Growing Up with HIV: Transition in Children's and Adult Services:

A Chiva/NHIVNA National Audit 2025–26

No conflicts of interest

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Chiva and NHIVNA Nurse-Led Transition Audit 2025

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Chiva's mission

To ensure that children, young people and young adults growing up with HIV become healthier, happier and more in control of their own futures.

Transition Clinic Models

Young Adult Clinic

- Clinic specifically designed for young people and young adults who have grown up with HIV – Some have no upper age limit, some do.

Lifelong Clinic

- Care continues with the children's team along with adult colleagues

Adult clinic same hospital

- Transition to an adult service within the same hospital or trust

Adult clinic elsewhere

- This includes sexual health clinics and other clinics away from the children's clinic hospital

Background

- Transition care is a complex aspect of the management of children and young people living with HIV and service delivery varies hugely across the UK.
- Transition care encompasses not only the transfer of medical care from paediatric to adult teams but also the holistic management of young person and the problems they face.
- This national clinical audit was designed to explore the variation between these services and how they handle the transition from paediatric to adult HIV services.
- Service practices were benchmarked against the Chiva Standards of Care, BHIVA Standards of Care, Chiva Transition Guidance, and recommendations from the BHIVA transition audit.

Aims

Assess the current landscape of transition care and the different transition models in practice across the UK

Benchmark responses against the current guidelines and standards of care

Provide Recommendations for future practice

Methods

- The audit was piloted in a large paediatric, adult and young adult clinic before national distribution to confirm feasibility of the audit.
- Services were contacted between June – December 2025.
- Contacts were initially gathered via NHIVNA and Chiva memberships, national conferences and mailouts.
- Follow up communication was via targeted email contact.
- Responses were recorded using a Microsoft Forms platform for both service evaluation and case note reviews.
- Standard were benchmarked at ≥90% unless otherwise stated in published national standards.

Results

Service Evaluations

Responses were received from 24 adult and 17 Children's services. One response was excluded due to duplication.

Case Note Review

86 Case note reviews were received in total. 52 reviews from adult services and 34 from children's services.

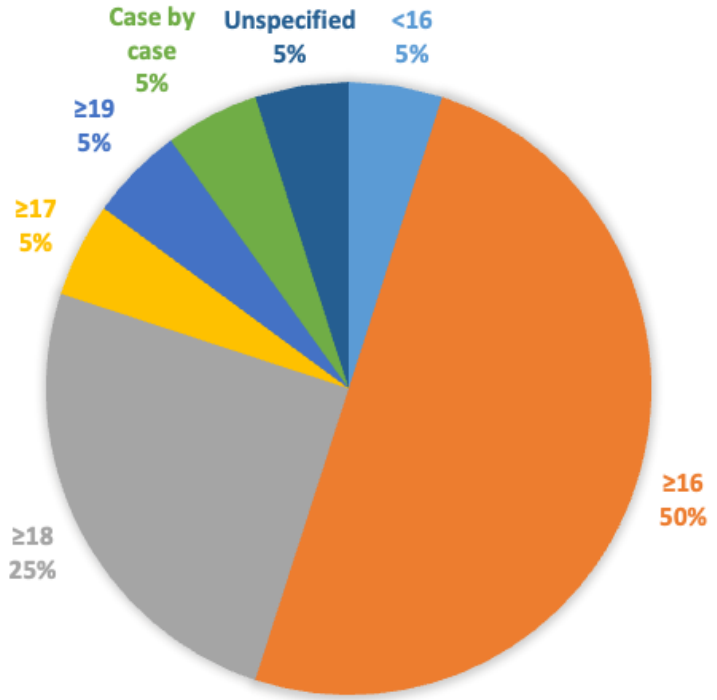
Audit Responses

Standard	Children's service audit response (n=16)	Adult Service audit response (n=24)	Combined	Standard met[1]
90% of young adults have met the adult team before transition	93.8% (15)	66.7% (16)	77.5% (31)	No
Documented discussion of transition document with the young person	75% (12)	N/A	N/A	Yes
Young people supported in developing independence by attending clinic alone	100% (16)	N/A	N/A	Yes
Documentation of Adverse Childhood experiences e.g Familial death related to HIV	93.8% (15)	100% (24)	97.5% (39)	Yes
Sexual health support and advice offered in clinic	100% (16)	100% (24)	100% (40)	Yes
Availability of sexual health screening	62.5% (10)	95.8% (23)	82.5% (33)	No
Discussion of U=U documented	100% (16)	100% (24)	100% (40)	Yes
Availability of contraception in clinic	15.8% (3)	62.5% (15)	45% (18)	No
Discussion about access to PrEP	93.8% (15)	95.8% (23)	95% (38)	Yes
Discussion about access to PEP	93.8% (15)	95.8% (23)	95% (38)	Yes
Mental Health screening carried out routinely?	50% (8)	70.8% (17)	62.5% (25)	No
Adherence and challenges to taking medications explored	100% (16)	100% (24)	100% (40)	Yes
Side effects monitored / asked regularly	100% (16)	100% (24)	100% (40)	Yes
Service having a dedicated transition MDT	43.8% (7)	45.8 (11)	45% (18)	No
Service having a named transition lead	75% (12)	75% (18)	75% (30)	No
Adult services having young people disengage with care post transition	N/A	37.5% (9)	N/A	N/A
Standard	**Children's Service Case Note review (n=34)**	**Adult Service Case Note Review (n=52)**	**Combined Case Note Review (n=86)**	**Standard met[1]**
Paediatric team involvement 12 months post transition	67.6% (23)	42.3% (22)	52.3% (45)	No
Documentation of Transition Document	79.4% (27)	65.4% (34)	70.9 (61)	No

