



CHIVA Guidance on Transition for adolescents living with HIV

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Summary

When to start transition?

- Transition preparation for both the young person and the family can begin when an adolescent is fully aware of their HIV diagnosis
- It is a gradual process that goes at a different pace for different young people but should be centred around the needs and wishes of the adolescent

Each young person should have a documented transition plan in their notes outlining:

- Date of naming of HIV
- Knowledge of HIV and confidentiality
- Opportunity to be seen alone
- Sexual health discussions and literature given

Care following Transition:

- The paediatric team should ensure that the young person is well engaged in adult services for the first 12 months following transfer of care before formally discharging them.
- Increasing evidence suggests that those young people who have poor adherence in the later years of paediatric care and enter adult services with virological failure and lower CD4 counts are the most at risk of disease progression in the years following transfer.

Introduction

Following the introduction of combination antiretroviral therapy (ART), perinatally acquired HIV infection has become a chronic condition of childhood with increasing numbers of infected children entering adolescence and transitioning towards adult services. This guidance outlines the management of transition for this population, summarising and updating two previous resources.^{1,2}

Virtually all children diagnosed with HIV infection living in the UK have been followed prospectively in the Collaborative HIV Paediatric Study (CHIPS), although future reporting will be through the national Integrated Screening Outcomes Surveillance Service (ISOSS).³ Cohort data on over 2,200 children ever registered to CHIPS shows that by April 2021 almost 1400 adolescents had already transferred to adult care at a median age of 18 years.⁴ Approximately 100 adolescents have transitioned to adult care each year over the last 5 years with an average of 35 newly diagnosed children reported annually since 2015. As of the end of March 2021, a total of 489 patients, median age 14.8 (IQR 12.0-16.9) years were alive and in active follow-up at a paediatric clinic in the UK or Ireland.⁴ Of these, just over half (58%) were female, 53% were born in the UK or Ireland, 73% were of black African ethnicity, and nearly all (92%) were known to have been infected through vertical transmission. Forty-one per cent of children were being seen at clinics in London, 51% in the rest of England, 5% in Scotland, 2% in Wales, and <1% in Northern Ireland.⁴

Whilst the process of transition from paediatric to adult care has been shown to be a time associated with an increased risk of disengagement in healthcare, increasing evidence suggests that the main predictor of HIV- associated morbidity and mortality following transfer adult care is evidence of poor disease control during the final years of paediatric care.⁵⁻⁸ Last CD4 count, prior CDC Category C diagnoses and viral suppression exiting paediatric care predict outcomes following transition.^{9,10} Viral suppression recorded in CHIPS until 2018, for those aged ≥ 13 years on antiretroviral therapy (ART) was 88% HIV viral load (VL) <400 c/ml with 77% <50 c/ml.⁴ Whilst adherence to ART has improved over calendar time, rates of viral suppression in the paediatric cohort remain lower than in UK adults and fail to meet UNAIDS 90:90:90 targets.¹¹⁻¹³

Increasing published data exists on the experiences and outcomes for those who have transitioned to adult services. Two common models of transitional care described are; (1) integrating transitional services into paediatric or adult clinics or (2) designing and utilizing a special adolescent clinic that can facilitate transition from paediatric to adult healthcare provider.¹⁴⁻¹⁷ Current qualitative evidence suggests that both approaches can work well as measured by retention in care on suppressive ART, with high numbers of successful transitions to adult services and patient and carer satisfaction.¹⁸⁻²⁰ However relatively small numbers in observational cohorts limit interpretation, and randomised controlled trials and prospective cohort studies comparing different transition models within a single country/region are ongoing.²¹⁻²³

Cohort Complexity

Adolescents living with HIV have additional complex medical and psychological stressors, many of which are not typically seen in other chronic diseases of childhood but potentially impact throughout adolescence, transition and into adult care.

