# Improving Transition

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| 10:00 | **Registration**  Tea and coffee on arrival. | |  |
| **SESSION** **1** Chair: Simon Pleydell, Chair of the External Advisory Board to the Programme | | | |
| 10:30 | Introduction. | | Jim Mackey  Chief Executive, NHS Improvement |
| 10:40 | Background to transition and the implications of our research. | | Allan Colver |
| 11:15 | What works in transitional care?  What does economic analysis tell us? | | Helen McConachie  Luke Vale |
| 11:35 | Discussion and questions. | |  |
| 11:50 | **Coffee and biscuits** | |  |
| 12:10 | What is Developmentally Appropriate Healthcare?  Lessons learnt and implications for commissioners. | | Tim Rapley  Greg Maniatopoulos |
| 12:30 | Discussion and questions. | |  |
| 12:40 | What are the implications of the research findings for adults’ services? | | Helena Gleeson, Royal College of Physicians |
| 12:50 | Discussion and questions. | |  |
| **SESSION 2a** | | | |
| 13:00 | Breakout sessions. | |  |
|  | A Launch of Toolkit to support the delivery of:  ‘Developmentally Appropriate Healthcare’  There will be a short presentation, then opportunity to view the toolkit, then discussion about how it might be used  B Patient and public involvement in the Programme  i) Young person's advisory group UP: one minute introduction on each of three posters, then viewing  ii) PPI lead: Reflections on PPI  iii) Council for Disabled Children: Development of facilitator guides  C Indicators for Transition  Teresa Fenech from NHS England will lead discussions on possible indicators of transition. | | Jeremy Parr  Janet McDonagh  George Forsyth  Joseph McElderry  Athena Winchester-Shore  Gail Dovey-Pearce  Caroline Bennett  Teresa Fenech  NHS England |
| 13:35 | **Lunch** | |  |
| **SESSION 2b** | | | |
| 14:15 | Repeat of breakout sessions. | |  |
| **SESSION 3** Chair: Ann Le Couteur | | | |
| 14:50 | Keynote critique:  What are the implications of the research findings for the NHS? | Jackie Cornish, National Clinical Director for Children, Young People and Transition to Adulthood | |
| 15:00 | Discussion and questions. |  | |
| 15:10 | Keynote critique:  How do the research findings relate to international research in the field? | AnneLoes van Staa, Professor of Transitions in Care, Rotterdam University of Applied Sciences | |
| 15:20 | Discussion and questions. |  | |
| **Session 4** Panel discussion with the audience | | | |
| 15:30 | Chair of Panel: Helena Gleeson | Members of panel: Debbie Reape, Jackie Cornish, AnneLoes van Staa, Allan Colver, Athena Winchester-Shore and Gail Dovey-Pearce | |
| 15:55 | Concluding remarks. | Allan Colver | |
| 16:00 | **Finish** |  | |

**Conference on Transition of young people with long term conditions from child to adult services**

**Marlborough Theatre, Kings Fund, London**

**Thursday October 12, 2017**

# Purpose of the meeting

Dissemination of the findings and implications of the Transition Research Programme for Transition of young people with long term conditions from child to adult services.

# Disclaimer and thanks

This conference summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0610-10112). The views expressed are those of the presenters and not necessarily those of the NHS, the NIHR or the Department of Health

We acknowledge the support of the NIHR Clinical Research Network

We thank the sponsor, Northumbria Healthcare NHS Foundation Trust

The presentations are made on behalf of the Transition Collaborative Research Group

**The website of the Research Programme is**: <http://research.ncl.ac.uk/transition/>

**This pack can be down-loaded from our website – as can the PowerPoint presentations from the Research Team**

**Today’s talks are being video recorded and in due course will be available on our website**

# Key implications for the practice of commissioners, managers and clinicians

**1 Transitional care should be commissioned by commissioners of adult services as well as by commissioners of child services.**

We found that commissioners and providers regarded Transition as the responsibility of children’s services; this is inappropriate as Transition extends to approximately age 24.

**Where an adult service to which to transfer young people with a long term condition is not commissioned, commissioners should set out explicitly that the transfer arrangements will usually be to primary care, and require appropriate documentation and assistance to the young person to make their first appointment.**

**2 A framework to provide ‘Developmentally Appropriate Healthcare’ across NHS organisations should be commissioned, with the stipulation that this is owned at Chief Executive and Board level.**

‘Developmentally Appropriate Healthcare recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations.

In operational terms Developmentally Appropriate Healthcare focuses on the approach of healthcare professionals to and engagement with each young person and their carers, alongside the structure of the organisations in which care takes place.’

**3 NHS organisations should adopt a Trustwide approach to implementation of better transitional care. A Transition Steering Committee, chaired by a Trustwide Transition Coordinator, can facilitate this.**

We found that in many Trusts good practice led by enthusiasts rarely generalised to other specialties or to adult services. At sites we visited where there was a Transition Steering Committee, chaired by a Trustwide Transition Coordinator, this took advantage of the skills and enthusiasm of those already providing good practice; and assisted with training and consistent implementation in adult and child services and across specialties.