Service Evaluation

Age of Transition

- In 2 of the 40 centres that responded young people transitioned to adult services before the age of 16.
- In half of the centres that responded the lower age limit to transition from children's to adult services was 16 years old.
- 25% of the centres that responded transition their young people at 18 years old.
- In 2 centres their decision to transition a child or young person over to the adult team was determined on a case-by-case basis.
- In all centres where young people may stay in paediatric services above 18 years of age this was due to evaluation of that person's specific care needs, i.e. a learning disability.



Service Evaluation

Mental Health Screening

- Only half of children's services screen for mental health routinely. 37.5% (6) do not screen for mental health routinely.
- Only 3 services screen at every appointment, the majority of responses (7) screen on an as required basis. 5 of the services did not provide qualification on if/when screening is carried out.
- 25% (4) of services use a psychologist for this screening, 5 use specific questions, 2 use general questions and 1 service uses a questionnaire and mental health worker.
- 70.8% (17) of adult services screen for mental health issues routinely, 3 services do not routinely screen.
- 7 services screen at every appointment, 5 screen annually, 7 screen on an as required basis. 4 services did not qualify the frequency of their screening and 1 service was unsure.
- 62.5% (17) of the services use specific questions to screen and 4 services use a questionnaire. 1 service uses both of these methods to screen.

Service Evaluation

Transition Documentation

- Transition documents help structure the process of moving from children's to adult services and are designed to be digestible by the child or young person.
- 50% (8) of the children's services reported that they use the 'Ready Steady Go' transition document, whilst 75% (12) of services use a transition document.
- 31.3% (5) of the children's services think that a digital version of a transition document would be beneficial and 50% (8) were unsure.
- Only half of the services reported always going through the transition document with their young people, and 25% (4) never do this.
- Less than half (7) always offer a copy of the documentation to young people, 3 services never do this.
- In 71% (61) of the case note reviews there is evidence of a transition document.

Service Evaluation

45% (18) of all services have a dedicated transition MDT.

75% (30) of the services have a dedicated paediatric lead for transition, 67.5% (27) have a dedicated adult lead.

37.5% (9) of adult services report that some young people stopped attending post transition.

All services regularly ask and document about side effects of medications.

Adherence and challenges to taking medications are regularly explored in all services.

All services have documented discussions about U=U.

Case reviews

Contact post-transition

- In 53.5% (46) of the case note reviews (24 children's services and 22 adult) there is evidence that the paediatric team remains in contact with the young person for 12 months following transition.

Date of naming HIV

- A clearly documented date of naming HIV to the child or young person exists in 61.6% (53) of the case notes (25 children's, 28 adult)

Choice of adult centre

- In 85.3% (29) of the case note reviews from the children's services, there is documentation that the young person is asked their preference of adult centre to be transitioned into.

Date of meeting adult team

- In 61.8% (21) of the Children's service case note reviews there is a documented date of the young person meeting the adult service staff prior to transition.

Case Reviews

Paediatric follow-up.

- Only 23% (12) of adult case note have documentation that the young person was informed of their paediatric team following their care post-transition and only 10 services have documented consent of this.

Fraser competence.

- Fraser competence was only documented in only 20.9% (18) of all case reviews, 11 from children's services and 7 from adult services.

Joint meetings.

- In 40 of the case note reviews (16 from children's services and 24 from adult) there is documentation of a joint meeting of the services prior to transition.

Knowledge of HIV

- In 75.5% (65) of the case note reviews there is documented information detailing the young person's knowledge of HIV and confidentiality.

Summary

- The audit has highlighted the complexity of transitional care and variation in service delivery.
- Significant gaps in care were reported, with only ½ of children's services routinely screening for mental health issues, and only ¼ of services having access to a psychologist.
- This audit highlights the disparity between services across the UK, likely due to different funding, models and priorities in their patient populations.
- The audit has identified examples of good practice, and addresses gaps in care, informing future service development through findings and amplifying the unique needs of young people growing up with HIV.

Recommendations for future practice

- Services should prioritise adherence to the standards, supported by appropriate resource allocation.
- Develop transition MDTs as a service standard that includes named lead professionals.
- Paediatric teams should remain involved for a minimum of 12 months post-transition.
- All services should offer to share documentation with young people.
- Integrate transition frameworks with the digital age.
- Increase engagement of children and young people with their health.

Chiva

GROWING TOGETHER FOR HEALTH AND HAPPINESS

Thank you

References

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