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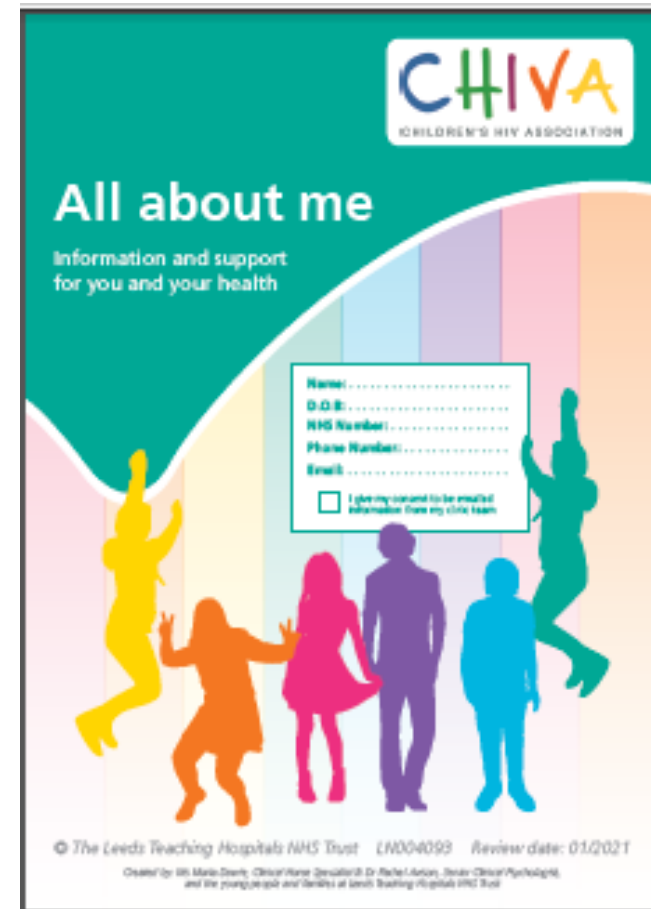
NATIONAL **HIV** NURSES ASSOCIATION
support | research | education

21st Annual Conference *of the* **National HIV Nurses Association (NHIVNA)**

27–28 June 2019 • Manchester Conference Centre

Transition: The Leeds Approach

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Children and Young People's
HIV Clinical Nurse Specialist



Transition: The Leeds approach

- Transition Improvement Model within Leeds Teaching Hospitals
- Established Transition clinic
- Recently developed Young adult service
- Development of “All about me”(AAM) – Health information pack (Joint project with Rachel Avison Senior clinical Psychologist)

Introducing West Yorkshire!



