

Transition for adolescents living with HIV

Amanda Ely¹, Julia Kenny² and Amanda Williams³

¹CHIVA CEO, UK

²Consultant in Paediatric Infectious Diseases and Immunology, Evelina London Children's Hospital, UK

³CHIVA Chair/Consultant Paediatrician and Specialist in Paediatric Infectious Diseases, London North West University Healthcare NHS Trust, UK

Abstract

Transition takes place at a time when young people are experiencing a period of developmental and social change. It is essential to understand the family experience of HIV for young people and the medical and social complexities of having grown up with HIV.

Experiences of young people living with HIV in the UK are discussed, including recent data on outcomes post transition, along with experiences of transition for young people living with HIV in other countries and with other chronic illnesses. Challenges and barriers to successful transition and effective approaches are explored.

Practice tools and approaches which support successful transition include: assessments of readiness; multidisciplinary support; early preparation; empowerment of young patients; and engaging professionals in adult settings as named 'transition leads'.

Establishing successful transition can be critical to ensuring long-term health for young people with perinatally acquired HIV, requiring structured provision, clear processes and good communication between paediatric and adult clinics.

Keywords: HIV transition, young people, perinatal HIV, youth-friendly services

A. Revalidation

This article has been prepared with continuing professional development (CPD) in mind and can be used to support your revalidation. It is estimated that 2 hours of CPD activity will be required for completion of the reading, 'time out' activities, the quiz and writing a brief reflective account in relation to your learning and its applicability to your practice. There is a self-assessment quiz at the end of this article for you to assess what you have learnt.

B. Learning outcomes

After reading this article, undertaking the activities and completing the self-assessment quiz you should have:

- an enhanced understanding of particular experiences of HIV in childhood, and the family experience;
- an understanding of barriers and challenges to a successful transition;
- an understanding of the risks associated with poor transition experiences;
- an appreciation of the healthcare and support needs of young people as distinct from younger children and adults;
- an understanding of how adult clinics might best respond to such distinct needs through development of youth-friendly approaches and enhanced knowledge and understanding of young people's needs among healthcare professionals;
- an opportunity for reflective practice to consider how 'youth friendly' your service is currently; and

- access to identified resources for further reading and application to practice.

C. Introduction

Transition is defined as '*the 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].

Since the start of the HIV epidemic, perinatally acquired HIV infection has now become a chronic condition of childhood with life expectancy approaching that of the general population. This is owing to earlier diagnosis, improved treatment options and delivery of antiretroviral (ARV) medications.

Transition from paediatric specialist care to adult-oriented health care is a process every young adult with a chronic health condition must navigate. This is a challenging time, the adolescent brain is not fully developed and young adults, often used to having parental/carer support and supervision alongside paediatric clinical nurse specialists, find this support drastically reduced at a time when they may need it most. Some adolescents transition with limited interruptions to their care. Others drop out and do not return to access medical care until much later when a medical problem arises.

Studies demonstrate the complex medical and psychosocial issues faced by some young adults with

perinatally acquired HIV. Adolescents transitioning now are from a generation where HIV diagnosis was often delayed, treatment options were limited and ARV treatment was not commenced until late in the condition process. Strong evidence from the Children with HIV Early Antiretroviral Therapy (CHER) trial in 2008 demonstrated that commencing infants on effective ARV medication as soon as they are diagnosed significantly reduces the morbidity and mortality associated with untreated perinatally acquired HIV [2]. Untreated, a significant proportion of babies will die within their first year of life and those that survive may develop HIV encephalopathy, growth stunting, recurrent infections and other chronic conditions. Cognitive deficits may be severe and significant.

A combination of these factors contribute to significant risks and mortality that have been identified for this cohort [3].

Time out activity 1

Make a list of social, medical and psychological issues faced by children and young people growing up with HIV that may shape their experience of transition.

Come back to this list once you have read the whole article, and add any further points.

