

# A transition pathway: “All about me” – The Leeds approach (UK) Transition guidelines for clinics

**Maria Dowie**  
**Children and Young People’s**  
**HIV Clinical Nurse Specialist**



## Transition



UK statistics (CHIPS Data)

Transition Improvement model within Leeds Teaching Hospitals

CHIVA Transition document

Development of “All about me” (AAM) – Health information pack – Joint project with Dr Rachel Avison – Clinical Psychologist

Clinics - models, what young people want

Where do we go from here?



## Definition

**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> National Service Framework for children, young people and maternity services 2004.

[www.dh.gov.uk/publications](http://www.dh.gov.uk/publications).

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.

Department of Health CHaMSB. Transition: getting it right for young people. [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications).



## Mortality pre and post transfer to adult care (S.E. England) (Fish et al, HIV Medicine 2015 )

Age group/Type of care	Rate/100 person years	Rate ratio
13-15 yrs paediatrics	0.2	1.0
16-20yrs , paediatrics	0.3	1.4
16-20yrs, adults	0.5	2.7
>21yrs old, adults	0.9	4.9

### Contributing factors

- Long term non adherence – (79% children/adolescents undetectable on ARV's - Adults 97%)
- Treatment experienced older adolescents – (YAC 18 – 25yrs – 62% undetectable)
- Risky adolescent behaviour
- Sociodemographics
- High risk of mental health issues
- Neurocognitive impact
- Disengaging from adult care
- Reduction in cohort – reduction in specialist services



# UK Chips Data March 2019



- Multi centre cohort study
- 1908 children were last followed up or in shared care at clinics in the England network (including transfers to other clinics after March 2019)
- Follow-up status
  - 583 children in paediatric care
  - 105 left the country
  - 33 lost to follow-up<sup>1</sup>
  - 1084 transferred to adult care<sup>2</sup>
  - 103 died (2 in 2011, 1 in 2010, 6 in 2009, 7 in 2008, 3 in 2007, 4 in 2006, 3 in 2005 & 77 before 2005)

<sup>1</sup> Reported as lost to follow up by the clinic

<sup>2</sup> Includes 18 aged ≥21 years on 31<sup>st</sup> March 2019 and have no follow-up data reported to CHIPS for ≥5 years and assumed to have transferred to adult care

## Introducing West Yorkshire



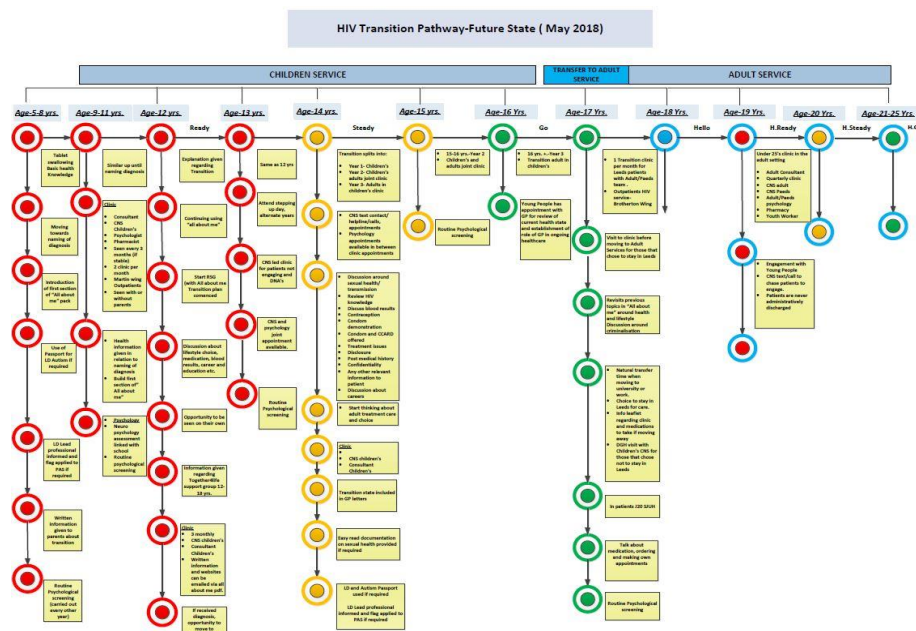
Age	Children & Young People
0 - 5	4
6 - 10	2
11 - 15	15
16 - 18	10
18 - 25	85
(Young Adults Clinic)	
26+ Adults	2,000