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

Transition Improvement Model

Leeds Teaching Hospitals NHS Trust

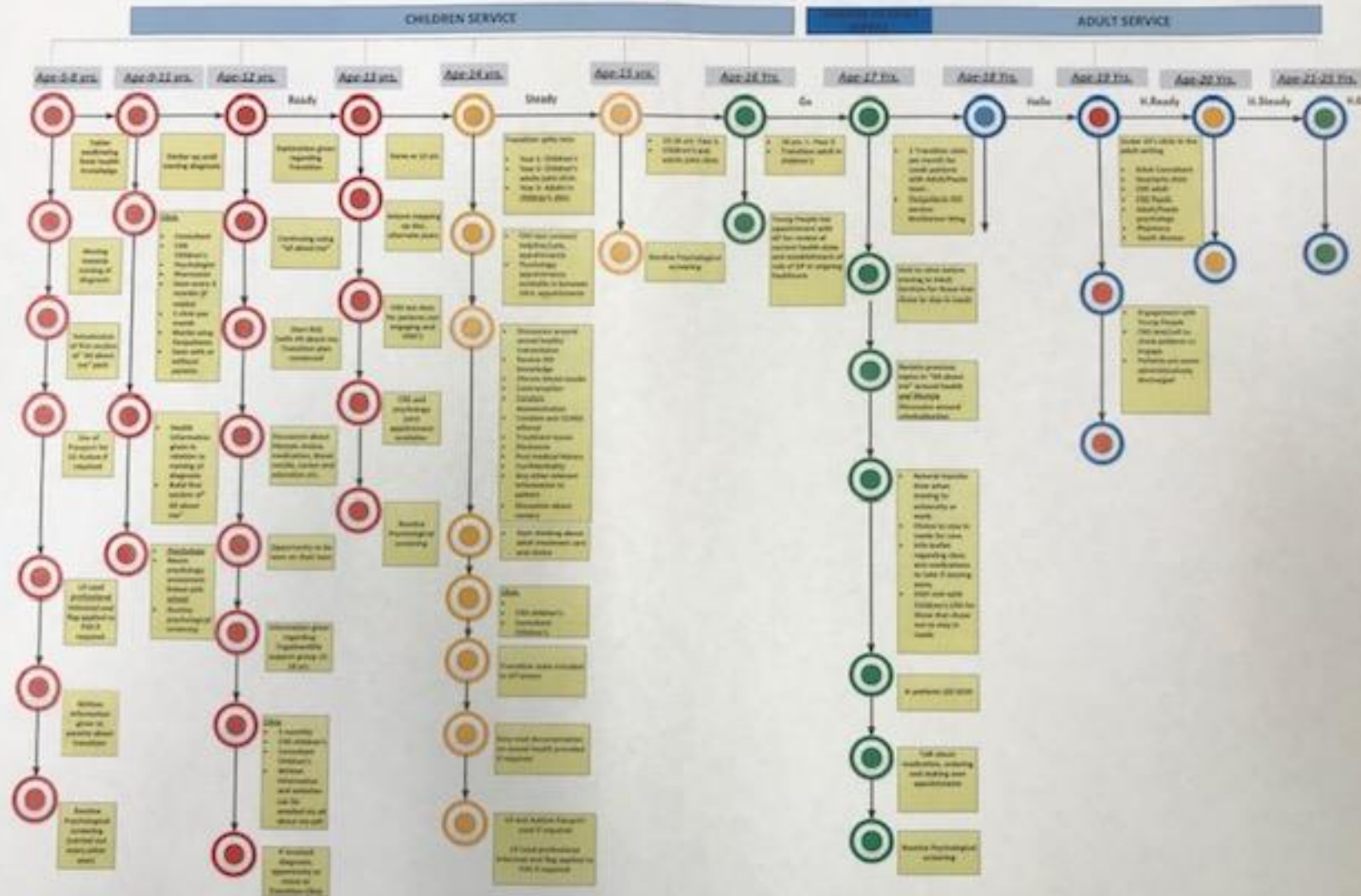
- Transition integral part of HIV services for many years
- Burdett Trust funding - transition nurses (2015)
- Identify stakeholders
- Current state mapping/Benchmarking
- Future state mapping

(You're welcome quality criteria, Nice guidance 2016)

- Gap analysis and implementation

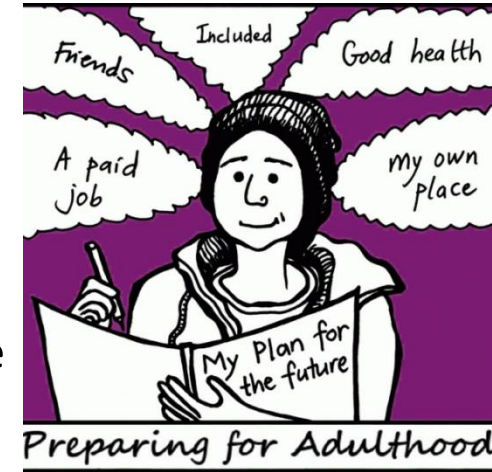


HIV Transition Pathway-Future State (May 2018)



Transition model

- 2010 – current transition model implemented into practice questionnaires, in depth discussions, review of services
- Monthly MDT Transition clinic
- MDT meeting prior to clinic
- Clinic time chosen by YP - 3pm – 6pm
- Continuity of staff between Transition/YAC
- Initially YP can be seen by paed/s/adult team together
- AAM embedded into clinic – initial transition work commenced by paed/s then adult consultant
- Topics important to YP – Seen as *whole person* - social, emotional, education
- Attend from 12 years (support group from 12yrs)
- Neurocognitive testing – Clinical psychologist
- Parents initially present during consultations then time spent alone with YP
- Transfer to adult service – personal choice