**4 Child clinicians should plan Transition procedures jointly with the relevant named adult clinicians and general practitioners.**

This is not just about the transfer of individual young people; it is also about joint planning of the services for transitional care; in other words the framework of Developmentally Appropriate Healthcare and the features of transitional care services the Research Programme found to be beneficial.

**5 Child and adult healthcare providers should explore with a young person how they approach Transition and personalise the clinical approach thereafter.**

We found there were four broad interaction styles that young people adopted when approaching their Transition: ‘laid back’, ‘anxious’, ‘wanting autonomy’, and ‘socially oriented’ (welcomed support from and frequent discussions with family, friends and all healthcare professionals).

**6 The features ‘Appropriate parent involvement’, ‘Promotion of young people’s confidence in managing their health condition (health self-efficacy)’ and ‘Meeting the adult team before transfer’ were associated with greater satisfaction with services, participation, subjective wellbeing and measures of disease control.**

Therefore, we advise consideration should be given to ensuring that a commissioning specification includes that these feature are delivered by NHS organisations.

**7 Maximal service uptake would be achieved by a service which encouraged parental involvement, ensured the same staff were seen at each clinic, emphasised the importance of good communication with young people, and encouraged young people to make decisions about their care.**

**Good value for money would be offered by a service which provided: ‘Parental involvement that suited both parent and young person’, and a ‘Protocol for promotion of young people’s confidence in managing their health condition’.**

# Developmentally Appropriate Healthcare - Definition

Developmentally Appropriate Healthcare (DAH) recognises the changing biopsychosocial developmental needs of young people, and the need to empower young people by embedding health education and health promotion in consultations.

In operational terms DAH focuses on the approach of healthcare professionals to and engagement with each young person, alongside the structure of the organisations in which care takes place.

One workshop at the conference launches the toolkit we have developed on this topic. The toolkit is available from: https://www.northumbria.nhs.uk/dahtoolkit

# New understanding of adolescent brain development

This intriguing area of new knowledge results from all the new techniques available to image the human brain, at rest and undertaking mental tasks. We now know that the anatomy of the brain changes massively between ages 11 and 24; some regions of the brain become more dominant for a time and are then restrained by the later maturation of other regions. Information processing speeds up and becomes more focused as connections between brain cells (grey matter) are pruned; and tracts (white matter) between regions of the brain transmit more efficiently as they enlarge and become better insulated.

On the surface of the brain, near the front, is the region (the pre-frontal cortex) responsible for more-or-less conscious control of short and long term planning, emotional regulation, decision making, impulse control and reflective thought. This is the last part of the brain to mature, not achieving this until age 24. Its relatively immature control at age 11 may be over-ridden by regions in the centre of the brain (limbic system and basal ganglia) which mature faster. These latter regions generate behaviours such as novelty seeking, risk taking and peer interaction which are reinforced by dopamine – a chemical transmitter in the brain which increases during adolescence. Much of the time, this potential imbalance between central stimulation and inhibition by the prefrontal cortex is kept in check but at times of excitement or stress and especially when with peers, inhibition may be overridden (so-called hot cognition).

Contrary to popular belief, the sex hormones (‘raging hormones’) are not responsible for these changes in the structure and function of the brain or the characteristic behaviours of adolescents. Of course, the sex hormones do determine the development of sexuality; but they are not responsible for the moodiness, excitability, increased reliance on peers, risk taking and the imaginative grasping of life which teenagers display.

Whilst many healthcare professionals seek to understand their adolescent patients and empathise with the challenges they face, some healthcare professionals feel out of their depth, may be upset by their interpretation of what an adolescent has said (or not said) and may even be irritated by adolescents. Understanding how different the adolescent’s brain is to their own may help child and adult healthcare professionals relate better to adolescents and thereby promote their health.

More information: Colver A, Longwell S. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. Archives of Disease in Childhood 2013:98(11):902-7.

# Lessons about involvement of young people in research

The length of our Research Programme really helped. The members of the young person’s advisory group (UP) could pace their engagement. Some avenues of work did not really work but in a five-year programme there was plenty of time to try other directions. Further, it took at least four meetings before the members of UP began to feel relaxed in each other’s presence. Elements that were important during those four meetings and subsequently were:

Code of conduct (ground rules)

Peer support workers

Practical help with travel to meetings (taxis etc.)

The members of UP grew in confidence. Whilst this was not the primary purpose of having a group, it is pleasing to know that all the effort UP members put in was also helpful to them.

# Academic publications

These are listed on and downloadable from the transition website <http://research.ncl.ac.uk/transition/>resources/papers

We have published:

A review article on adolescent brain development

The protocol for the longitudinal study

Analysis of baseline data in the longitudinal study

Young people’s approach to transition

Findings from interviews with commissioners

Two articles on Developmentally Appropriate Healthcare

An article on the properties of a mental health instrument

Seven further articles are submitted or are in preparation

# Final Report

This has been submitted to NIHR and in due course will be published in the NIHR Publications Library.

# Chairs and Speakers

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