

SNAPSHOT OF 2015

The Transition Programme continues to march on at a good pace and it is hard to believe that the study will be celebrating its fourth birthday in a few months. Over the past year, a couple of the **Programme's studies** have come to a close; the focus for those studies is now on analysing the findings and presenting results:

- The Q-Sort study asked young people about the aspects of transitional care they felt were important, and what successful transition might look like. These features were then ranked in order of importance by the young people, and areas of difference and commonality analysed. A paper outlining findings from this study is currently going through the publications process and will be available shortly.
- Interviews with clinicians and healthcare professionals around Developmentally Appropriate Healthcare (DAH) have concluded and some of the findings published (see p4). Despite its use in clinical settings, there is confusion over the definition of DAH. Further papers are to follow, which will outline some of the barriers and facilitators for implementing DAH.

The Programme's largest study, the longitudinal study, is now in its final year. Many of the young people taking part are being interviewed for the fourth (and final) time about their health services, well-being and quality of life. Retention remains strong at over 80%. Baseline data from this study has been published and some findings from the second visits will be published in due course (some early findings for the diabetes cohort are available in poster form on the Programme's website: <http://research.ncl.ac.uk/transition/resources.>)

Visits are also continuing for the qualitative 'YETI' study, which sees 15 of the longitudinal participants share their experiences of transition in more detail. Interviews and health appointment observations conclude in early 2016.

In other activity, the Transition Programme has organised and attended several **conferences** this year, including leading a workshop for fellow health professionals at the Royal College of Physicians. The Council for Disabled Children also organised a seminar for young people with long-term health conditions on behalf of the Programme. A graphic capturing discussions from the day is below:



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The seminar provided an opportunity for the Programme to hear the views of young people on some key transition issues:

- Young people's attitudes towards transition and the transfer to adult services —what were their priorities as they moved to adult services? Were they anxious about the move?
- Health passports - are these helpful? What features of health passports work well?
- Developmentally appropriate healthcare—what is DAH? What are the key behaviours and aspects of care associated with DAH?

The seminar was planned and chaired by young people, who also led the three interactive and fun workshops.

Looking Ahead....

Looking ahead to 2016, one key area of Programme activity will be the research into commissioning. This study is already underway and will be vital in ensuring that the Programme's recommendations are practical and workable in an NHS environment. Researchers have already interviewed a variety of health professionals about what helps and hinders successful commissioning for transition. In the New Year, they will be visiting a few case study sites, to look in detail at how some approaches to commissioning for transition are working on the ground. In 2016/7 the Programme will be meeting with commissioners, presenting the Programme's findings and exploring together how these could inform future service provision.

The commissioning work package pulls together findings from all three of the Programme's objectives:

- Finding out what aspects of transition are important to young people;
- Learning what aspects of transitional care are effective and improve outcomes;
- Deciding how transition services should be commissioned.

In 2016, data collection for the longitudinal study will end and analysis will start in earnest. Combined with the in-depth data from the qualitative interviews and observations, this should provide a huge insight into the experiences of young people as they move between child and adult services, and what impacts on their health and wellbeing outcomes.

In the New Year development will start on an online toolkit for Developmentally Appropriate Healthcare. Details about this will follow in the next newsletter, along with **an account by the young people's working group 'UP'** on their participation in the 'take-over day' at the Department of Health in London.

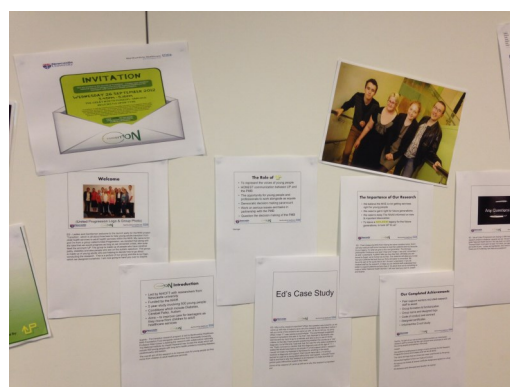
Transition has an **updated website**. We hope you'll find it easier to navigate so please take a look!

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



You can also follow us on Twitter **@TransitionRes**

For the past 18 months, the Programme's young people's group 'UP' has been undertaking a preliminary piece of research into Health Passports, to see whether they might help young people move between child and adult services. In the summer they presented to the programme team on their work to-date and initial findings.



A Health Passport is a document which contains key information about the young people and their health condition, as well as how they want professionals to communicate with and support them.

What were the aims of the research?

To find out what young people using health passports thought about their health passports

To find out the strengths and weaknesses of a universal versus a condition-specific health passport

To address these aims, the UP group held a teleconference with healthcare professionals who work with young people using health passports. These interviews helped to inform the development of a questionnaire for young people using the passports, however the process was a new experience for the UP members:

"I was quite nervous at the start but 5-10 minutes into it my nerves just disappeared".

"We did lots of practice – speech sheets and role playing. It was a good learning process to prepare us for what we might and might not have expected."

Following the teleconference, UP devised a questionnaire for young people who were using health passports at a couple of UK hospitals. The first site, Walsall has already sent through responses, which UP have analysed. From this they have identified key themes, and also gaps in the information, which will influence the evolution on the questionnaire for a second site.

Findings from UPs research will follow in due course, but if you are want more information on the group you can see the Transition website <http://research.ncl.ac.uk/transition/index.html> or search the hashtag #UsInUp on Twitter.

The importance of the research

There are lots of different approaches to health passports but little research into their effectiveness. Similar research has been done in Canada; however this is the **first UK study evaluating health passports**. Another 'first' is that the results will be interpreted from young people's

There have now been 3 publications from the Transition Programme, and a further 2 are pending publication. Details are listed below and all the papers can be found on the Transition website at <http://research.ncl.ac.uk/transition/resources/>

- Study protocol: Longitudinal study of the transition of young people with complex health needs from child to adult health services
- Characteristics of young people with long term conditions close to transfer to adult health services. This paper presents some of the baseline data from the longitudinal study.
- Developmentally Appropriate Healthcare for Young People: a scoping study. This paper looked at the use of the term 'Developmentally Appropriate healthcare' in scientific literature and what the term meant in relation to young people.

On the website, you can also find presentations and posters by the Programme, a video by the young people's working group 'UP' and a paper on adolescent brain development by the Programme's Chief Investigator, Prof. Allan Colver.

Events of Interest

- **February 25th-26th 2016 A New Look At Young People's Health**
Manchester
<http://www.youngpeopleshealth.org.uk/events>
- **March 9th-12th 2016 Society of Adolescent Health and Medicine**
Washington DC
<https://www.adolescenthealth.org/Meetings/2016-Annual-Meeting.aspx>
- **June 1st—4th 2016 European Academy of Childhood Disability**
Combined meeting:
5th International Conference of Cerebral Palsy (ICPC)
28th Annual Meeting of the European Academy of Childhood Disability (EACD)
1st Biennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD)
Stockholm
<http://eacd2016.org/>



**Wishing you a Merry
Christmas and a Happy
2016**



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