1. Psychological issues

- **Impact of HIV as a family disease:** some have lost one or more family members to HIV and may live without close parental role models as they grow through adolescence. Others are young carers for parents with HIV associated disease and may have extended caring roles for younger siblings.²⁴
- **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 the HIV diagnosis within the family.²⁵ Many adolescents have never disclosed their status to anyone and hence cannot access support from their peers and wider family.²⁶

- **Diagnosis in adolescence:** a small proportion of children born with HIV may remain asymptomatic for many years, within the CHIPS cohort up to half those diagnosed for the first time in adolescence were identified on screening following the diagnosis of a family member.⁴
- **Migration:** half of the children followed by CHIPS have been born abroad, the majority from sub-Saharan Africa and adjusting to the cultural and social differences can be complex for adolescents and their families.⁴
- **Psychiatric morbidity:** some studies, suggest higher levels of psychiatric morbidity, particularly depression and anxiety, in young people living with HIV when compared to the aged matched general population although levels are often similar to those seen in HIV exposed uninfected siblings suggesting that the wider family and socioeconomic setting may be more influential than HIV infection per se.²⁷⁻²⁹ Recent early data suggesting rates of psychosis in young adults living with perinatal HIV are significantly higher than in the general population and warrants further investigation.³⁰

2. Medical issues

- **Neurocognitive impact** of living with HIV on the developing brain, particularly for those presenting with a CDC Category C diagnosis including infantile HIV encephalopathy in infancy results in a wide spectrum of learning difficulties with poorer school performance and particular difficulties in executive functioning.³¹⁻³³ The interplay of many of these complex factors, plus the period of adolescence itself, impacts on the ability of some young people to negotiate their 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 has improved over calendar time in the CHIPS cohort but remains poorer than in adults.⁴ Following transition to adult care adherence rates are lowest in 15-24 year olds and when disaggregated by route of transmission, youth with perinatally acquired HIV have lower rates of ART uptake than their horizontally infected peers.¹³ Effective interventions to improve adherence are urgently required.³⁴⁻³⁶
- **Treatment experienced cohort:** within CHIPS half of the adolescents are triple class experienced however second generation integrase inhibitors and single tablet regimens mean that almost all young people have the option

of once daily single/dual tablet regimens.³⁴ Currently within CHIPS half (55%) are on integrase-based regimens with 83% prescribed a fixed dose combination.⁴ Any adolescent on an ART regimen consisting of more than 2 tablets once daily should be discussed at a regional virtual clinic to consider treatment simplification.

- **Side effects of prolonged exposure to HIV/ART.**
 - **Cardiovascular risk factors:** dyslipidaemia, altered glucose metabolism, inflammation and immune activation are increasingly reported in paediatric populations and may be compounded in adolescence by smoking, alcohol and recreational drug use.³⁷ Whilst the direct outcomes of cardiovascular risk are not apparent during adolescence, concern is growing for the possible effects in middle age. Additionally **lipodystrophy**, at an age when body image is so important, may have a negative impact on psychological well being and impact on ART adherence.^{38,39} Recent concerns of an association tenofovir alafenamide and weight gain in adults requires further elucidation in adolescents but is of concern given high rates of obesity in UK adolescents.⁴
 - **Bone health:** HIV is associated with delayed growth and puberty and reduced bone mineral density.⁴¹ The long-term impact and management of vitamin D deficiency and exposure to drugs that potentially impact on bone health such as tenofovir disoproxil and the contraceptive depot medroxyprogesterone acetate requires further elucidation however alternatives should be considered where available.⁴²
 - **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.^{6,7,43} Almost 1 in 10 young people experienced a new AIDS diagnosis and/or death within a median of 3 years post transition to adult care.⁷ Almost all deaths were due to HIV and associated with prolonged poor adherence to ART but not due to multi-drug resistant untreatable virus. Emerging data suggests a tenfold risk of malignancy when compared to aged matched population data, driven by lymphomas.⁴⁴⁻⁴⁶ In addition to addressing traditional risk factors including optimising HPV and HBV vaccination, clinical vigilance for early diagnosis is required.

