric care

There were a total of 171 children and young people who were reported to have transferred out of paediatric care since last report to CHIPS and median age at transfer was 18 years [IQR: 17, 18]. The proportion of those who have transferred by region is presented in Table 3. The South West had the highest proportion

transferring (88.2%). This region now has very few children and young people remaining in active paediatric care (section 4.1).

Table 3. Proportion of children and young people transferring out of paediatric care among all 481 children reported to CHARS in 2022-2023

Region	Denominator	Number	Percent transferring out of paediatric care
London	220	69	31.4%
Midlands	104	22	21.2%
East of England	15	8	53.3%
North East and Yorkshire	57	34	59.6%
North West	49	17	34.7%
South East	19	6	31.6%
South West	17	15	88.2%
All of England	481	171	35.6%

Overall, 73.1% (125/171) had viral load measurements reported to CHARS at their last paediatric visit before transfer, and 62.6% (107/171) had CD4 count measurements (Table 4). At transition, 84.0% (105/125) had undetectable viral load (≤≤200 copies/mL) and 66.4% (71/107) were classified as having Stage 1 infection based on age-specific CD4 counts. Future linkage to HARS datasets will allow greater insights into the impact of transition into clinical care.

Table 4. Clinical markers at transfer out of paediatric care among children and young people with HIV in England

	Total
Denominator	171
Median age at transfer (years) [IQR]	18 [17-18]
Immunological status at transfer* (n=107)	
Stage 1	71 (66.4%)
Stage 2	31 (29.0%)
Stage 3	5 (4.7%)
Viral load status at transfer (n=125)	
≤50 copies/mL	84 (67.2%)
>50 & ≤200 copies/mL	21 (16.8%)
>200 & ≤400 copies/mL	2 (1.6%)
>400 copies/mL	18 (14.4)

7. Pregnancies reported to CHARS in 2022-2023

Of 222 females reported to CHARS in 2022-2023, 8 (3.6%) were pregnant in their most recent reported follow up. Of these 8 women, 6 were aged 15 to 19 years old, and 2 were 20 years or older. Two women were still in active paediatric care and last reported to CHARS in 2022. The remaining 6 women have transferred out of paediatric care.

Two pregnancies resulted in termination, three resulted in live births, and three resulted in stillbirth. Of these 8 women, 7 acquired HIV vertically. ISOSS collects further information on these pregnancies and has recently looked at greater detail at pregnancies to women with vertically acquired HIV. Findings show that these women are more likely to deliver with a detectable viral load compared to pregnant women that did not acquire HIV vertically.

8. Metrics

As part of indicators reported to NHS England, the following outcomes were observed across all children and young people living with HIV in active paediatric care reported to CHARS since January 2022 in England (n=271). Some outcomes are limited to those newly diagnosed in 2021 (n=6). These data are presented for those diagnosed in England in 2021 only, because these children and young people had complete follow-up data for the 12 months following diagnosis.

- Immune status
    - Immune status of newly diagnosed children and young people: 6 of 6 (100%) children and young people newly diagnosed in England in 2021 had a Stage 1 immune status based on age-specific CD4 cell counts.
    - Immune status of all children and young people in active paediatric care since January 2022: 212 of 259 (81.9%) in active paediatric care since January 2022 had a Stage 1 immune status based on age-specific CD4 cell counts.
- Viral load
    - Viral load of newly diagnosed children and young people: 6 of 6 (100%) children and young people newly diagnosed in England in 2021 had an undetectable viral load (≤200 copies/mL) within 12 months after diagnosis.
    - Viral load of all children and young people in active paediatric care since January 2022: 245 of 264 (92.8%) in active paediatric care since January 2022 had an undetectable viral load (≤200 copies/mL).
- ART
    - ART status of newly diagnosed children and young people: 6 of 6 (100%) children and young people newly diagnosed in England in 2021 were on ART within 12 months after diagnosis.
    - ART status of all children and young people in active paediatric care since January 2022: 266 of 270 (98.5%) in active paediatric care since January 2022 were on ART.
- Mortality

- No deaths have been reported for any children and young people in paediatric care reported to CHARS since 2016 (according to final CHIPS report). Due to changeover in reporting between CHIPS and CHARS, it could be that there is a reporting delay for deaths. CHARS does not collect information on deaths after transfer to adult or adolescent care.

9. Summary and next steps

The number of children and young people living with HIV in active paediatric care remains low and has been declining over time, reflecting robust antenatal HIV screening and effective clinical management of those diagnosed in pregnancy, both in England and abroad. Most children and young people reported to CHARS remain in active paediatric care, though approximately 1/3 have transferred to adolescent or adult care. Very few have left the country or been lost to follow up. Almost half of those in active paediatric HIV care were born abroad, and almost all acquired HIV vertically. Nearly all children and young people are on some form of ART, with Triumeq as the most commonly reported regimen. Clinical markers among children and young people living with HIV in England are reassuring with nearly 90% virologically suppressed and 80% with Stage 1 immune status.

Since January 2020, there have been only 36 new diagnoses in children and young people in England. Of these children, 87% now have undetectable viral loads and 97% are on ART. No paediatric deaths have been reported to CHARS. National surveillance of the increasingly small number of children and young people accessing paediatric HIV care remains vital to ensure the unique needs of this population are met.

Most of the children and young people in CHARS follow up are teenagers (median age of 16 years). As most of this population will be transferring out of paediatric care, ongoing work is required to understand any challenges relating to retention in care across the transition period and inti adult care. CHARS will continue to monitor key areas of interest. These include measuring inequalities such as social services or safeguarding involvement, as well as issues engaging with healthcare. Additionally, the plan is for CHARS data to be linked to HARS in the future to allow further analysis of the cohort of children and young people transferring out of paediatric care, to measure and identify any issues in continuum of care. Further, NHS England is working towards CHARS data being made available for research purposes within the first quarter of 2024, and this will allow more detailed analyses of the health outcomes of children living with HIV, and ART drug safety, including by the European Pregnancy and Paediatric Infections Cohort Collaboration (EPPICC).

National surveillance carried out by CHARS provides valuable insights into the cohort of children and young people in paediatric HIV care in England to inform

guidelines, including the revised Chiva Standards of Care. CHARS will continue to publish annual reports summarising those children and young people in paediatric HIV care.

Acknowledgement

Achievement of this completeness of 2-3 years' worth of catch up data required a significant contribution to CHARS reporting by clinicians across England committed to maintaining the care and surveillance of children living with HIV. The CHARS team greatly acknowledge this collective effort.