The stigma surrounding HIV compounds the difficulties of achieving successful transitions into adult care in which effective self-management is established and social adjustment achieved. Despite commonalities with other complex paediatric health conditions, from which much can be learned in terms of effective approaches and models of care, there are currently unique social aspects to growing up living with HIV. HIV-related stigma can result in a great deal of prejudice, anxiety, fear and social isolation for those affected by it. Secrecy within a family affects family dynamics and trust. Concerns around sharing the diagnosis with education providers may prevent the young person's educational psychology review being shared, for fear that the HIV diagnosis is accidentally revealed, which can result in young people not receiving the educational support they need.

In this context HIV typically becomes something that young people work hard at keeping hidden. Having to carry medications on school trips, sleepovers or on a night out can cause worry and stress for fear of their condition being discovered by others.

Such complexities of the experience of transition for young people living with HIV are outlined in the CHIVA Guidance on Transition for Adolescents living with HIV [4]. In addition to the usual challenges of adolescence, many young people with perinatally acquired HIV are dealing with grief, anger, ongoing secrecy, denial and also trying to negotiate their sexual debut and ongoing sexual relationships with the fear of passing on HIV. Over the last 2 years the finding that Undetectable equals Untransmittable (U=U) has provided a hugely positive message, giving young people, if they take

their ARVs and achieve an undetectable viral load for over 6 months, the assurance that there is no risk of HIV being passed from them to their partner.

Although HIV is not the only sexually transmitted disease and the risk of other STIs and pregnancy has to be discussed, U=U has helped with the stigma towards HIV.

HIV is a family disease for the majority of young people living HIV in the UK. One or both parents may also be living with HIV, and for many young people a parent or sibling may have died. HIV can impact and shape family relationships, where knowledge of HIV is not held by everyone in a family or household, young people are having to manage such 'secrecy' within their family relationships and often with their siblings. This can be something young people have had limited control over as younger children, but as they become older can seek to control more of the decisions regarding who they share their HIV information with. Although many have not told anyone about their HIV and therefore seeking support from wider family and friends around their HIV is not possible, as they get older they may start to think about this and consider telling people who they are close to. Young people often describe anger and resentment at not being allowed to take control over this decision about who they can talk to about their HIV and seek increasing control over 'their HIV.'

Where there is limited or no open discussion about HIV in the family context such issues can remain unaddressed for many years, they can present tensions and stress in family relationships with emotional issues relating to HIV left unresolved.

Sometimes adults in the family have found adjusting to and accepting their own HIV diagnosis difficult, and may not have accessed any wider support around this themselves. These responses to HIV can be mirrored by the young person who is working out what this means to them. Parents who struggle to take their ARV medication often have young people who experience the same difficulties. Such difficulties in coping with HIV impacts the family, highlights the need for family support and wider support for young people. In particular, contact with peers who also live with HIV, with whom supportive relationships can be formed from uniquely shared experiences, can help to foster strength and resilience and lead to greater empowerment.

There is a high incidence of family migration to the UK among this cohort, fears over gaining a right to remain, sudden moves away from friends and family or deportation can affect access to treatment and support networks, causing further isolation and presenting significant stressors. In addition, many children and adolescents may need to be carers of their parents suffering complications of HIV.

The transitioning cohort of young people can be medically complex. There may have been years of suboptimal ARV regimens, with the development of

resistance to different ARV classes, which then affects and reduces subsequent treatment options.

With a push to simplify medications, one tablet a day regimens are proving very popular. However some tablets are quite large and can be difficult to swallow, others have food restrictions and have to be taken with a meal, which is not always easy in a less predictable adolescent lifestyle. Having been on medication daily throughout childhood and with medication being a constant reminder of HIV, treatment fatigue can feature for many young people, coupled with changes in lifestyle and challenges managing medicine in an increasingly peer-centred world and remaining adherent to medicine during this stage is challenging for many young people, and poorer adherence to ARVs in adolescence is well documented.