3. Relationships and sexual Health

- Adolescents born with HIV have to negotiate their first relationships with a sexually transmissible disease before they have ever had sex.
- A third of UK adolescents are sexually active by 16 years, and the age of coitarche in perinatally infected adolescents, is similar to their uninfected peers.⁴⁷ High rates of unplanned pregnancy reported in perinatal cohorts highlight the need for integrated sexual health and HIV services including contraception.⁴⁸⁻⁵²
- Sexual health promotion including Hepatitis B and HPV vaccination with sexual health education for adolescents needs to start in paediatric services prior to coitarche, continue through transition and into adult services.

Specific guidance is available on CHIVA website:

<https://www.chiva.org.uk/infoprofessionals/guidelines>

Broader sexual health guidance for young people available through the British Association for Sexual Health and HIV (BASHH) and Adolescent Special Interest Group: <https://www.bashhguidelines.org/media/1268/children-and-yp-2021.pdf>
<https://www.bashh.org/bashh-groups/special-interest-groups/adolescent-sexual-health/>

- Prior to the onset of sexual activity adolescents need to be fully aware of “U=U” ie undetectable = untransmissible and the potential for future conception without risk of transmission to partner and future offspring.⁵³ Those struggling with adherence to ART and detectable viraemia require strategies to manage condom failure including disclosure and partner post exposure prophylaxis (PEP).⁵⁴ The option for ongoing risk reduction and partner access to Pre Exposure Prophylaxis (PrEP) should also be discussed.⁵⁵
- Adolescent relationships are often transient, within a close social group such as a school and therefore issues of disclosure and maintaining confidentiality are extremely complex.⁵⁶ In addition young people infected perinatally potentially disclose not only their own status but that of their mother and other family members.

- Supporting adolescents in negotiating relationships is important but often occurs at a difficult time during transition when healthcare providers are changing and new professional relationships are forming. These conversations need to start early in adolescence and continue through the transition process into adult care.

Transition

Transition is 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.”⁵⁷ NICE Guidance sets clear recommendations for transitional care supported by a wealth of Department of Health (DOH) guidance and resources.⁵⁸ In contrast, **transfer** is the physical event of the young person moving from paediatric to adult services and if unsupported by the process of transition has been associated with increased morbidity and mortality in other chronic diseases of childhood.^{59,60}

Different models of transition exist and the model chosen is determined by the patient group, available resources and geographical setting. It is thought that there is no superior transition mode and that the key to a successful transition is a flexible approach paced to the individual needs of the adolescent.^{16,17} In other chronic diseases carefully planned transition has been associated with enhanced attendance in adult care, reduced morbidity and improved patient and carer satisfaction.^{61,62} Meeting the adult team prior to transfer (see model 2) has been shown to reduce anxiety and improve attendance.^{16,17} Some examples of transition models are outlined below:

Model 1 – Family Clinics: Integration

Where HIV positive adolescents 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 services are also present. The setting remains familiar but the young person begins to take responsibility for their own health, and visit or 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 transfer of care from paediatric to adult services is possible with a carefully planned and comprehensive transition programme. This may be the model suited to smaller centres; it can only work when paediatric and adult services fully understand the transition process and work together productively.

Model 3 – Specialist Services: Separate Youth Clinic

Creating a separate “youth friendly” clinic where young people can choose to go for their care offers a tailor-made specialist clinic that has only adolescents/young adults attending and taking responsibility for their own sexual and medical health needs.

This may also give young people the opportunity to interact with other HIV positive young people, access peer support and help shape the clinic to their own specific needs.^{5,20,43} However it may require a further transition into adult services at some future point.

Setting up a multidisciplinary transition service

Effective implementation of any transition model requires **a named lead for transition** to develop and maintain the multidisciplinary linkage between paediatric and adult services. This may be a nurse, health advisor, psychologist, doctor or allied professional from either paediatric or adult services. If the lead is primarily based in paediatric services identifying an adult practitioner who has an interest in young people who can continue to follow up their attendance and care in the years post-transfer is important. The numbers of perinatally infected young people may be extremely small within much larger adult cohorts and multidisciplinary resources may be 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.

When to start transition?

