

# CHIVA Guidance on Transition for adolescents living with HIV

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**This document replaces 2 previous CHIVA documents:**

**“Guidance on transition and long term follow up services for adolescents with HIV infection acquired in infancy”, Melvin et al 2005.**

**“Growing up, Gaining independence: Principles for transitional care”, Hermione Lyall 2003 (updated 2007).**

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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

## 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 growing population, summarising and updating the two previous resources listed above.<sup>1,2</sup>

Virtually all children diagnosed with HIV infection living in the UK and Ireland are followed prospectively in the Collaborative HIV Paediatric Study (CHIPS). Cohort data on over 1,950 children ever registered to CHIPS shows that by 2016 nearly 800 adolescents had already transferred to adult care at a median age of 17.6 years (IQR 16.7-18.5).<sup>3</sup> In 2016, the median age of patients in paediatric care at time of last visit was 14.5 (IQR, 11.2-16.5); 48% were aged  $\geq 15$  years. As of the end of April 2016, a total of 905 patients were alive and in active follow-up at a paediatric clinic in the UK or Ireland. Of these, just over half (53%) were female, 50% were born in the UK or Ireland, 78% were of black African ethnicity, and nearly all (93%) were known to have been infected through mother-to-child transmission. Forty-six per cent of children were being seen at clinics in London, 42% in the rest of England, 4% in Scotland, 1% in Wales, 6% in the Republic of Ireland, and 1% in Northern Ireland.<sup>3</sup> A detailed analysis of the clinical status of adolescents with perinatal HIV at transfer to adult care in the UK/Ireland by Collins et al is currently in press.<sup>4</sup> A similar aging pattern is seen in most well-resourced countries with access to ART, a high uptake of antenatal testing and subsequent successful intervention in prevention of mother-to-child transmission. The impact of long term survivors of mother-to-child transmission (MTCT) in sub-Saharan Africa to the demographics of paediatric HIV in the UK is becoming apparent, reflected in the increasing age of newly diagnosed children living in the UK but born abroad.<sup>5,6</sup> HIV is the leading cause of death among adolescents in Africa, the second most common cause of death among adolescents globally, and is the only age group in which deaths due to AIDS increased between 2005 and 2012.<sup>7,8</sup> Whilst the majority of deaths are thought to be in perinatally infected adolescents, amongst new HIV diagnoses, adolescent girls and young women aged 15–24 years are disproportionately affected, accounting for 20% of all new diagnoses, even though they represent just 11% of the adult population.<sup>9</sup>

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<sup>10-12</sup> or (2) designing and utilizing a special adolescent clinic that can facilitate transition from paediatric to adult healthcare provider<sup>13-16</sup>. Current qualitative evidence suggests that both approaches can work well as measured by retention in care and on treatment, with high numbers of successful transitions to adult services and patient and carer satisfaction. However small numbers limit further interpretation, and randomised controlled trials, or prospective cohort studies comparing different transition models within a single country/region are lacking. Currently available data on adolescents transitioning with HIV is comprehensively reviewed by Judd et al, and more widely for childhood chronic diseases has been the subject of a Cochrane review.<sup>17,18</sup>

*For a review of transitional care for adolescents please see the special Transitional Care edition of the Journal of the International AIDS society due for publication in 2017.*

## 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 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.<sup>19</sup>
- **Stigma and secrecy** around HIV remain largely unchanged 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 diagnoses within the family.<sup>20</sup> Many adolescents have never disclosed their status to anyone and hence cannot access support from their peers and wider family.

- **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.<sup>6</sup>
- **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.<sup>3</sup>
- **Psychiatric morbidity:** some studies, mainly from the US, suggest higher levels of psychiatric morbidity, particularly depression and anxiety, although studies vary as to whether this is greater than that seen in affected siblings and in other chronic diseases of childhood.<sup>21,22</sup>

## 2. Medical issues

- **Neurocognitive impact** of living with HIV on the developing brain is becoming increasingly apparent, with poorer school performance and particular difficulties in executive functioning.<sup>21</sup> 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 HAART** is poorer in adolescence, and is worse in horizontally infected young people when compared to older adults.<sup>23-25</sup>
- **Treatment experienced cohort:** within CHIPS half of the adolescents are triple class experienced and often do not have once daily low pill burden options available. Almost one tenth of the young people who had ever started HAART and followed in CHIPS were off therapy due to poor adherence/refusal.<sup>3,20</sup>
- **Side effects of prolonged exposure to HIV/HAART.**
  - **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.<sup>26</sup> Whilst the direct outcomes of cardiovascular risk are not apparent during adolescence, concern is growing for the possible effects in early 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 adherence.

- **Bone health:** HIV is associated with delayed growth and puberty and reduced bone mineral density. The long-term impact and management of vitamin D deficiency and exposure to drugs that potentially impact on bone health such as tenofovir and the contraceptive depot medroxyprogesterone acetate require elucidation.<sup>19</sup>

### 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 yrs, and although UK data is limited regarding the age of coitarche in perinatally infected adolescents, it appears to be similar to their uninfected peers with high rates of unplanned pregnancy reported in cohorts from both UK and US.<sup>27-29</sup>
- Sexual health promotion including Hepatitis B and HPV vaccination and sexual health education for adolescents needs to start in paediatric services prior to coitarche, continue through transition and into adult services. Specific guidance for this unique population is available from The HIV in Young People Network (HYPNet)<sup>30</sup> at <http://www.chiva.org.uk/guidelines/sexual-and-reproductive-health/> or <http://www.hypnet.org.uk/pages/guidelines.php>
- 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. 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. Therefore these conversations should start early in the transition process.

