



Guideline on Transition for Adolescents Living with HIV

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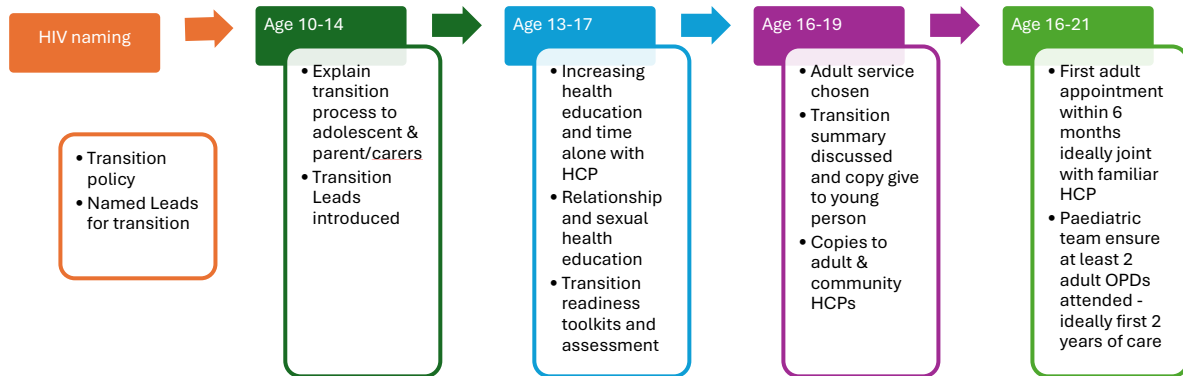
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Summary

Transition from paediatric to adult care is a process over many years with movement through the stages of transition taking into consideration of both developmental stage and chronological age of a young person (summary figure 1).



When to start transition from paediatric to adult care:

- Transition preparation for the young person and their family should begin during the primary school years, when the young person is fully aware of their HIV diagnosis, and should progress through adolescence
- It is a gradual process at a variable pace according to the needs and wishes of the young person

Each young person should have an individualised care/transition plan documented in their notes outlining:

- Date of naming of HIV
- Knowledge of HIV and confidentiality
- Opportunity to be seen alone
- Health promotion and sexual health discussions
- Peer support offered and uptake

Care following transition:

- The paediatric team should ensure that the young person is well engaged in adult services for a minimum of 12 months following transfer of care before formally discharging them. Longer involvement may be needed for complex cases.
- Data suggest that those young people with poor adherence in the later years of paediatric care and who enter adult services with virological failure and lower CD4 counts, are the most at risk of disease progression and death in the years following transfer.

Introduction

Following the introduction of antiretroviral therapy (ART), perinatally acquired HIV infection (PaHIV) has become a chronic condition of childhood.

Whilst the majority of individuals born with HIV who have ever received paediatric care in the UK have already transitioned into adult services, transition is ongoing for adolescents born in more recent years. This guideline outlines the management of transition for this population with transition defined as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems.”¹

Epidemiology

Virtually all children diagnosed with HIV living in the UK were followed prospectively in the Collaborative HIV Paediatric Study (CHIPS) until January 2022 when reporting moved to the Children’s HIV and AIDS Reporting System (CHARS) commissioned by NHS England and therefore only covers children and young people receiving paediatric care in England.² Between January 2000 and January 2025, 1,569 children and young people living with HIV in England have been monitored by CHIPS and/or CHARS, 80% of whom are now aged over 20 years and have transitioned to adult care.³

The number of children in paediatric care in England (approximately 300) has remained constant since 2023, with the number of adolescents transitioning to adult services matched by the number of new children and young people entering paediatric care.³ The last reported death in a child living with HIV in paediatric care was in 2016, with deaths in individuals with PaHIV reported post transition to adult services.³

Of the 302 children and young people in paediatric care in January 2025, 167 (55.3%) were female and 136 (45.0%) were born in the UK or Ireland. Most were of black African ethnicity (78.9%). Among those born abroad with available information 64% (99/153) were diagnosed before arrival in the UK.³ Overall, 87.7%, (265/302) were reported as having acquired HIV vertically, while nine (3.0%) had non-vertical acquisition and 28 (9.3%) had an unknown mode of acquisition. The majority of children and young people were receiving HIV care in London (134/302, 44.4%), followed by the Midlands (80/302, 26.5%).³

The current median age was 15.0 (IQR 12.0 17.0) years. Overall, 98% (299/302) were receiving ART and of those, 96% (287/299) were on triple therapy and 86% were based around an integrase inhibitor. Three were ART naïve. 90.7% (264/291) of children and young people on ART with viral load data had a viral load ≤ 200 copies/mL.