Transition preparation for both the young person and the family can begin when an adolescent is fully aware of their HIV diagnosis, often before entry to secondary school although there will always be circumstances which mean that exceptions occur and full disclosure is delayed, especially in children with neurocognitive delay and families with complex psychosocial issues such as those relating to stigma, denial and undisclosed adoption. Transition is a gradual process that goes at a different pace for different young people but should be centred around the needs and wishes of the adolescent. All About Me (Avison & Dowie, 2018)⁶³ 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. ‘Treat me like this’⁶⁴ is a brief guidance document developed in consultation with young people which shares their views on what they would like during the transition process.

Each young person should have a documented transition plan outlining:

- Knowledge of HIV and confidentiality
- Opportunity to be seen alone
- Sexual health discussions and literature given
- Assessment of Fraser competency
- 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
- 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 over the first 12 months of adult care and to receive correspondence during that 12 month period from the adult team to ensure they integrate well within their new service.

Written 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 teenager moves to adult services they may too have to move health care setting as they no longer have a child within the family clinic. This can be particularly difficult for parents who have been within a service for many years and may include those who have lost other children during that time and they too require careful exploration of their service options.

Encouraging 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 unwilling to ask in front of parents/carers either through embarrassment or fear of upsetting them. Initially this may be a very short time before being joined by the parent/carer for the remainder of

the consultation, but increasing over time encouraging autonomy and self management which have been shown to have a positive impact on transition outcomes in other settings. The principles of confidentiality should be clearly explained to the young person and they should be made aware of who else, such as the GP, has been aware, with their parent's permission, of their HIV status.

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 perinatally infected young people from the age of 14, despite access to healthcare services.⁵² This may be a good opportunity to introduce adult health care 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 it appears appropriate for the individual and after discussions, and with agreement from the young person, the parents and the team, joint consultations with the paediatrician and the adult HIV doctor should begin. For adolescents attending a clinic a significant distance from home discussions as to whether adult care will continue in that centre or more locally should occur, taking into account any plans such as moving out of home for tertiary education and potentially the feasibility for shared care. In a family clinic where most of the young people have attended for many years the adult doctor may already be a well known face. Parents may or may not be part of this. Over a period of time the adult doctor will take over the consultations, this may be as short/long a time as is considered necessary. Although the young person's doctor may no longer be the paediatrician, other team members e.g. the psychologist or clinical nurse specialist may still be actively involved.

Prior to transfer

Young people usually need a review of their HIV history during the transition process, and it is good practice to offer and encourage the young person to receive or have access to a copy of their discharge summary and to agree which shared care 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 a number of years commencing at secondary school

age. The point of transfer needs to 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 – 2 years of age, depending on locally available services e.g. provision of designated young adult clinic.

Information at the time of transfer needs to include:

- 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
- CHIPS number if known (to enable this data to be linked to adult data)
- 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, HB)
- 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 as this could infringe their confidentiality
- Peer support

- When they became aware of own HIV diagnosis and any issues surrounding disclosure including wider disclosure to 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

References

1. Melvin D et al. Guidance on transition and long term follow up services for adolescents with HIV infection acquired in infancy” CHIVA Guidelines 2005.
2. Lyall H. Growing up, Gaining independence: Principles for transitional care. CHIVA Guidelines 2003(updated 2007).
3. Integrated Screening Outcomes Surveillance Service ISOSS
<https://www.ucl.ac.uk/integrated-screening-outcomes-surveillance/> [Accessed 29.05.21]
4. CHIPS Cohort Summary Data April 2021. Available from:
<http://www.chipscohort.ac.uk/patients/summary-data/> [Accessed 29.05.21].
5. Foster C, Fidler S. Optimising HIV transition services for young adults. *Curr Opin Infect Dis* 2018; 31(1):33-38.
6. Asad H, Collins IJ, Goodall R, Crichton S, Hill T et al. Mortality and AIDS-defining events among young people following transition from paediatric to adult HIV Care in the UK. *HIV Med* 2021 May 3. doi: 10.1111/hiv.13096. Online ahead of print
7. Judd A, Collins IJ, Parrott F, Hill T, Jose S et al. Growing up with perinatal HIV: changes in clinical outcomes before and after transfer to adult care in the UK. *J Int AIDS Soc*. 2017 May 16;20(Suppl 3):21577. doi: 10.7448/IAS.20.4.21577.
8. Collins IJ, Foster C, Tostein A, Tookey P, Riordan A et al. Clinical status of adolescents with perinatal HIV at transfer to adult care in the UK/Ireland. *CID* 2017 15; 64(8): 1105-1112.
9. Ritchwood TD, Malo V, Jones C, Metzger IW, Atujuna M et al. Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: a systematic review. *BMC Public Health*. 2020 Aug 3;20(1):1195. doi: 10.1186/s12889-020-09312-1.
10. Berzosa Sánchez A, Jiménez De Ory S, Frick MA, Menasalvas Ruiz AI, Couceiro JA et al; Corispe-Faro Cohort Working Group, Spain. Mortality in Perinatally HIV-infected Adolescents After Transition to Adult