Funding and commissioning varies by age and area, within the paediatric clinic there is often more freedom to individualise ARV regimens, however when moving to adult care commissioning criteria have to be stricter and some treatment options may not be available after transition, as such this may be another aspect to the change for the young person after transition to adult care.

There is limited information about how to determine when young people are adequately prepared and ready to successfully transition to adult medical care. Each patient is an individual, a sexually active 15-year-old may prefer the anonymity of a new clinic away from the toys and team who have looked after them for many years and know their family. Conversely a 19-year-old with learning difficulties used to the structure of the paediatric clinic and the familiarity with the team may prefer to remain in paediatric care. Different centres are trying different approaches: joint paediatric-adult clinics, transition clinics and staged transfer. This is all challenging within the constraints of the NHS and there is a need to fully consider the infrastructural and support requirements to enable successful transition.

Time out activity 2

How would you set out to engage young people with their HIV care?

What strategies might you use?

Identify local policies and agencies that would support you with this.

D. UK experience

Children and young people in paediatric HIV clinical care in the UK and Ireland are followed up by the Collaborative HIV Paediatric Study (CHIPS) cohort study.

The study was established in 2000 and is a collaboration between clinics caring for children with HIV, the National Surveillance of HIV in Pregnancy and Childhood (NSHPC) at the UCL Great Ormond Street Institute of Child Health, and the MRC Clinical Trials Unit at University College London.

CHIPS has provided detailed clinical data on these children for the past 20 years, allowing an understanding of their treatment experience and clinical care needs.

Of the just over 2000 children with perinatally acquired HIV who are being followed up in the CHIPS cohort study from 2006 onwards, over 50% have now transferred to adult clinics and between 50 to 120 patients have been transferring to adult clinics each year from 2009, with the mean age of 18 years [5].

CHIPS has allowed understanding of where children are being treated; currently 41% of young people are being seen in clinics in London, 46% in the rest of England, 4% Scotland, 2% Wales, 1% Northern Ireland and 7% in the Republic of Ireland [5].

It is worth noting that young people not living in London may have been accessing paediatric care in one of the London tertiary centres for a range of reasons. Some of the reasons are rooted in the origins of the network model of specialist HIV paediatric care, which identified three lead specialist tertiary centres for HIV paediatric care in 2006 as part of the hub model that was developed to provide a paediatric and family treatment network in London and across the UK. However, when these young people transition to adult care it may be that they prefer to attend an adult clinic at a secondary care provider closer to their home. This could be in the surrounding regions for those in London centres. Therefore the figures above may not fully correlate with the location of young transitioned patients now in adult care.

CHIPS also provides demographic data: around 50% of the young people with perinatally acquired HIV were born abroad, mostly in African countries, a further approximately 30% were born in the UK to parents who had migrated to the UK.

Consequently, the majority of young people with perinatally acquired HIV are from a minority ethnic background. Many will have been in the asylum system and some may have remaining unresolved immigration status and face associated social and economic challenges and uncertainty about their future. High numbers of children have experienced close family bereavements, disruptions and changes to their main carer and family household composition.

We are beginning to understand more about the experiences of young people post transfer to adult care. Previous studies in the UK have highlighted the increased rate of mortality and hospitalisation among young people with perinatally acquired HIV in adult care as compared to younger children [3]. There is also indication that risks to health increase in adolescents compared with younger children, with children >15 years of age less likely to be virally suppressed or have a better immune status than younger children [6].

There is concern to ensure data on the clinical experiences of this particularly vulnerable patient group, which have been so carefully tracked through the CHIPS cohort study during their entire paediatric care experience in

the UK, are not lost once they transfer to adult care and are part of a much larger diverse patient cohort. The CHIPS cohort study provides essential monitoring of ongoing clinical and support needs that are likely to remain distinct from the wider adult HIV patient group, who acquired HIV behaviourally later in life.