Stepping Up Days



- Transition days – held every other year
- Interactive , fun – icebreakers, games, quiz...
- Particular importance for the YP that don't attend Together4Life support group
- Cover a wide variety of topics affecting adolescents including Uni talk, emotional well being, mindfulness, peer support
- Young people talking about personal experiences of transition
- Pizza
- Cinema



Young Adults Clinic (YAC)

- Initially monthly <25's MDT meeting
- Consultations with YP
- First YAC clinic - July 2017
- Open to all – predominantly VT
- Adult dept only open to <25's
- Three times yearly – Uni hols
- MDT model
- Youth worker
- Dedicated social area - Music, food, games, yoga, chat (option of another waiting area)
- YP chose 3pm – 6pm
- Average 6 – 8 young people per clinic



Young adult clinic feedback

- 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*



All about me (AAM)

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



- Was under Paediatric HIV care since aged 4
- 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?”

Eh?

Eeh by gum. 'appen wi' flummoxed!



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?

Lack of repetition?



Language?

Too much/ too little info?

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 'Stepping Up' 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)

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
- Used alongside 'RSG'
- 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

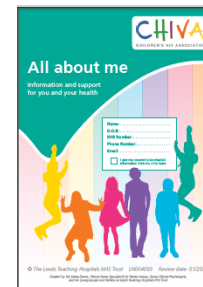
Who was involved:

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

What was involved:

- Applying for funding - graphic design & printing
- Time! – developed over a year
- Regular review and updates

AAM launched Jan 2018



All About Me

What is HIV?

HIV stands for: **H**uman **I**mmunodeficiency **V**irus

Human just means people.

Immunodeficiency is when our 'immune system' (how our bodies fight off illness) is not working as well as it could.

Virus is a really, really small organism that can live in the blood and can only be seen under a microscope.

You may have also heard of the term **AIDS** - This stands for **A**cquired **I**mmune **D**eficiency **S**yndrome and is very rare because medicines work really well to fight the virus.

As you will know, without your medicines you can become very unwell. This is because the HIV virus can multiply (make copies of itself), which means it takes over a healthy immune system. Medicines work brilliantly when you take them every day. Doing so helps you to keep well and live a long, healthy life.

What is viral load?
Viral load is the number of copies of the virus per ml of blood.

What is a CD4?
CD4 is a type of white blood cell, you may remember we have called these 'soldier cells'. The CD4 cells protect your body from infection.

Did you know?
World Aids Day is celebrated on the 1st December each year!

Image of a HIV cell by IVE

Image of a HIV cell by M&L

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You now know the name of your virus!

Well done! You now know that your virus is called HIV. As we have talked about together this stands for Human Immunodeficiency Virus and we will go into detail on the next pages. For now, it is important that you know, you are still the same amazing person! Having HIV does not define you and you can live a long, happy and healthy life alongside HIV.

Have a look at Person A and Person B below. You will see that they are both living with HIV. However, for Person B, HIV is a very small part of their life and they have many other things that make them unique.

Person A:
School
HIV

Person B:
School
Talents & Skills
Goals for the future
Activities
Hobbies & Interests
Family
Beliefs & Values
Clubs
Friendship
Personal Qualities
Personnel, Goals & Beliefs

HIV

Can you draw your circle which represents you, your life and the many things that are unique about you?

We love to hear about your talents, ambitions, hopes and dreams for the future!

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What is drug resistance?

Resistance is when something slows down and stops working as well as it should. Sometimes this happens with medicines and is known as drug resistance. It occurs when the virus changes its structure in a way that stops the medicine from working. These changes are called 'mutations'. There is a risk of resistance when your medicine levels drop. This can be as a result of incorrect doses (e.g. while you are growing) or missed doses (e.g. forgetting). If your viral load increases on treatment this could be as a result of drug resistance.

How can I avoid resistance?
As we have talked about previously, taking medicines as advised by your clinic team is important. This is also the best way to avoid resistance. This will allow your medicines to work for many years. Resistance can be difficult to understand at first. Read the story below and think about the various obstacles that prevent the car from working as it should.

Imagine you are on a long car journey: it's a nice calm day and the road ahead is clear. As you travel along you notice the road gradually starts to get bumpy and obstacles begin to appear. You are running low on petrol but decide to continue your journey without filling up. Further along the road you come to a speed restriction which slows you down, then a red light and finally a large stop sign. Your journey comes to an end and you can no longer travel on that particular road.