- Care in Spain. *Pediatr Infect Dis J*. 2021 Apr 1;40(4):347-350.
11. Chappell E, Lyall H, Riordan A, Thorne C, Foster C et al on behalf of the Collaborative HIV Paediatric Study (CHIPS) Steering Committee. The cascade of care for children and adolescents with HIV in the UK and Ireland, 2010 to 2016. *Journal of the International AIDS Society*. 2019; 22(9): e25379. doi: [10.1002/jia2.25379](https://doi.org/10.1002/jia2.25379).
 12. UNAIDS 90-90-90: Treatment for all. <https://www.unaids.org/en/resources/909090> [accessed 29.05.21]
 13. Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. Health Protection Report volume 14 (20) November 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/959330/hpr2020_hiv19.pdf [accessed 29.05.21]
 14. Miles K, Edwards S, Clapson M. Transition from paediatric to adult services: experiences of HIV-positive adolescents. *AIDS Care* 2004; 16(3): 305-14.
 15. Tassiopoulos K, Huo Y, Patel K, Kacanek D, Allison S et al; Pediatric HIV/AIDS Cohort Study (PHACS). Healthcare Transition outcomes among Young Adults with Perinatally Acquired Human Immunodeficiency Virus Infection in the United States. *Clin Infect Dis*. 2020 Jun 24;71(1):133-141.
 16. Judd A, Sohn AH, Collins JI. Interventions to improve treatment, retention and survival outcomes for adolescents with perinatal HIV-1 transitioning to adult care: moving on up. *Curr Opin HIV AIDS*. 2016 Sep;11(5):477-486.
 17. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database Syst Rev* 2016; 4: CD009794.
 18. Bundock H, Fidler S, Clarke S et al. Crossing the divide: Transitional Care Services for young people with HIV – their views. *AIDS Patient Care STDS* 2011;25(8):465–73.
 19. Halyard AS, Doraivelu K, Camacho-González AF, Del Río C, Hussen SA. Examining healthcare transition experiences among youth living with HIV in Atlanta, Georgia, USA: a longitudinal qualitative study. *J Int AIDS Soc*. 2021 Feb;24(2):e25676. doi: [10.1002/jia2.25676](https://doi.org/10.1002/jia2.25676).
 20. Kim S, Kim SH, Fidler S, Foster C. Transition to Adult services; a positive step. *AIDS Care* 2016;15:1-5.
 21. Njuguna IN, Beima-Sofie K, Mburu CW, Mugo C, Neary J et al. Adolescent transition to adult care for HIV-infected adolescents in Kenya (ATTACH): study protocol for a hybrid effectiveness-implementation cluster randomised trial. *BMJ Open*. 2020 Dec 2;10(12):e039972. doi: [10.1136/bmjopen-2020-039972](https://doi.org/10.1136/bmjopen-2020-039972).
 22. Sam-Agudu NA, Pharr JR, Bruno T, Cross CL, Cornelius LJ et al. Adolescent Coordinated Transition (ACT) to improve health outcomes among young people living with HIV in Nigeria: study protocol for a randomized controlled trial. *Trials*. 2017 Dec 14;18(1):595. doi: [10.1186/s13063-017-2347-z](https://doi.org/10.1186/s13063-017-2347-z). Erratum in: *Trials*. 2018 Feb 13;19(1):104.
 23. Judd A, Davies MA. Adolescent transition among young people with perinatal HIV in high-income and low-income settings. *Curr Opin HIV AIDS*. 2018 May;13(3):236-248.
 24. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. *J Int AIDS Soc*. 2017 May 16;20(Suppl 3):21497. doi: [10.7448/IAS.20.4.21497](https://doi.org/10.7448/IAS.20.4.21497).