In total, 54 children and young people newly presented for paediatric HIV care in England between 1 July 2023 and 31 January 2025 at a median age of 10 [IQR: 3-15] years. Overall, 83% (45/54) were born abroad; of these 91.1% (41/45) were already diagnosed prior to arrival in the

UK.³ Two young people presented as late diagnoses, with missed opportunities for HIV testing in UK healthcare settings.⁴ During the same time period, 57 young people transitioned to adult services at a median age of 17 years (IQR 17-18), 85.1% (40/47) had a viral load ≤ 200 copies/mL and 92.7% had a CD4 > 350 cells/ μ L.³

Post-Transition Outcomes

Whilst the process of transition from paediatric to adult care is recognised as a period of increased risk of disengagement from healthcare, evidence suggests that poor disease control during the final years of paediatric care is the main predictor of HIV-associated morbidity and mortality following transfer to adult care.⁵⁻⁸ Last CD4 count, prior CDC Category C diagnoses and viral suppression exiting paediatric care predict outcomes following transition.⁵⁻⁸

However, with many adults with PaHIV now in their 30s, there is an increasing recognition of HIV-associated morbidity and mortality well beyond the post transition period.^{7,9-13} Whilst adherence to ART has improved over time, rates of viral suppression remain lower in both the paediatric cohort and young adults post transition to adult care than among adults in the UK. Recent data from England reports rates of viral suppression (< 200 c/mL) of 90% for those in paediatric care, 96% for young people aged 15-24 years and 99% in adults in older age groups.^{3,14}

Extensive published data exist on the experiences and outcomes for those who have transitioned to adult services, although there are fewer randomised controlled trials of interventions to improve transition outcomes.¹⁵⁻²¹ Two common models of transitional care are described, (1) integrating transitional services into paediatric or adult clinics or (2) designing and utilising a special adolescent clinic facilitating transition from paediatric to adult healthcare providers.¹⁵⁻²¹

Qualitative evidence suggests that both approaches can be effective, as measured by retention in care on suppressive ART, high numbers of successful transitions to adult services and patient and carer satisfaction.¹⁵⁻²¹ A recent Chiva audit of 24 adult and 17 paediatric services in the UK highlighted wide variation in transitional care services, particularly in relation to routine mental health screening, access to psychology and the digitalisation of patient resources.²⁰

Psychosocial, Medical and Sexual Health and Relationship Considerations

Adolescents living with HIV have additional complex psychological stressors and medical and sexual health needs that potentially impact throughout adolescence, transition and into adult care.

1. Psychosocial Issues

- **Impact of HIV as a family disease:** historically almost half have lost one or both parents to HIV and may live without close parental role models as they grow through

adolescence.³ Others are young carers for parents with HIV associated morbidity and may have extended caring roles for younger siblings.^{7,13}

- **Stigma and secrecy** around HIV remains a major issue for many adolescents and their families; HIV is often not openly discussed within families. Some have adolescent siblings and other close family members who do not know of the HIV diagnoses within the family.²²⁻²⁴ Many adolescents have never shared their status with anyone and hence cannot access support from their peers and wider family.²²⁻²⁴
- **Diagnosis in adolescence:** a small proportion of children born with HIV may remain asymptomatic for many years and are diagnosed as adolescents/young adults, highlighting the importance of family screening of all children irrespective of age (August 2026: Chiva testing and “Don’t Forget the Children” guidelines are being updated- <https://www.chiva.org.uk/professionals/clinical-guidelines/>).^{4,25,26}
- **Migration:** half of those living with PaHIV in the UK were born abroad and adjusting to the cultural and social differences can be complex.³⁻⁵
- **Psychiatric morbidity:** some studies suggest higher levels of psychiatric morbidity, particularly depression and anxiety, in young people living with PaHIV when compared to the aged matched general population, although levels are often similar to those seen in siblings who were HIV-negative infants exposed to HIV, suggesting that the wider family and socioeconomic setting may be more influential than HIV per se.²⁷⁻²⁹ Rates of psychosis in young adults living with PaHIV are reported as being significantly higher (x6) than in the general population.³⁰