# Transition Improvement Model

## Leeds Teaching Hospitals NHS Trust

- Transition – integral part of HIV services for many years
  - Burdett Trust funding – Transition nurses (2015)
  - Identify stakeholders
  - Current state mapping/benchmarking
  - Future state mapping
- (You're Welcome Quality criteria, Nice guidance 2016)
- Gap analysis and implementation



## CHIVA guidance on Transition for adolescents living with HIV (2017)

([www.chiva.org.uk](http://www.chiva.org.uk))

### Models used in the UK

- *Specialist services handing over*  
Smaller centres
- *Family clinics*  
Arranged clinic times with adult services
- *Specialist service: separate youth clinic*  
Adolescent/transition clinics



## CHIVA guidance on Transition for adolescents living with HIV (2017)

### Overview

- Cohort complexity:  
medical issues, psychological issues, relationships/sexual health
- 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
- Encourage autonomy
- Meet the adult team
- Each YP should have a documented transition plan: date of naming of HIV, HIV knowledge, sexual health discussion, Frazer competency, discharge summaries
- List of information at transfer: medical history, social history



## AAM Health information pack

### Original idea



- Established transition pathway
- Develop localised information pack with yp
- Used throughout the whole time in the service as well as within support group
- Brief overview of a wide range of topics – tool to enable further discussions
- All using same language and information



## Sara



- Under Paediatric HIV care since 4 years old
- 18 at time of transfer to Adult HIV Service following planned transition
- Due to start Uni
- No concerns about cognitive function
- Adult team very surprised to discover...



***"Sara says she has never heard of CD4 or viral load?"***



Confused??



Team reflections

Is Sara’s story unique?

- Wanted to hear info back?
- Unable to say?
- Distracted?



- Lack of confidence?
- Felt uncomfortable to say?
- Retention of info?

- Was it us?
- Wrong timing?



- Language?
- Too much/ too little info?

Lack of repetition?

Different explanations in team?



## What we thought had gone well

- Documented information building (ages 4 – 18)
- Completed transition plan & 'Ready, Steady, Go'
- Attendance at local support group for 5 years
- Attended Transition Day



## Questions

- How do our young people best learn?
- How do we optimise their learning?
- How do we promote information retention?



## Step 1: How do young people learn & retain information?

### What we did...

- Focus group at local support group
- Discussions with young people & families in clinic
- Learning styles questionnaire ([www.educationplanner.org](http://www.educationplanner.org))

### What we found...

- Preference for visual learning
- Topics in smaller sections
- Interactive elements





## Step 2: Developing the pack with young people

### Young People

- Colourful
- Small units of information
- Own pack not an app
- Email-able pages if requested
- Pack held by clinic team
- Local information & services
- Ownership – illustrations by young people
- Quiz sections
- Fun facts



### The team

- For all – pre-naming to transfer
- Patient- centred/ flexible approach
- Evidence-based
- Guidance document re. current health info
- Learning log within pack to show progression
- Language age appropriate and reframed e.g. virus not referred to negatively
- Option to be continued in adult HIV service

## Step 3: Next steps

### Writing All About Me:

- Long process
- On-going review of content, format and layout
- Repeated drafts

### Who was involved:

- On-going focus groups with YP and families
- Medical illustration
- Peer review – colleagues locally/ regionally
- LTHT Governance panel approval