25. Deakin H, Frize G, Foster C, Evangeli M. 'We're touching the topic, but we're not opening the book:' A grounded theory study of sibling relationships in young people with perinatally acquired HIV. *J Health Psychol.* 2020 Oct 13:1359105320962271 epub.
26. Evangeli M, Foster C, Musiime V, Fidler S, Seeley J, Gnan G. A randomised feasibility trial of an intervention to support sharing of HIV status for 18-25-year olds living with perinatally acquired HIV compared with standard care: HIV Empowering Adults' Decisions to Share-UK/Uganda Project (HEADS-UP). *Pilot Feasibility Stud.* 2020 Sep 24;6:141. doi: 10.1186/s40814-020-00688-w.
27. Le Prevost M, Arenas-Pinto A, Melvin D, Parrott F, Foster C et al; Adolescents and Adults Living with Perinatal HIV (AALPHI) Steering Committee. Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England. *AIDS Care.* 2018 Aug;30(8):1040-1049.
28. Nyongesa MK, Mwangi P, Kinuthia M, Hassan AS, Koot HM et al. Prevalence, risk and protective indicators of common mental disorders among young people living with HIV compared to their uninfected peers from the Kenyan coast: a cross-sectional study. *BMC Psychiatry.* 2021 Feb 10;21(1):90. doi: 10.1186/s12888-021-03079-4.
29. Copelyn J, Thompson LC, Le Prevost M, Castro H, Sturgeon K et al; Adolescents and Adults Living with Perinatal HIV (AALPHI) Steering Committee. Self-harm in young people with perinatal HIV and HIV negative young people in England: cross sectional analysis. *BMC Public Health.* 2019 Aug 27;19(1):1165. doi: 10.1186/s12889-019-7424-7.
30. Mallik I, Pasvol T, Frize G, Ayres S, Barrera A et al. Psychotic disorders in young adults with perinatally acquired HIV: a UK case series. *Psychol Med.* 2020 Nov 13:1-7.
31. Judd A, Le Prevost M, Melvin D, Arenas-Pinto A, Parrott F et al; Adolescents and Adults Living With Perinatal HIV (AALPHI) Steering Committee. Cognitive Function in Young Persons With and Without Perinatal HIV in the AALPHI Cohort in England: Role of Non-HIV-Related Factors. *Clin Infect Dis.* 2016 Nov 15;63(10):1380-1387.
32. Coutifaris P, Byrd D, Childs J, Clark U, Posada R, Robbins R, Morgello S. Neurobehavioral outcomes in young adults with perinatally acquired HIV. *AIDS.* 2020 Nov 15;34(14):2081-2088.
33. Rowe K, Buivydaite R, Heinsohn T, Rahimzadeh M, Wagner RG, Scerif G, Stein A. Executive function in HIV-affected children and adolescents: a systematic review and meta-analyses. *AIDS Care.* 2021 Mar 25:1-25.
34. Foster C, Ayers S, Fidler S. Antiretroviral adherence for Adolescents living with HIV; drug delivery and forgiveness. *Ther Adv Inf Dis* 2020 May 7;7:2049936120920177.
35. Okonji EF, Mukumbang FC, Orth Z, Vickerman-Delport SA, Van Wyk B. Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10-24 years): a scoping review. *BMC Public Health.* 2020 Dec 1;20(1):1841. doi: 10.1186/s12889-020-09717-y.
36. Judd A, Melvin D, Thompson LC, Foster C, Le Prevost M et al. Factors Associated With Nonadherence to Antiretroviral Therapy Among Young People Living With Perinatally Acquired HIV in England. *J Assoc Nurses AIDS Care.* 2020 Sep-Oct;31(5):574-586.
37. Fortuny C, Deyà-Martínez Á, Chiappini E, Galli L, de Martino M, Noguera-Julian A. Metabolic and renal

