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!

<table>
<thead>
<tr>
<th>Age</th>
<th>Children &amp; Young People</th>
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<tr>
<td>0 - 5</td>
<td>4</td>
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<tr>
<td>6 - 10</td>
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<td>11 - 15</td>
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<td>16 - 18</td>
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<td>18 - 25</td>
<td>85</td>
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<td>(Young Adults Clinic)</td>
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<td>26+ Adults</td>
<td>2,000</td>
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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
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 paeds/adult team together
- AAM embedded into clinic – initial transition work commenced by paeds 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 says she has never heard of CD4 or viral load?”
Eh?

Eeh by gum. ‘appened 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?
Different explanations in team?

Language?
Too much/ too little info?
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?

You are HIV-positive, which means you have been infected with HIV, the virus that causes AIDS. HIV is a serious condition that can lead to death, but it is treatable and can be controlled with medication. It is spread through sexual contact, sharing needles, and from mother to child during pregnancy, childbirth, or breastfeeding.

What is drug resistance?

Drug resistance occurs when HIV becomes resistant to the medications that are used to treat it. This can happen when a person does not take their medications as prescribed or when they stop taking them too early. Drug resistance can make it more difficult to control HIV and can lead to more severe symptoms.

What is the name of your virus?

You have HIV, so your virus is HIV.

How do you feel about your virus?

I am living with HIV and I am proud of it. I am grateful for the support and understanding I have received.

What is your advice for others?

HIV is a serious condition, but it is treatable and can be controlled with medication. It is important to take your medications as prescribed and to get regular medical check-ups.

What is AIDS?

AIDS is a very serious condition that can lead to death. It is caused by HIV and is characterized by a number of symptoms, including weight loss, fever, and weakness.

What do you think about your virus?

I am living with HIV and I am proud of it. I am grateful for the support and understanding I have received.

How do you feel about your virus?

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Step 5: Evaluation

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 6 (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 6 (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 6 (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).

All About Me Evaluation - Professionals

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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 6 (Excellent)

4. Was this pack a useful tool in enabling further conversations?
   (Poor) 1 2 3 4 5 6 (Excellent)

5. What do you like most about the pages in this pack? (Please also use the back of this evaluation form).

6. Is there anything you would like to change/ add to improve the pack? (Please also use the back of this evaluation form).
Quantitative feedback – young people

How does the pack look?
- Terrible: 8%
- Poor: 56%
- Satisfactory: 36%
- Good: 27%
- Excellent: 27%

How you rate the content?
- Terrible: 8%
- Poor: 27%
- Satisfactory: 46%
- Good: 27%
- Excellent: 27%

How useful you found the pack?
- Terrible: 8%
- Poor: 36%
- Satisfactory: 37%
- Good: 27%
- Excellent: 27%
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?

- Terrible
- Poor
- Satisfactory
- Good
- Excellent

How do you rate the content?

- Terrible
- Poor
- Satisfactory
- Good
- Excellent

How useful you found the pack?

- Terrible
- Poor
- Satisfactory
- Good
- Excellent

Was this pack a useful tool in enabling further conversations?

100%
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.leedstnhs.uk/LN004093.pdf

  Generic copy found here:  

• 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