2. Medical Considerations

- **Neurocognitive** impact of living with HIV on the developing brain, particularly for those presenting with a CDC Category C diagnosis, including infantile HIV encephalopathy, results in a wide spectrum of learning difficulties with poorer school performance and difficulties in executive functioning.³¹⁻³³ The interplay of these complex factors, plus the period of adolescence itself, impacts on the ability of some young people to negotiate healthcare.
- **Adherence** to medication for chronic diseases is poorer in adolescence when compared to adherence in younger children or to older adults.³⁴ Adherence to ART improves over calendar time but remains poorer than in adults.³ Following transition to adult care, adherence rates are lowest in 15–24-year-olds. When disaggregated by route of transmission, youth with PaHIV have lower rates of ART uptake than their peers with horizontally acquired HIV.¹⁴ Effective interventions to improve adherence are required.³⁴⁻³⁶
- **Treatment experienced cohort:** half of UK adolescents are triple class experienced, however, second generation integrase inhibitors mean that almost all young people have the option of once daily single/dual tablet regimens.^{3,37} More than a third of young

people born after 2000 have acquired drug resistance to at least one drug class, most frequently to non-nucleoside reverse transcriptase inhibitors which considered a contraindication to long-acting cabotegravir and rilpivirine.³⁷ Any adolescent on an ART regimen consisting of more than two tablets once daily should be discussed at the perinatal virtual clinic to consider options for treatment simplification.³⁸

- **Side effects of prolonged exposure to PaHIV/ART:**
 - **Cardiovascular risk factors:** dyslipidaemia, altered glucose metabolism, inflammation and immune activation are increasingly reported and may be compounded in adolescence by weight gain, smoking, alcohol and recreational drug use.³⁹ Whilst the direct outcomes of cardiovascular risk are not apparent during adolescence, concern is growing for the possible effects in middle age.^{7,11} ART associated weight gain is predominantly a return to health phenomenon and traditional risk factors for obesity should be addressed.^{39,40}
 - **Bone health:** HIV is associated with delayed growth and puberty and reduced bone mineral density, and traditional risk factors should also be considered.^{41,42} All individuals living in England aged <25 years are eligible for tenofovir alafenamide which is preferred to tenofovir disoproxil fumarate due to improved bone and renal safety profile.^{43,44}
 - **Mortality and malignancy:** Despite advances in ART, mortality for youth living with PaHIV following transition to adult care is more than 10x the aged-matched UK population.^{4,7,45} Almost 1 in 10 young people experienced a new AIDS diagnosis and/or death within a median of three years post transition to adult care.⁴ Almost all deaths were due to HIV and associated with prolonged poor adherence to ART, but not due to multi-drug resistant untreatable virus. Data suggests a tenfold risk of malignancy when compared to aged-matched population data, driven by lymphomas.⁴⁶⁻⁵⁰ In addition to addressing traditional risk factors including optimising HPV and HBV vaccination and smoking avoidance/cessation, clinical vigilance for early diagnosis is required.^{51,52}

Further information: Chiva Good Practice Guidance. [Outcomes-for-Adults-Living-with-Perinatal-HIV.pdf](#)

3. *Relationships and Sexual Health*

- Adolescents born with HIV have to negotiate their first relationships with a sexually transmissible infection before they have ever had sex.⁵³
- A third of UK adolescents are sexually active by 16 years, and the age of coitarche in adolescents with PaHIV is similar to their peers.⁵⁴
- High rates of unplanned pregnancy reported in perinatal cohorts highlight the need for integrated sexual health and HIV services including contraception.⁵³⁻⁵⁶