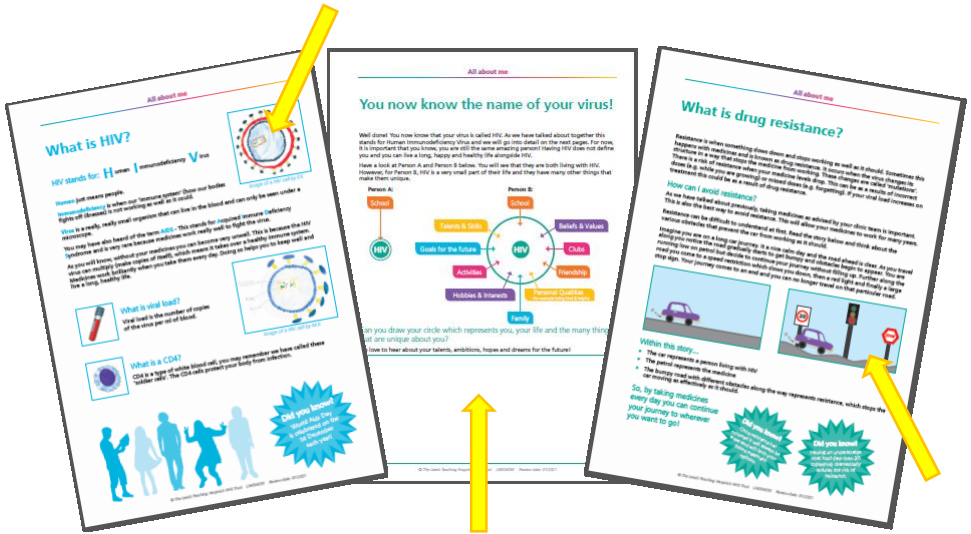


## Step 4: All About Me Launch Jan 2018

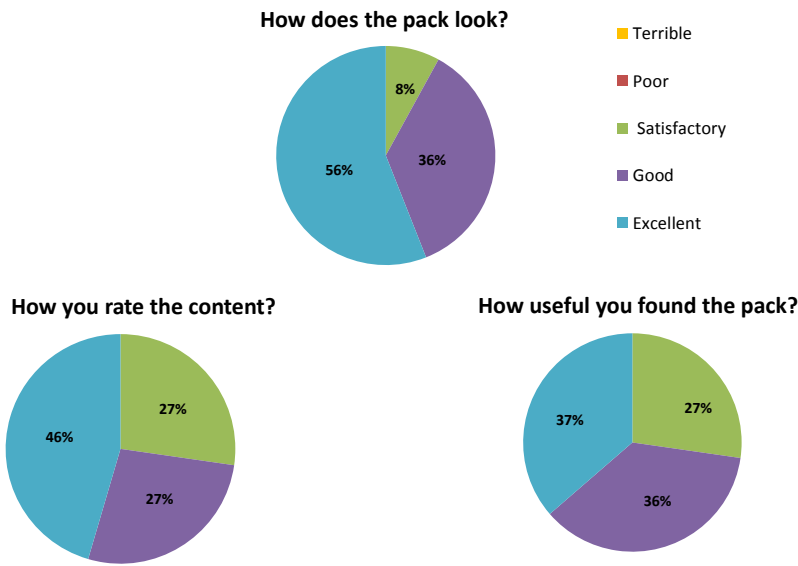
- All About Me (localised version) established in Paediatric & Transition clinics (Leeds)
- Developed a generic version for national use. Reviewed by CHIVA Youth Committee
- CHIVA website May 2019 [www.chiva.org.uk](http://www.chiva.org.uk)



# All About Me



## Quantitative feedback – young people



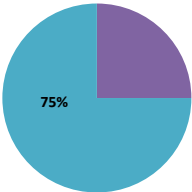
# Qualitative feedback – young people

*“Unique”*  
*“Very detailed and intriguing”*  
*“I like how there is so much advice and how it gives you your local information”*  
*“When there are pictures and diagrams it helps you understand better”*  
*“I’ve learnt much more that I didn’t know or understand before”*  
*“I like how questions are given to help you remember”*  
*“The ‘Did you know’ really reassures me”*  
*“It contains a lot of useful information for the future”*  
*“It is very colourful”*  
*“It is very useful as if I want a question answered I can search for it and discuss it”*  
*“It helps with how I am taking my medicine”*  
  
*“I might change the colours maybe”*  
*“Maybe you could add mini games in the sheets”*

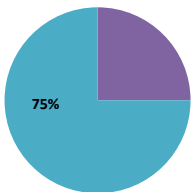


# Quantitative feedback – professionals

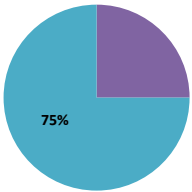
How does the pack look?