Analysis of overall CHIPS data indicated that the majority of adolescents with perinatally acquired HIV were on stable antiretroviral therapy (ART) at transfer to adult care with relatively high CD4 T cell counts and good virological control. Although 12% had triple-class resistance and one-quarter were treatment naive or off ART at transfer and more likely to be severely immunosuppressed and at risk of disease progression [7].

A recent study seeking to track mortality and AIDS-defining events in young patients following transition to adult care linked just under 500 transitioned young patients to the adult UK Collaborative HIV Cohort (CHIC) Study, which collates routinely collected data on individuals with HIV attending one of seven clinical centres in the UK since 1996.

In adult care, 7% of the young transitioned patients experienced a new AIDS event, and 3% died. Overall 8% ($n=30$) had the composite endpoint of AIDS or death. Age at death ranged from 19 to 24 years, and occurred at a median of 4 years post transition [8]. Patients with a prior AIDS diagnosis in paediatric care, or transitioning earlier in age were at higher risk of mortality or AIDS post transition. This transitioned young patient cohort within the CHIC cohort were also tracked for severe immunosuppression and viral failure in adult care: 20% experienced severe immunosuppression, and 36% viral failure in adult care [9]. Over 4 years of follow-up in adult care, a quarter of patients experienced severe immunosuppression and one third viral failure. Poor virological and immunological status prior to transition were predictive of these poor outcomes in adult care.

In a separate study, clinical outcomes including mortality, retention in care, viral suppression, AIDS and mental health diagnoses were observed in a retrospective study of a cohort of 180 young people attending a youth-friendly clinic in a specialist tertiary care hospital spanning an 11-year period. At the end of the period 86% had remained in care, just under 81% of whom had a viral load of <200 copies/mL (all of the 31 patients with a detectable viral load at the end point had documented adherence issues), 14 had transferred care to other services, 4 were lost to care, and 4 had died, 3 deaths were related to advanced HIV and all had long term poor ART adherence [10].

Further complexity was evident for the 21% who were diagnosed with anxiety and/or depression. Suicide, self-harming, alcohol and drug dependency were also noted though in smaller numbers and also 7% had had at least one episode of psychosis, with the median age at the first episode of 21 years.

Death rates for adults living with HIV are largely comparable with the general population (if late diagnoses

are excluded) [11]. Even the relatively low death rates in the cohort study of young transitioned patients described above indicates greater risk of death in young adults with perinatally acquired HIV than in adults with behaviourally acquired HIV [10].

Further national data provide evidence of increased risk of mortality in this cohort post transition [8] and are distinct from data on deaths in paediatric care, where between 2013 and 2016 no deaths were reported in the CHIPS cohort, with one death being reported in 2016 [5,6].

Poorer outcomes among young adults with perinatally acquired HIV illustrate the increased need for support for this group and in particular support around adherence difficulties, which are likely to have been present prior to transition.

E. Challenges to transition: assessing readiness and identifying barriers

Transition is understood as a complex process reaching beyond a change in healthcare provider from paediatric to adult-oriented care, but encompassing all aspects of life. It signifies a stage in the young person's life that requires the young person to become more mature and independent of parents or carers.

A chronic illness can make this transition more complex. Moving from paediatric care to adult care can be experienced as a loss, leaving the place where the child (and frequently their carers in relation to perinatally acquired HIV) has received their care, sometimes from birth or early childhood, and the trusting relationships that have been formed with medical staff. In the UK, research seeking to understand changes in clinical outcomes following on from transfer to adult care illustrated that the average time a child had spent accessing paediatric care was 11 years [12].

There is evidence that morbidity and mortality increases for young people following the move from paediatric to adult services in wider long-term chronic disease experiences, for example in diabetes [13–15].

Transition may involve moving to a care provision that may be differently structured and perhaps without the same capacity or experience to provide youth-friendly services, such as flexible appointments and access to multidisciplinary team support that may include: social, psychological, community-based and peer support.