- Sexual health promotion including Hepatitis B and HPV vaccination with sexual health education for adolescents should begin in paediatric services prior to coitarche, continue through transition and into adult services.^{57,58}
- Prior to the onset of sexual activity, adolescents need to be fully aware of “U=U” (undetectable = untransmittable) and the potential for future conception without risk of transmission to either a partner or future offspring.⁵⁹ Those struggling with adherence to ART and detectable viraemia require strategies to manage condom failure including: sharing HIV status with the partner; partner post exposure prophylaxis (PEP) and partner access to Pre Exposure Prophylaxis (PrEP).^{53,57,60}
- Adolescent relationships are often transient, within a close social group and therefore issues of sharing ones HIV status and maintaining confidentiality are complex.^{22,23,53,57} In addition, young people with PaHIV potentially risk both sharing their own status and that of their mother and other family members.^{22,23}

Further information: Chiva Sexual Health Guidance <https://www.chiva.org.uk/wp-content/uploads/2026/02/Sexual-Health-Guidance-Final.pdf>

Transition

NICE Guidance provides comprehensive recommendations for transitional care, supported by a wealth of Department of Health (DOH) guidance and resources.¹ In contrast, **transfer** is the physical event of moving from paediatric to adult services. In the absence of a well-planned transition process, transfer has been associated with increased morbidity and mortality, across many diverse chronic childhood diseases.^{5,7}

Different models of transition exist, and the model chosen is determined by the patient group, available resources and geographical setting. Whilst there is no superior transition model, the key to a successful transition is a flexible approach paced to the individual needs of the adolescent. From early adolescence, care should progressively move from a family-centred to a young person-centred model, supporting the development of skills and confidence needed for independent healthcare management. Individual care/transition plans, named transition leads within both the paediatric and adult healthcare team, use of peer/third sector support and meeting adult healthcare providers prior to the first appointment in adult services have all been associated with improved transition outcomes.¹⁵⁻²¹

Models of transition (see Figure 1)

- **Model 1 – Family clinics: integration:** Where adolescents living with HIV are cared for by Family Clinics, the transition to adult care can occur in an integrated fashion. Special clinic times within the Family Clinic can be set where adult HCPs are also present. The setting remains familiar, but the young person begins to take responsibility for their own health and have consultations with the care teams on their own. The time period for this transition depends on each young person and his or her readiness to take on this new responsibility.

- **Model 2 – Specialist services: handing over:** Where a family or adolescent clinic does not exist, the transition of care between paediatric to adult services is possible with a carefully planned and comprehensive transition programme. This may be the model suited to smaller centres; it works when paediatric and adult services fully understand the transition process and work together productively and facilitate joint consultations either in person or virtually.
- **Model 3 – Specialist services: separate youth clinic:** Creating a separate “youth friendly” clinic offers a tailor-made specialist clinic that has adolescents/young adults attending and taking responsibility for their own sexual and medical health needs, typically staffed by both paediatric and adult healthcare providers. However, such models may have a maximum age ceiling (e.g. 24 years) and young adults may require a further transition into adult services.

MODELS OF TRANSITION

Three pathway models to support adolescents and young people living with HIV to move from paediatric to adult care.



Setting up a multidisciplinary transition service

Effective implementation of any transition model requires **a named lead for transition in both paediatric and adult services**, to develop and maintain the multidisciplinary linkage. They may be a nurse, health advisor, psychologist, doctor or allied professional. It is important that the adult practitioner can continue to follow up the young person’s attendance and care in the years post-transfer. The numbers of young people with PaHIV may be extremely small

within much larger adult cohorts and multidisciplinary resources more limited. Involvement of the voluntary sector and the use of peer support can be extremely beneficial for some young people and can increase support through the transitional period. Chiva resources can be found at <https://www.chiva.org.uk/our-work/chiva-support/>.

When to start transition?