How do you rate the content?

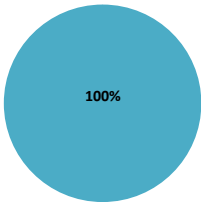


How useful you found the pack?



- Terrible
- Poor
- Satisfactory
- Good
- Excellent

Was this pack a useful tool in enabling further conversations?



## Qualitative feedback – professionals

- "We now have consolidated info"*
- "Colleagues can all work together"*
- "Good terminology in speaking about HIV"*
- "Bright and attractive"*
- "YP friendly language"*
- "Allows basic review in fact finding way"*
- "Triggers further discussions"*
- "User friendly – not overwhelming"*
- 
- "VL and CD4 charts need to be visible together"*
- "You could give pre appointment to choose topics"*
- "Use of e-version for updatable online records?"*



## Transition clinic

- Monthly MDT Transition clinic – Long established
- MDT meeting prior to each clinic
- Clinic runs 3pm to 6pm
- Same paed's CNS and Adult consultant within transition and young adult clinics
- Initially YP can be seen together with paed's/adult team
- Paeds team undertake early transition work and adult Consultant then takes over – topics important to them (AAM)
- Attend from 12 years
- Parents initially present during consultations then time spent alone with YP
- Adult service – personal choice



## Neurocognitive function

- Neurocognitive impact of living with HIV on the developing brain is becoming increasingly apparent.
- School performance, executive functioning..
- Yearly neurocognitive testing by Clinical Psychologist
- The WISC-IV (*Wechsler Intelligence Scale for Children- Fourth UK Edition*) assesses 4 main areas of thinking skills:

Verbal Comprehension; Perceptual Reasoning; Working Memory; and Processing Speed.

- Leeds cohort all below average for FSIQ
- Results shared in clinic as well as in education (With consent)



## Young Adults Clinic

- Initially monthly <25's MDT meetings
- Commenced YAC July 2017
- Majority vertical transmission but open to all
- Adult dept only open to <25's
- Three times yearly – Uni hols
- Clinic runs 3pm to 6pm
- MDT model
- Youth worker
- Music, food, games, yoga, social (option of another waiting area)
- Average 6 – 8 young people per clinic



# Feedback from young adults

Evaluation form completed at each clinic

## Young Adults:

- *It's a comfortable atmosphere*
- *Able to have more support*
- *I enjoyed meeting people*
- *I know everyone and they are all friendly*
- *I enjoy playing games and chatting to everyone*
- *Makes me feel more comfortable being with my age group*
- *Relaxing and friendly*
- *Fun activities*



## Professionals

- *Slightly chaotic – need to stick to appointment times*
- *Good for bringing young people together*
- *Less wary of attending adult clinic*
- *Some new patients shocked at the thought of socialising*
- *Nodes of possibility e.g. mentor/advise for each other*
- *Plenty of laughter filling clinic*



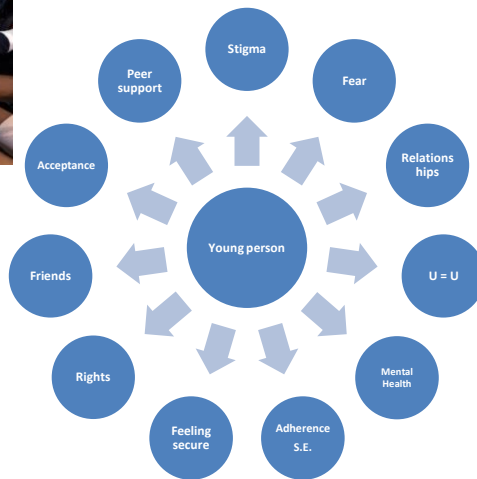
## Stepping Up Days



- Transition days – held every other year
- Interactive , fun – icebreakers, quiz,
- Cover a number of topics affecting adolescents including Uni talk, emotional well being, mindfulness
- Young people talking about personal experiences of transition
- Pizza
- Cinema



## HIV can be a small part of life but....What young people tell us



## What do young people tell us they want from clinic services/want services to acknowledge (CHIVA Youth Committee):

- Know what you're talking about
- Talk to me, not my parent/carer
- Private conversations about me make me feel anxious, involve me
- Take the time to give me medicine choices and explain the side effects
- Treat me my age
- Don't make assumptions
- Show an interest in my life
- HIV doesn't define me; I'll always be me first
- HIV does not stop me achieving my ambitions
- Confidentiality is really important to me; my health isn't something to gossip about
- HIV affects my mental health as well as my physical health
- Stigma hurts



## Treat me like this project



A group of young people living with HIV formed a guidelines group for clinic providers, parents and young people.