A study in the US that explored transition readiness, anxiety, and potential barriers to a successful transition among a group of young people living with HIV in Washington DC, suggests:

While age, developmental readiness, and resistance predominate the concerns of earlier studies on transitioning chronically ill youth to appropriate adult care, more recent investigations have emphasized the increasingly difficult barriers of inadequate systemic and infrastructure support [16].

This US study sought to assess readiness for transition by measuring its association with levels of anxiety;

findings of poor readiness scores in a questionnaire completed by young people prior to transition were associated with high anxiety levels. Participants had been receiving care in the paediatric treatment centre for an average of 10 years. However following a period of increased support lasting 7 months that focused on preparation for transition, provision of increased support including social work and community based support, and improving knowledge including medication knowledge, scoring on readiness for transition increased significantly. This led the authors to claim:

Confidence or self-efficacy in selfcare might explain the association between reduced needs and lower anxiety scores at the time of transition especially if increased self-efficacy to manage health care needs can result in uninterrupted care and/or positive health care outcomes [16].

This study points to the need for 'transition readiness assessments' with support programmes available to address identified needs in relation to young people's readiness for transition. It also suggests the need to identify potential barriers to a successful transition early on. This approach places an emphasis on the preparation and support a young person will require to develop knowledge and skills, so transition here is aligned with personal development. In addition the need for ongoing multidisciplinary support and youth-focused flexible approaches to care, including access to community and social support, indicates the structural support requirements.

Other studies on the transition experience point to this need for clear planning and needs assessments in preparation for transition.

'Project Access' was developed at the University of Maryland HIV Paediatric Clinic USA, as part of a package of care for young people living with HIV. This protocol created a transition team, consisting of medical, psychosocial, case management, and peer navigators. Patients were to meet regularly with team members at clinic visits to determine ongoing barriers to transition success. The 'transition advocate' would meet with the patient and review the transition action plan a minimum of 1 year prior to planned transition, engaging them in a process of identifying needs to prepare for transition.

Key findings from a study into the effectiveness of this programme identified that although the linkage rates from paediatric to adult clinics were high the length of time variation was large (up to 579 days to be successfully linked into adult care) emphasising the importance of an individualised and flexible transition process.

Those retained in adult care at 12 months after transition were more likely to be retained in care ongoing at follow up (24 months) [17]. This identifies the critical opportunity presented at the time of transition to enable positive engagement with adult care services and emphasises the need to minimise disruption to care following on from paediatrics.

Studies such as the latter support the need for structured provision and processes that include the creation of multidisciplinary transition teams, as described above, and include adult providers with clear communication between paediatric providers and adult care, as well as an individualised process addressing HIV education, and barriers to transition such as stigma, mental health, cognitive disorders, and psychosocial factors [17].

Focus groups carried out with adolescents living with sickle cell disease and their caregivers to understand their perspective of the transition process found adolescents have three major concerns about transitioning to adult care providers:

- leaving people they are familiar and comfortable with;
- seeing a doctor who is unfamiliar with their medical condition; and
- having fears that their parent/caregiver would not let them grow up.

The caregivers identified similar concerns including:

- leaving a familiar place with staff they trust;
- losing their own support system;
- anticipating their own role change;
- concerns the adolescent won't advocate for themselves; and
- the adolescent seeing a doctor who is unfamiliar with the disease or condition [18].

In the UK a patient engagement project delivered by CHIVA in 2015 'Treat Me Like This' consulted young people on their experiences of transition. The positive aspects of their experiences in paediatric clinics are shown in Box 1 and the differences in paediatric and adult care the project identified are shown in Box 2.