- adverse effects of antiretroviral therapy in HIV-infected children and adolescents. *Pediatr Infect Dis J*. 2015 May;34(5 Suppl 1):S36-43.
38. Innes S, Harvey J, Collins IJ, Cotton MF, Judd A. Lipoatrophy/lipohypertrophy outcomes after antiretroviral therapy switch in children in the UK/ Ireland. *PLoS One*. 2018; 13(4): e0194132.
 39. Kenny K, Doerholt K, Gibb DM, Judd A on behalf of the Collaborative HIV Paediatric Study (CHIPS) Steering Committee. Who gets severe gynaecomastia among HIV-infected children in the UK and Ireland? *Paediatric Infectious Disease Journal*. 2017; 36 (3): 307-310.
 40. Venter WDF, Sokhela S, Simmons B, Moorhouse M, Fairlie L et al. Dolutegravir with emtricitabine and tenofovir alafenamide or tenofovir disoproxil fumarate versus efavirenz, emtricitabine, and tenofovir disoproxil fumarate for initial treatment of HIV-1 infection (ADVANCE): week 96 results from a randomised, phase 3, non-inferiority trial. *Lancet HIV*. 2020 Oct;7(10):e666-e676.
 41. Jacobson D, Liu JZ, Lindsey JC, Shiao S, Coull B, Aldrovandi G. Immune Markers and Their Association with Bone Density in Children, Adolescents, and Young Adults with Perinatally Acquired HIV. *AIDS Res Hum Retroviruses*. 2021 Feb;37(2):122-129.
 42. Clinical Commissioning Policy: Tenofovir Alafenamide for treatment of HIV 1 in adults and adolescents (2017). NHS England Available at: <https://www.england.nhs.uk/wp-content/uploads/2017/03/f03-taf-policy.pdf>
 43. Foster C, Ayers S, McDonald S, Frize G, Chhabra S, Pasvol TJ, Fidler S. Clinical outcomes post transition to adult services in young adults with perinatally acquired HIV infection: mortality, retention in care and viral suppression. *AIDS*. 2020 Feb 1;34(2):261-266.
 44. The European Pregnancy and Paediatric Infections Cohort Collaboration (EPPICC) study group. Malignancies among Children and Young People with HIV in Western and Eastern Europe and Thailand. *AIDS* in press 2021.
 45. Chhabra S, Fidler S, Ayers S, Bower M, Lyall H, Foster C. Malignancy and all-cause mortality; incidence in adolescents and young adults living with perinatally acquired HIV. *J Virus Erad*. 2020 Feb 20;6(1):30-33.
 46. Eades CP, Herbert SA, Edwards SG, et al. High rate of lymphoma among a UK cohort of adolescents with vertically acquired HIV-1 infection transitioning to adult care in the era of antiretroviral therapy. *AIDS* 2016; 30(1): 153– 156.
 47. Judd A, Foster C, Thompson L, Sturgeon K, Le Provost M et al. Sexual Health of young people with perinatal HIV and HIV negative young people in England. *PLoS One*. 2018 Oct 12;13(10):e0205597.
 48. Byrne L, Sconza R, Foster C, Tookey PA, Cortina-Borja M, Thorne C. Pregnancy incidence and outcomes in women with perinatal HIV infection. *AIDS* 2017; 31(12): 1745-1754.
 49. Kourtis AP, Mirza A; COMMITTEE ON PEDIATRIC AIDS. Contraception for HIV-Infected Adolescents. *Pediatrics*. 2016 Sep;138(3):e20161892.
 50. Haddad LB, Brown JL, King C, Gause NK, Cordes S, Chakraborty R, Kourtis AP. Contraceptive, condom and dual method use at last coitus among perinatally and horizontally HIV-infected young women in Atlanta, Georgia. *PLoS One*. 2018 Sep 12;13(9):e0202946.
 51. Trahan MJ, Boucher M, Renaud C, Karatzios C, Metras ME et al. Pregnancies Among the First Generation of Survivors of Perinatal HIV Infection. *J Obstet Gynaecol Can*. 2020 Apr;42(4):446-452.