Within this story...

- The car represents a person living with HIV
- The petrol represents the medicine
- The bumpy road with different obstacles along the way represents resistance, which stops the car moving as effectively as it should.


So, by taking medicines every day you can continue your journey to wherever you want to go!

Did you know?
Once resistance has occurred it will always be there and will only be managed with your doctor.

Did you know?
Having an unprotected viral load (over 20 copies/ml) dramatically reduces the risk of resistance.

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Step 5: Evaluation

 Leeds Children's Hospital

All About Me Evaluation - Young People

We would really value your feedback on the new All About Me pack.


1. How would you rate how the pack looks? (e.g. layout, design, colour)
Please circle a number on the scale below between 1 and 5:

(Poor) 1 _____ 2 _____ 3 _____ 4 _____ 5 (Excellent)
2. How would you rate the content in the pack? (e.g. written information, the interactive sections). Please circle a number on the scale below between 1 and 5:

(Poor) 1 _____ 2 _____ 3 _____ 4 _____ 5 (Excellent)
3. How would you rate how useful you found the pack? Please circle a number on the scale below between 1 and 5:

(Poor) 1 _____ 2 _____ 3 _____ 4 _____ 5 (Excellent)
4. What do you like most about the pages in this pack? (Please also use the back of this evaluation form if needed).
5. Is there anything you would like to change/ add to improve the pack? (Please also use the back of this evaluation form if needed).

The Leeds Teaching Hospitals NHS Trust

 Leeds Children's Hospital

All About Me Evaluation - Professionals

We would really value your feedback on the new All About Me pack.

1. How would you rate how the pack looks? (e.g. layout, design, colour)
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(Poor) 1 _____ 2 _____ 3 _____ 4 _____ 5 (Excellent)
3. How would you rate how useful you found the pack? Please circle a number on the scale below between 1 and 5:

(Poor) 1 _____ 2 _____ 3 _____ 4 _____ 5 (Excellent)
4. Was this pack a useful tool in enabling further conversations?

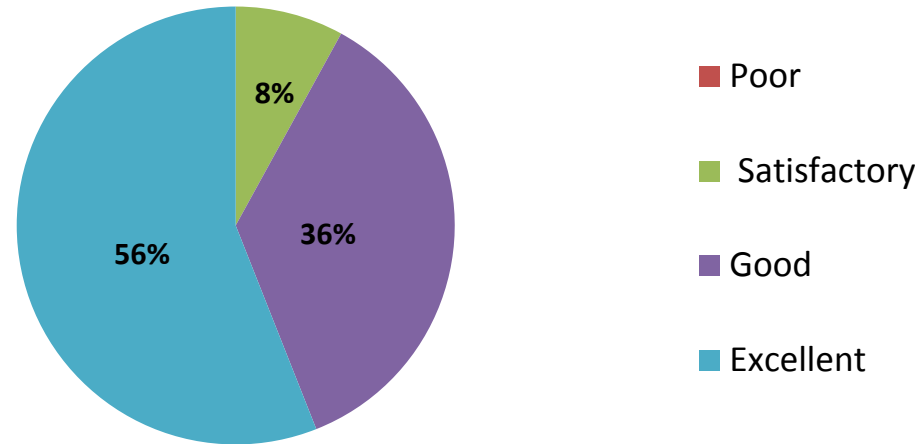
(Poor) 1 _____ 2 _____ 3 _____ 4 _____ 5 (Excellent)
5. What do you like most about the pages in this pack? (Please use the back of this evaluation form).
6. Is there anything you would like to change/ add to improve the pack? (Please use the back of this evaluation form).