Several key characteristics of the transition process illustrate it is multifaceted and impacts not only on

Box 1. Some positive aspects of young people's experience of attending paediatric clinics

- Being able to access clear information on medicine
- Friendly staff/seeing familiar faces each time
- Being rewarded for taking medicine
- Staff being protective over your health, feeling looked after
- Having extra time in appointments
- Working with you and your parents

Box 2. Some key differences described by those who had transferred to adult clinics

- You are expected to be more independent
- The clinic is less noisy and calmer
- It is less fun and there is no food!
- More people your age
- It can feel uncomfortable and awkward
- Doctors rely on you to look after yourself – the responsibility for your health changes

the medical care but also psychosocial and educational needs of adolescents. It is also relational, and may be associated with relationship loss for young people who have spent many years in paediatric care with well-established relationships, and the loss of parental or carer involvement in clinical care. It signifies a time of change and increased responsibilities for which some will be more ready and prepared for than others.

F. Conclusion

Transition represents a time of uncertainty, and may follow a long period of medical and social complexity in young people's lives. Long-term positive health prognosis can hinge on a successful transition from paediatric to adult-oriented care.

Transition presents an opportunity to engage young people in adult-oriented care successfully and avoid disruptions to care when well planned and fully supported. However transition also presents risks. It can result in disengagement from care and risks to health, which may be most acute for young people living with HIV in early adulthood, and especially so for those with known difficulties around adherence.

Barriers to successful transition can be down to a lack of readiness in the young person, insufficient support and attention to knowledge and skill requirements, and poorly-defined structural processes to support the transition to adult care, with a lack of flexibility in approach.

Successful transition is framed around assessment of readiness and attention to knowledge and skills-development support for young people, addressing psychosocial issues and mental health support needs, providing early opportunities to support empowerment, as well as the development of clear structural models and processes that are flexible enough to meet individual needs. Those working in adult clinic settings and wider support services need to be prepared to meet young people where they are and have an open, holistic, and flexible approach to addressing their needs. This may require adaption to working practice, ethos, culture, approaches and organisational structures, which are more typical in adult-oriented clinical settings, to ensure healthcare professionals are able to provide support and care aligned to the distinct needs of young people.

G. Further information and resources

1. CHIVA Transition Guidelines (2017)

As well as outlining the specific complexities for many in this group of young patients, as explored earlier in this article, the CHIVA Transition Guidance illustrate different models of transition that may be adopted in various settings [4].

Model 1 – Family clinics: where young people are cared for by Family Clinics, the transition to adult care can be integrated. 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 can visit or have consultations with the care teams on their own.

Model 2 – Specialist services: 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, and will require paediatric and adult services fully understanding the transition process and working 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. However it may require a further transition into adult services at some future point.

This guideline suggests that any chosen model will require a named lead for transition to develop and maintain the multidisciplinary links between paediatric and adult services. The guideline emphasises the relationship between paediatric and adult services as ongoing, and the need for a named practitioner in adult services who will continue to follow up the attendance and care in the years following transition.

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 transition period.

Time out activity 3

Do you have a named transition lead in your clinic? Find out who this is.

What is the transition model used where you work?

If you are not familiar with this find out how transition is managed in your clinic.

The CHIVA Transition Guidance is available at: www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf

2. The Royal College of Paediatrics and Child Health

The organisation identifies points for successful transition, one of which is developing a person-centred transition plan that is developmentally appropriate and regularly reviewed. Here there is a focus on the need to empower young patients and actively support them becoming involved in their healthcare decisions.

A key approach shared in this guidance is to engage young people in *asking three questions* in relation to choices, which need to be made about their health care:

- What are my options?
- What are the pros and cons of each option for me?

- How do I get support in making a decision that is right for me?

Royal College of Paediatrics and Child Health's Best practice examples of health transition can be found at: www.rcpch.ac.uk/resources/best-practice-examples-health-transition/

3. Ready Steady Go

The 'Ready Steady Go' transition resource pack was developed by the Transition Steering Group led by Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust.

Ready Steady Go is a structured, but adaptable, transition programme. A key principle throughout Ready Steady Go is empowering young people to take control of their lives and equipping them with the necessary skills and knowledge to manage their own health care confidently and successfully in both paediatric and adult services [13].