Transition preparation for both the young person and the family should begin during the primary school years, when the young person is fully aware of their HIV diagnosis, and should progress through adolescence. There may be circumstances which mean that exceptions occur and full naming of HIV is delayed, especially in children with neurocognitive delay. “All About Me” is a working tool that can support the process of transition, help establish readiness to transfer and offer a structure for building young people’s knowledge about HIV <https://www.chiva.org.uk/files/8215/5739/8393/AllAboutME.pdf>.⁶²

“Treat Me Like This” is a set of brief guidance documents developed in consultation with young people which shares their views on what they would like during the transition process. See the Tools Created with Young People section at: www.chiva.org.uk/tools

Each young person should have a documented individualised care/transition plan, including:

- Knowledge of HIV and confidentiality including timing of naming
- Assessment of capacity and documentation of any learning difficulty
- Documentation of being seen alone
- Sexual health discussions
- Peer support received/offered
- Young person’s views on choice of adult care centre
- Introduction to adult staff
- Joint meeting with staff if transferring to geographically separate service
- Contact with specialist services also requiring transition e.g. metabolic, ophthalmology, neurology, respiratory
- Discharge summaries – medical, psychology and nursing with a record of the up-to-date email, mobile, phone number, residential address and with documentation of permission to contact a relative in case of emergency or repeated non-attendance
- Documentation of the young persons’ permission for the paediatric team to remain in contact for a minimum of 12 months of adult care, and to receive relevant correspondence from the adult team throughout this period, to support successful integration within their new service.

Written/digital information about the local clinic’s transition services can help both young people and their carers see the way forward. For some parents who are currently seen in a family service, when their adolescent moves to adult services, they may too have to move healthcare setting as they no longer have a child within the family clinic.



Developing autonomy

Once a young person is fully aware of their HIV diagnosis, they can begin to spend time with health professionals alone allowing them to ask questions they may be less able to ask in front of parents/carers, either through embarrassment or fear of upsetting them. Initially, this period may be brief, with the parent/carer joining for the remainder of the consultation. However, the time spent alone with the young person should increase over time to encourage autonomy and self-management, both of which have been shown to have a positive impact on transition outcomes in other settings.¹⁵⁻²¹

The principles of confidentiality should be clearly explained to the young person and their parent/carer. The young person should also be made aware of who else, has been aware of their HIV status, such as the GP, with their parent's permission.

This one-to-one time with a healthcare professional is also an opportunity for education around relationships, sexual health and contraception, particularly in light of reports of high UK rates of unplanned pregnancy in this cohort despite access to healthcare services.^{53,55} This may be a good opportunity to introduce adult healthcare providers such as clinical nurse practitioners and health advisors to provide both education and to strengthen familiar links between paediatric and adult services for the young person.

Meeting the adult team

When appropriate for the individual, and after discussions and agreement between the young person, their parents/carers and the healthcare team, joint consultations with the paediatrician and the adult HIV doctor should begin. For adolescents attending a clinic a significant distance from home, plans for future adult care should be discussed, including whether care will continue at the current centre or be provided more locally. Consideration should be given to any future plans such as moving out of home for tertiary education, and to the feasibility of shared-care arrangements.

For individuals receiving medication by Home Delivery services; both the place of delivery and contact details need review, particularly for those planning to move out of home/care leavers.

Over time the adult doctor will increasingly lead consultations, with the pace of this transition tailored to the needs and readiness of the young person. Although the young person's doctor may no longer be the paediatrician, other paediatric team members e.g. the psychologist, clinical nurse specialist or peer educator may still be actively involved during the transition period.²⁰ The paediatric team should ensure that the young person is well engaged in adult services for a minimum of 12 months following transfer of care before formally discharging them. Longer involvement may be needed for complex cases.

Prior to transfer

A comprehensive review of the young person's history is an essential component of the transition process. As part of this process, it is good practice to encourage the young person to receive or have access to a copy of their discharge summary. Agreement should be reached with the young person on which health and social care professionals are permitted to receive a copy of the discharge summary and what confidential information can be included. Any further summaries e.g. psychological, dietetic, etc. can also be provided, with the adolescent's knowledge and consent.

