

SNAPSHOT OF 2017

The Transition Research Programme ended in October 2017. Over the last year since we last contacted you, we have been analysing all the data and writing our final report. This has been submitted to NIHR and in due course will be published in the NIHR Publications Library. We cannot share all the findings with you yet but have included in this newsletter what we is in the public domain.

We closed the programme with a meeting at the Kings Fund in London to share some of our findings and begin discussions on how the key implications could be taken forward. Jim Mackey, Chief Executive, NHS Improvement opened the meeting for us and the day was a great success. In attendance were healthcare providers from children’s and adult services, commissioners, researchers and representatives from the Department of Health. Everyone was impressed with the research and acknowledged the importance of the findings.



The event was an opportunity for us to share some of the key implications from the research. We also had three breakout sessions:

1. Launch of Toolkit to support the delivery of ‘Developmentally Appropriate Healthcare’. This is a toolkit aimed at clinicians: www.northumbria.nhs.uk/dahtoolkit
2. Patient and public involvement in the Programme:
 - i) Young person’s advisory group UP presented posters of their work over the 5 years
 - ii) PPI lead, Gail Dovey-Pearce offered some reflections on PPI
 - iii) Council for Disabled Children presented the development of facilitator guides
3. Teresa Fenech from NHS England led discussion on the possible indicators for transition.

We were also very grateful to have Jackie Cornish, National Director for Children, Young People and Transition to Adulthood, provide a keynote critique on “What are the implications of the research findings for the NHS?”

AnnLoes van Staa, Professor of Transitions in Care, Rotterdam University of Applied Sciences, provided a final keynote critique on “How the research findings relate to international research in this field.”

Presentations from the day can be found on our website: research.ncl.ac.uk/transition

Inside this issue	P2: Implications from the Transition Research Programme P3: UPdate P4: Publications P4: Thank you
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KEY IMPLICATIONS FROM THE PROGRAMME

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.

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.

Transition has an **updated website**. We hope you'll find it easier to navigate so please take a look!



<http://research.ncl.ac.uk/transition>

You can also follow us on Twitter [@TransitionRes](#)

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'.



Update

The UP group, short for United Progression, played a vital role in the development and running of the Transition Research Programme. The amount of work they have contributed was reflected in the three posters they presented during their workshop at the final meeting.

You can see more details about the involvement of UP in the programme and what they have achieved on our website: <http://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeoplesworkinggroup-up/>

The young people who joined UP have described some of the positives and rewards from being part of the group:

"Amazed to have done what I've done. Quite a transformation to be honest."

"UP's been massive in my life. I was short of confidence and was not certain I was going to see it through."

My life's got better because of UP (for example) I've got voluntary work now."



There have been two new publications so far this year, with several articles out for review and others are in progress:

- What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview study. N. Kolemäinen, S. McCafferty, G. Maniatopoulos, L. Vale, A. Le Couteur, A. Colver. *BMJ Paediatrics Open* (2017).
- The Hospital Anxiety and Depression Scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. M. Uljarević, A.L. Richdale, H. McConachie, D. Hedley, R.Y. Cai, H. Merrick, J.R. Parr, & A. Le Couteur. *Autism Research* (2017).

On the website, you can also find presentations and posters by the Programme, as well as links to our previous publications <http://research.ncl.ac.uk/transition/resources>

THANK YOU

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