Explore and reflect upon their own experiences and use this to support clinical understanding of need.

Guidance for clinics:

Medication

- Consequences of not taking meds – non threatening, not applying pressure
- Understanding their lifestyles – medication regime
- Letter explaining ARV's/Side effects
- Making it clear they can ask about changing regimes
- Convey empathy re adherence challenges

Transition

- Ask if ready to move to adult clinic
- Try to ensure p/rent/carer attends first adult appointment
- Keep support from children's services going for a while
- Transferring with friend if possible can be helpful
- Leaflet on guide to changes
- Adult doctors need to be friendly
- Transition letter
- Offer topical anaesthetic in adult clinics



## Treat me like this project



Guidance on sexual health conversations:

- Hold general conversation first
- Use checklist of topics
- HCP knowledge and confidence
- Offer information in different ways
- Not in front of parents
- Convey positive messages

[www.chiva.org.uk](http://www.chiva.org.uk)





# Check list for clinic consultations

**Check list for clinic consultations:**  
This checklist was suggested by young people who took part in the CHIVA Treat Me Like This patient engagement project. To be used in clinic consultations to ensure that patients are able to decide what happens in their consultation.

**HIV Knowledge and Understanding:**

	Yes	No
What does viral load mean		
What does CD4 count mean		
How HIV is passed from one person to another		
How do children like me get HIV		
How HIV affects other people in my family		
How does my immune system work		

**Medicine:**




How do HIV medicines work		
What does resistance to HIV medicine mean		
Side effects from medicine		
Changing the time I have to take my medicine		
Tips to help me with taking my medicine		
I'm finding taking medicine really difficult at the moment		

**Friendship and relationships:**

	Yes	No
How to tell a friend or partner about my HIV		
Having safer sex		
How to use condoms		
Whether I have to tell someone I'm having sex with about my HIV		
HIV transmission in different sexual activities		
STIs		
How to have a baby without passing on HIV to the baby		
Having a sexual relationship with someone else who has HIV		

**Emotional and Social well being:**

Feeling low and worried		
Finding it difficult to be motivated		
Feeling angry and upset about having HIV		
Wanting to harm myself		
Feeling worried about my future with HIV		
How to meet other young people with HIV		
Struggling with my school or college		
Unhappy at home		
Not feeling safe		



## Where do we go from here?



- **Are we all aware whether young adults transferred from your paediatric care are still in active follow up in adult services?**

Monthly young adults MDT meeting to discuss under 25's  
Check on attendance - DNA process, never discharged from service. YP know we will always be there when needed.

- **Do we adequately address mental health issues?**  
Access to on going therapeutic support, quality of life questionnaire prior to each appointment to aid discussion during appointment, <25's support group, peer support , peer mentors – telephone support
- **Do we routinely ask about what else is going on in life?**

- **Can young adults see the same practitioner at appointments?**  
Transition/adolescent clinics, awareness of this issue when rebooking

- **Is the clinic environment youth friendly?**

Small changes can make a big difference

- **How are we giving up to date information?**

AAM, research: Injectables – Mocha trial

- **Are there any tips from young people you can implement in your clinic?**

Discussion/Questionnaires/focus groups and feedback





[www.chiva.org.uk](http://www.chiva.org.uk)

[https://www.youtube.com/watch?v=HHfW\\_uVzx8g](https://www.youtube.com/watch?v=HHfW_uVzx8g)

<https://youtu.be/7JyK1NUSzOQ>

## With thanks!

- Young people & families - Leeds Children's Hospital
- Leeds Paediatric and Adult HIV teams
- CHIVA