The programme works towards the young person being seen in clinic on their own, being responsible for changing their appointments and knowing from whom and when they should seek help. This comprehensive resource is now used widely across a broad range of transitioning services. The tools support holistic assessments of needs and assess readiness to transition and ongoing needs post transfer to adult care. Separate assessment tools have been developed for use in paediatric and adult care settings.

The assessments are framed for the 'Ready', 'Steady', 'Go' stages. The 'Go' stage indicates readiness to transition and includes '*knowledge*', broken down into sub-categories, such as '*describes condition effects and prognosis*', '*knows how to make/alter appointments*', and '*knows key team members and their roles*' with the traffic light system applied to indicate progress. Further assessment areas include '*self-advocacy*', and an understanding of the issues around a '*healthy lifestyle*', including sexual health. Reviewing '*educational and vocational issues*' to ensure young people have a plan to achieve their potential, and '*psycho-social issues*'. The questions are deliberately broad, providing an opportunity for discussion. The aim of 'Ready Steady Go' is that the young person will be able to manage their health care successfully not just in their local service but in any adult service across the country.

During the 'Go' stage, the young person is introduced to the adult team. It is suggested the introduction should be at least 1 year prior to transfer and earlier in the programme if resources permit. The number of joint clinics with the adult team will be dependent on the needs of the young person and their carer. Prior to the move, a letter is written to the adult team summarising the medical condition of the young person and their progress through the 'Ready Steady Go' programme and any issues that are outstanding or of concern.

At the first appointment in adult services the young person completes a 'Hello to Adult Services'. The 'Hello' questionnaire follows the same format as the 'Go' questionnaire for familiarity and to support the continued delivery of holistic care, self-management and shared decision making in adult services. Any issues raised are addressed, goals set, progress monitored and recorded in the 'Hello to Adult Services' transition plan. Periodically the 'Hello' questionnaire is reused to ensure they maintain knowledge and skill levels and that any new or ongoing concerns or problems are addressed [13].

More information on the Ready Steady Go programme is available at: www.uhs.nhs.uk/readysteadygo

4. Home, Education/employment, Peer Group Activities, Drugs, Sexuality, and Suicide/depression (HEADSS) tool

This psychosocial interview tool is for use with adolescents to enable broad wellbeing assessments and supports a psychosocial history to be taken in a health settings. It provides guidance on types of questions and framing to enable supportive conversations with adolescents, to establish trust and open dialogue, with an emphasis on open, non-judgemental and confidential approaches.

The HEADSS tool can be viewed here: www.bcchildrens.ca/Youth-Health-Clinic-site/Documents/headss20assessment20guide1.pdf

5. Developmentally Appropriate Healthcare Toolkit

Developmentally Appropriate Healthcare (DAH) recognises the need to empower young people by embedding health education and health promotion in consultations. This toolkit gives practical suggestions about how health care can be tailored to young people's needs as they develop and change through adolescence into young adulthood. Aimed at 10–24 year-olds DAH focuses on the approach of healthcare providers, articulating that young people need to be acknowledged as a distinct group, considering how healthcare professionals engage and communicate with young people and how services are planned, delivered and commissioned. The toolkit emphasises focus on the specific needs of young people as a distinct group working across teams in the organisation.

Key steps to achieving developmentally-appropriate health care for young people are outlined, such as:

- Participation, engagement and co-production opportunities for young people in the organisation
- Organisational culture and environment – adapting the environment and the culture in ways to ensure young people feel it is a safe and appropriate space for them
- Training and development opportunities – support staff training on youth friendly approaches, see 'Your Welcome' Quality criteria for health services. DH 2011.

The toolkit by DAH: Making healthcare work for young people is available at: www.northumbria.nhs.uk/wp-content/uploads/2017/04/nhs-making-healthcare-work-web-02.pdf

H. Acknowledgements

Funding

This article has been supported by an educational grant from the MAC AIDS fund. The company has had no editorial input to the article.