## 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.”<sup>31</sup> The UK National Service Framework (NSF) sets clear recommendations for transitional care supported by a wealth of Department of Health (DOH) guidance and resources.<sup>31-33</sup> 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.<sup>18, 32,34</sup>

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.<sup>17,18,34-37</sup> In other chronic diseases carefully planned transition has been associated with enhanced attendance in adult care, reduced morbidity and improved patient and carer satisfaction.<sup>36,37</sup> Meeting the adult team prior to transfer (see model 2) has been shown to reduce anxiety and improve attendance.<sup>17,18</sup>

### 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. However it may require a further transition into adult services at some future point.

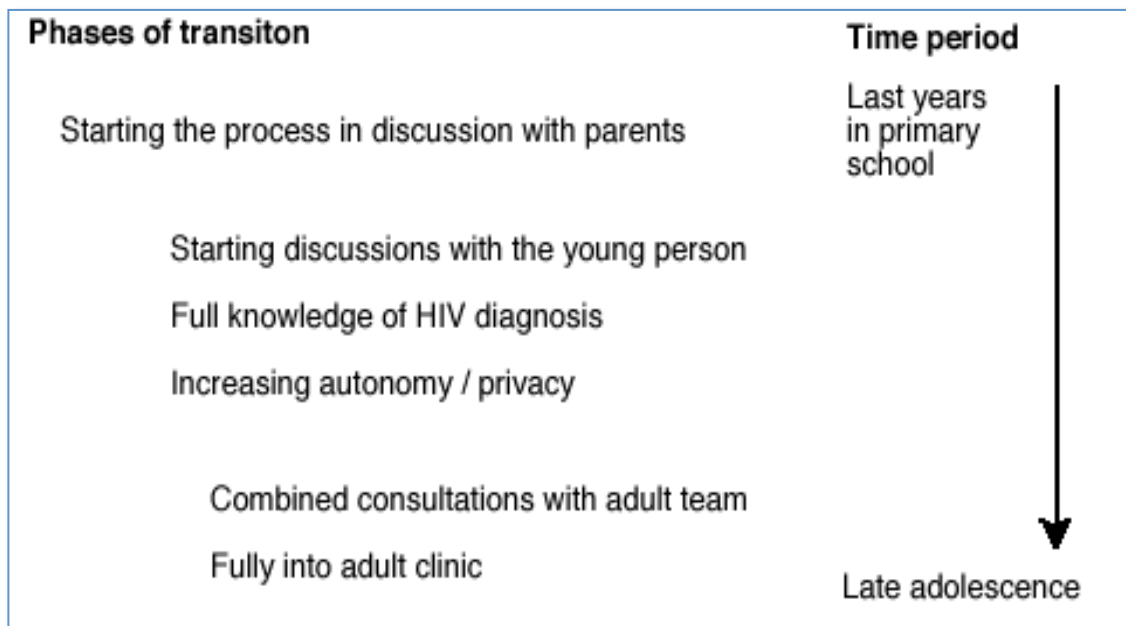
### Setting up a multidisciplinary transition service

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.





*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
- 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, nursing with up to date email, mobile, phone, address and permission to contact a relative in case of emergency or repeated non-attendance.

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 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 a recent report of high UK rates of unplanned pregnancy in perinatally infected young people from the age of 14, despite access to healthcare services.<sup>28</sup> 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 will 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.

### *Information at the time of transfer needs to include:*

- Contact details
- 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 / Sickle Cell screen if applicable
- Tanner stage / onset of menarche / recent weight and height
- Vaccination record
- Summary of all past Antiretroviral therapy [ART] with present regime and doses
- Adherence history, treatment side effects
- Copies of any HIV Resistance tests and Therapeutic Drug Monitoring
- CD4 percentages + counts (especially nadir before starting ART) 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 / Psychology
- Relevant social history, e.g. if parents have died / Social Care input / support networks. NB – be mindful of giving other family members details and information as this could infringe their confidentiality

- When became aware of own HIV diagnosis and any issues surrounding disclosure including wider disclosure to others
- Sexual history if known
- Current educational and employment situation.

*Copies of summary sent to:*

- Young person and / or family
- Adult consultant
- GP
- Social Services if in Foster care
- Medical Notes

## Conclusion

Transition from paediatric to adult services occurs at a time when adolescents living with HIV are managing the wide spectrum of change associated with later adolescence and particularly influencing independence and autonomy, sexuality and personal identity. Education and employment, relationships with families and peers are also in transition and will be affected by emotional as well as physical health. Transition services that support young people to manage their health within the context of their wider lives can occur in a wide range of settings that include multidisciplinary input from health and the voluntary sector.

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- Transition from children's to adults' services for young people using health or social care services. NICE guidelines [NG43] Published date: February 2016  
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