Please email to marladowle@nhs.uk or post to:
Marie Dowle, Children's Nurse Specialist
Room 29, Paediatric Office, 4 Floor, Grosvenor Wing, Leeds
General Infirmary, Great George Street, Leeds, LS1 5EQ

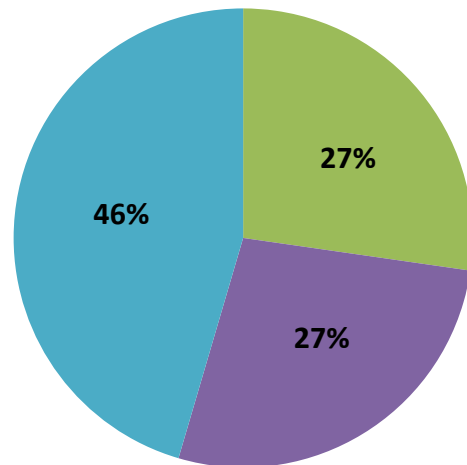
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Quantitative feedback – young people

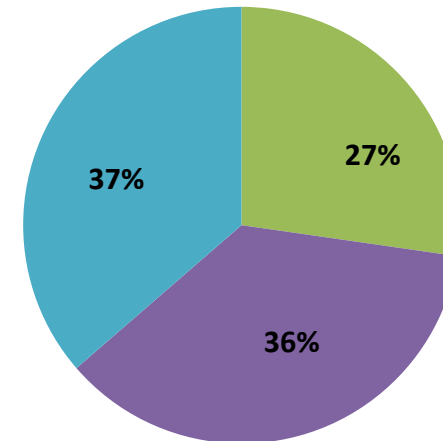
How does the pack look?



How you rate the content?



How useful you found the pack?



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”

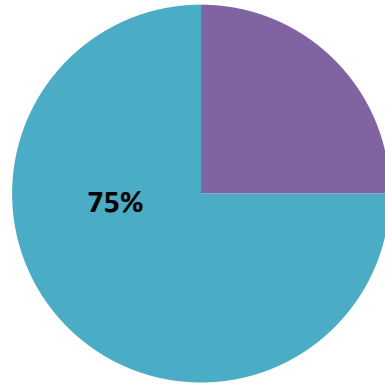
“It helps with how I am taking my medicine”

“I might change the colours maybe”

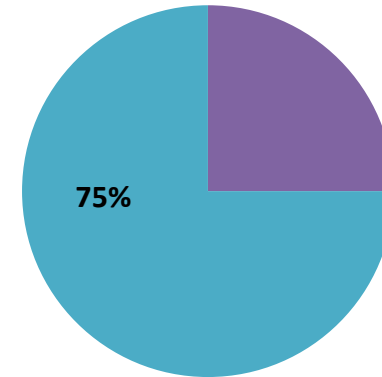
“Maybe you could add mini games in the sheets”

Quantitative feedback – professionals

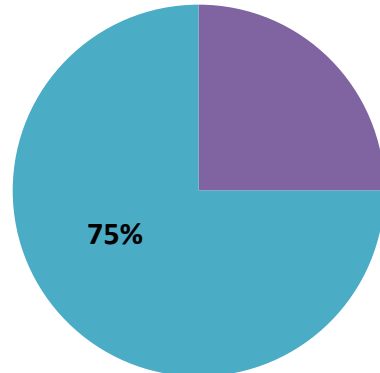
How does the pack look?



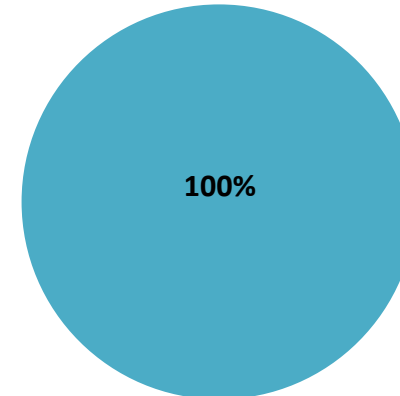
How do you rate the content?



How useful you found the pack?



Was this pack a useful tool in enabling further conversations?



- Terrible
- Poor
- Satisfactory
- Good
- Excellent

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?”

Next steps

- Generic version of AAM for national use - approved by CHIVA committee and CHIVA youth committee

Localised copy found here:

<http://flipbooks.leedsth.nhs.uk/LN004093.pdf>

Generic copy found here:

<https://chiva.org.uk/resources/> <https://chiva.org.uk/resources/all-about-me/>

- On-going evaluation and updates
- Receptive to all feedback. Please send to: **mariadowie@nhs.net**

- Filming planned for adolescent HIV transition service
<http://www.lchtv.com/transitions-films>



With thanks!

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