52. Kenny J, Williams B, Prime K, Tookey P, Foster C. Pregnancy outcomes in adolescents in the UK and Ireland growing up with HIV. *HIV Med.* 2012 May;13(5):304-8.
53. Rodger AJ, Cambiano V, Bruun T, Vernazza P, Collins S et al; PARTNER Study Group. Sexual Activity Without Condoms and Risk of HIV Transmission in Serodifferent Couples When the HIV-Positive Partner Is Using Suppressive Antiretroviral Therapy. *JAMA.* 2016 Jul 12;316(2):171-81.
54. Clinical Effectiveness Group BASHH (British Association of Sexual Health and HIV). UK Guideline for the use of Post-Exposure Prophylaxis for HIV Following Sexual Exposure (2021). <https://www.bashhguidelines.org/media/1269/pep-2021.pdf>. (accessed 20th May 2021).
55. BHIVA/BASHH guidelines on the use of HIV pre-exposure prophylaxis (PrEP) 2018. <https://www.bhiva.org/PrEP-guidelines>. (accessed 1st June 2021).
56. Kidman R, Violari A. Growing up positive: adolescent HIV disclosure to sexual partners and others. *AIDS Care.* 2020 Dec;32(12):1565-1572.
57. Department of Health CHaMSB. Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services. In: Health Do, editor. London: Department of Health, 2006. www.dh.gov.uk/publications.
58. 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>
59. Shulman R, Shah BR, Fu L, Chafe R, Guttman A. Diabetes transition care and adverse events: a population-based cohort study in Ontario, Canada. *Diabet Med.* 2018 Nov;35(11):1515-1522.
60. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol* 2000;14(6): 469-72.
61. Gray WN, Holbrook E, Dykes D, Morgan PJ, Saeed SA, Denson LA. Improving IBD Transition, Self-management, and Disease Outcomes With an In-clinic Transition Coordinator. *J Pediatr Gastroenterol Nutr.* 2019 Aug;69(2):194-199.
62. Stevens JP, Hall L, Gupta NA. TRANSITION of Pediatric Liver Transplant Patients to Adult Care: a Review. *Curr Gastroenterol Rep.* 2021 Jan 29;23(3):3. doi: 10.1007/s11894-020-00802-1.
63. Avison R, Dowie M (2018) All About Me. The Leeds Teaching Hospitals NHS Trust LN004093 and CHIVA. Available at: <https://www.chiva.org.uk/infoprofessionals/resources/>
64. Ely A (2015) 'Treat me like this': Guidance for clinics on transition. CHIVA. Available at: https://www.chiva.org.uk/files/1014/5079/3341/Guidance_for_Clinics_on_Transition.pdf

National Transitional Care Guidance

- Transition from children's to adults' services for young people using health or social careservices. NICE guidelines [NG43] Published date: February 2016 <https://www.nice.org.uk/guidance/ng43>
- Royal College of Paediatrics and Child Health (2003). The Intercollegiate Working Party on Adolescent Health. Bridging the gaps: health care for adolescents.

<http://www.rcpch.ac.uk/Education/Adolescent-Health-Project>

- National service framework for Children Young People and Maternity services (2004)<http://www.dh.gov.uk>
- Adolescent Transition Care. Guidance for nursing staff. Royal College of Nursing (2004)
www.rcn.org.uk
- National service framework for long term conditions (2005) www.dh.gov.uk
- You're Welcome quality criteria: Making health services young people friendly (2007)www.dh.gov.uk
- A Transition guide for all services. Key information about the transition process for disabled young people (2007)
<http://www.transitioninfonet.org.uk/resources.aspx>
- Transition Information Network.
<http://www.transitioninfonet.org.uk>
- Transition moving on well (2008).www.dh.gov.uk