The process of transition is likely to take several years with preparation starting at primary school age. The point of transfer should account for developmental maturity, readiness, neurocognitive ability, wishes of the young person, and may also be determined by service

provision or constraints. This typically results in transfer between 16 – 20 years of age, depending on locally available services e.g. provision of designated young adult clinic.²⁰

At the time of transfer, discharge summaries should include the following information:

- Contact details for young person
- Full name (and any previous or alias) / date of birth / present place of residence / family address (if different)
- Preferred route of contact: phone or mobile number / email
- Next of kin details and who can be contacted in case of loss to follow up post- transfer
- GP details
- Summary of medical history – birth history, any illnesses or infections, operations etc., including when first diagnosed HIV positive
- Any known allergies / HLA B5701 / Hepatitis B and C status / Haemoglobin electrophoresis
- Tanner stage / onset of menarche / recent weight and height/ BMI
- Vaccination record
- Summary of all past ART, reason for switch and current regime
- Additional medication
- Adherence history, treatment side effects
- Copies of all HIV resistance tests
- CD4 cell counts (including nadir) and viral loads
- Any relevant blood tests if abnormal (e.g. Lipids, HbA1C)
- Any other relevant investigations
- Any relevant past and present referrals, e.g. endocrine / cardiac
- Mental Health summary and whether full psychology summary attached
- Relevant social history, e.g. if parents/siblings have died / social care input / support networks. NB – be mindful of giving other family members details and information and maintain their confidentiality
- Peer support received/ongoing with worker details
- When they became aware of own HIV diagnosis and any issues surrounding this, including wider sharing with others
- Sexual and contraceptive history
- Alcohol, smoking and drug use
- Current educational and employment situation.

Copies of summary sent to:

- Young person (or legal guardian if the young person has significant learning difficulties)
- Adult HIV team
- GP
- Consultant lead managing comorbidities where appropriate

INFORMATION AT THE TIME OF TRANSFER

Essential information to be shared when transferring care to adult services



INFORMATION TO INCLUDE



1. Contact details for young person



2. Personal details

Full name (and any previous or alias) /
date of birth / present place of residence /
family address (if different)



3. Preferred route of contact

Phone or mobile number / email



4. Next of kin details

and who can be contacted in case of
loss to follow up post-transfer



5. GP details



6. Summary of medical history

Birth history, any illnesses or infections,
operations etc., including when first
diagnosed HIV positive



7. Key clinical information

Any known allergies / HLA B5701 /
Hepatitis B and C status /
Haemoglobin electrophoresis



8. Growth & development

Tanner stage / onset of menarche /
recent weight and height / BMI



9. Vaccination record



10. ART history

Summary of all past ART, reason for
switch and current regime



11. Additional medication

Including any regular or PRN medication



12. Adherence & side effects

Adherence history, treatment side effects



13. HIV resistance

Copies of all HIV resistance tests



14. HIV monitoring

CD4 cell counts (including nadir)
and viral loads



15. Relevant blood tests

Any relevant blood tests if abnormal
(e.g. Lipids, HbA1C)



16. Other investigations

Any other relevant investigations



17. Referrals

Any relevant past and present referrals,
e.g. endocrine / cardiac



18. Mental health

Mental health summary and whether
full psychology summary attached



19. Social history

Relevant social history, e.g. if parents/
siblings have died / social care input /
support networks.

*NB – be mindful of giving other family
members details and information and
maintain their confidentiality*



20. Peer support

Peer support received/ongoing
with worker details



21. Naming HIV

When they became aware of own HIV
status and any issues surrounding this
including sharing their status with others.



22. Sexual & reproductive health

Sexual and contraceptive history



23. Substance use

Alcohol, smoking and drug use



24. Education & employment

Current educational and employment situation

COPIES OF SUMMARY SENT TO



Young person
(or legal guardian
if the young person
has significant
learning difficulties)



Adult HIV team



GP



Consultant lead
managing comorbidities
where appropriate



Important: Ensure information is accurate, up to date and shared securely.
Obtain consent and explain how the information will be used.

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Appendix 1: National Transitional Care Guidance

- Transition from children's to adults' services for young people using health or social care services. <https://www.nice.org.uk/guidance/ng43/chapter/context>
- NHS England. Supporting young people to transition to adolescent and [adolescent-and-adult-services/](https://www.england.nhs.uk/long-read/supporting-young-people-to-transition-into-adolescent-and-adult-services/).
- Royal College of Paediatrics and Child Health (RCPCH) Transition to adult services <https://www.rcpch.ac.uk/resources/transition-adult-services>
- Royal College of Nursing. Children and Young People: Transition to adult services. <https://www.rcn.org.uk/library/Subject-Guides/children-and-young-people-transition-to-adult-services>
- Transition Information Network. <https://www.transitioninforonetwork.org.uk/>