Conflicts of interests

The authors declare no conflicts of interests.

I. References

1. Department of Health. National Service Framework for children, young people and maternity services 2004. Available at: assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/199952/National_Service_Framework_for_Children_Young_People_and_Maternity_Services_-_Core_Standards.pdf (accessed March 2020).
2. Violori A, Cotton MF, Gibb DM, et al. Early Antiretroviral therapy and mortality among HIV-infected infants. *N Engl J Med* 2008; **359**(21): 2233–2244.
3. Fish R, Judd A, Jungmann E, O'Leary C, et al. Mortality in perinatally HIV infected young people in England following transition to adult care: An HIV Young Persons Network (HYPNet) audit. *HIV Med* 2014; **15**(4): 239–244.
4. Foster C. CHIVA Guidance on transition for adolescents living with HIV. CHIVA, 2017. Available at: www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf (accessed January 2020).
5. Collaborative HIV Paediatric Study. *CHIPS Collaborative HIV Paediatric Study Annual Report 2018/19*. CHIPS, 2019. Available at: www.chipscohort.ac.uk/media/1089/2019-chips-annual-report-v10.pdf (accessed January 2020).
6. Chappell E, Lyall H, Riordan A, et al. The cascade of care for children and adolescents with HIV in the UK and Ireland, 2010 to 2016. *J Int AIDS Soc* 2019; **22**(9): e25379.
7. Collins J I, Foster C, Tostevin A, et al. Clinical status of adolescents with perinatal HIV at transfer to adult care in the UK/Ireland. *Clin Infect Dis* 2017; **64**(8): 1105–1112.
8. Asad H, Collins IJ, Goodall R, et al. Mortality and AIDS-defining events among young people with PHIV following transition to adult care in the UK. *10th International Workshop on HIV Paediatrics*. 21–22 July 2018, Amsterdam, the Netherlands. Poster abstract 27.
9. Asad H, Sabin C, Collins IJ, et al. Severe immunosuppression and viral failure in adult care among antiretroviral therapy-experienced young people with HIV in the UK. *10th International Workshop on HIV Paediatrics*. 21–22 July 2018, Amsterdam, the Netherlands. Abstract 19.
10. Foster C, Ayers S, McDonald S, et al. Clinical outcomes post transition to adult services in young adults with perinatally acquired HIV infection: mortality, retention in care and viral suppression. *AIDS* 2020; **34**(2): 261–266.
11. Brown AE, Nash S, Connor N, et al. Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK. *HIV Med* 2018; **19**(8): 505–512.
12. Judd A, Collins I J, Parrott F, 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; **20**(Supple 3): 21577.
13. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: Ready Steady Go. *Arch Dis Child Educ Pract Ed* 2015; **100**(6): 313–320.
14. Kipps S, Bahu T, Ong K, et al. Current methods of transfer of young people with type 1 diabetes to adult services. *Diabet Med* 2002; **19**: 649–654.
15. Bryden KS, Dunger DB, Mayou RA, et al. Poor prognosis of young adults with type 1 diabetes: a longitudinal study. *Diabetes Care* 2003; **26**(4): 1052–1057.
16. Wiener L, Battles H, Ryder C, Zobel M. Transition from a paediatric HIV intramural clinical research program to adolescent and adult community-based care services: assessing transition readiness. *Soc Work Health Care* 2007; **46**(1): 1–19.
17. Dowshen N, D'Angelo L. Health care transition for youth living with HIV/AIDS. *Pediatrics* 2011; **128**(4): 762–771.
18. Hauser E, Dorn L. Transitioning adolescents with sickle cell disease to adult-centered care. *Paediatr Nurs* 1999; **25**(5): 479–488.

Correspondence: Amanda Ely
amanda.ely@chiva.org.uk