

Recruitment Complete for Programme's Largest Study

Update by Sarah Nolan, Programme Administrator

Recruitment to the longitudinal study is now complete. We want to say a big **THANK YOU** to all the young people and their families who have decided to take part, and also to the clinicians who passed on information about the study.

The longitudinal study gives us the opportunity to find out in detail what young people experience as they make the step from children's and young people's services to adult healthcare. The young people are the real researchers - 'the eyes and ears on the ground'. The Research Assistants visit the young people annually for three years and work with them to complete a series of questionnaires, which capture their views on the transition to adult services.

Our final recruitment to the study represents the **largest cohort of young people with long-term conditions being followed during their transition**. This is a real testament to our Research Assistants, who have spent the past year doing everything possible to advertise the study and maximise recruitment. Our final figures look as if they will be:

Diabetes: 149 ASD: 124 Cerebral Palsy: 105

Recruiting to the study hasn't all been plain sailing. For instance, it took a bit longer than anticipated to get the Research Assistants in post. There were also unique challenges for some conditions – for example, it was harder to work out how best to reach young people with cerebral palsy because these young people are not usually seen in one particular clinic. Despite these challenges, we are now in a great position after the first year of the study. The Research Assistants have already started to contact young people about their second annual visits, and we'll let you know how this is going in the next newsletter.

We have already been examining some of the information collected from young people and their parents. We presented a poster at the October conference of the European Academy of Childhood Disability, examining the variation in how independent different groups of young people are, and what they think about the child health services they have received.

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Here is a brief overview of some of the progress made across the Programme during the past few months:

- Recruitment is coming to an end for our 'Q Sort' study. This study is looking at what is required from services for young people, who continue to need healthcare into adulthood. 'Q' is a method used to study individuals' views, opinions or beliefs about a subject (in this case the transition from child services to adult services.) We are delighted to **meet our recruitment targets** for this study, and need to thank all the adolescents and young adults taking part in the study, and also the clinicians who gave out information about the study to participants.
- Since our last newsletter, work has started on the early stages of work packages 3.2 and 3.3. These look at commissioning structures within the NHS, and will eventually translate some of the lessons from the Programme into the "what" and "how" of transition commissioning. These were the last work packages due to get going, which means that **all 9 work packages are now up and running!**
- The protocol for the Longitudinal Study was recently published in the **BMC Public Health** as an open access article. Objective 2 seeks to identify the features of transitional care that are effective and efficient, and it incorporates the longitudinal study. A copy of the protocol can be found here: <http://www.biomedcentral.com/1471-2458/13/675>
- We have also recently presented an academic poster with initial results from the baseline visits for the longitudinal study. As previously mentioned, this was presented at the recent **European Academy of Childhood Disability Conference** at the Sage, Gateshead. A copy of the poster can be found on our website: <http://research.ncl.ac.uk/transition/Latest%20news.html>
- The second meeting of the Programme's **External Advisory Board (EAB)** will meet on 20th November 2013. The EAB offers independent oversight and advice to the Programme, with representatives from young people, the voluntary sector and parents of children with long term health conditions.

Introducing the IDAHO Study

IDAHO (Implementation of Developmentally Appropriate Healthcare in an Organisation) is a qualitative study which is looking at how managers, clinicians and other healthcare professionals experience, understand and make Developmentally Appropriate Healthcare workable, and identification of the facilitators and barriers to the introduction of Developmentally Appropriate Healthcare for young people across NHS Trusts.

IDAHO uses ethnography to meet those objectives. Ethnography is the study of the ways of life and culture of a group and their organisation. It aims to be holistic, focusing on the history, context, social interactions and practices of people as they go about their everyday lives.

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Non participant observation and interviews are the main techniques being used to collect data for the study. The observations are taking place at management meetings, clinics and team meetings across three hospital Trust sites, and span six different areas: rheumatology, diabetes, trauma and orthopaedics, outpatients, emergency care and general paediatrics/ medicine.

The first phase of recruitment and data collection began in June 2013 and extends to the end of November 2013. Following this there will be two more phases of recruitment and fieldwork which will take place in 2014.

For further information please read our current blog: <http://research.ncl.ac.uk/transition/Blog.html> or contact the Research Associates working on the project: Dr Albert Farre: a.farre@bham.ac.uk and Dr Victoria J Wood: victoria.wood@newcastle.ac.uk

UPdate



United Progression or 'UP' is the young person's working group which represents the voices of young people on the Transition Programme. This month, Co-applicant Gail Dovey Pearce has had the opportunity to share some of her experiences of working with young people in research at the 'New Developments in Public Involvement in Research Conference' in Exeter, as she explains:

'Active involvement' of young people in a research study means they proactively contribute to the running and delivery of the research, rather than being participants or subjects. There is a growing national discussion around the need to develop high quality, evidenced and measurable approaches, to ensure young people are involved effectively, meaningfully and safely. As researchers, we need to share more about our approaches to involving young people.

With this stated aim, I will be presenting the important work of UP within the Transition programme, along with colleagues from Exeter Medical School and Coventry University, and their young researchers, who have carried out similar involvement work. Our workshop will provide practical tips on accessing and recruiting young people, providing appropriate support, maintaining interest and retaining participation. We will also highlight ethical issues that should be considered, including managing power imbalance and some safeguarding considerations. A video made by members of UP discussing these issues will be shown on the day.

I also look forward to learning from my colleagues and other delegates throughout the conference, to ensure that I continue to support UP as effectively as I can, in their central role within the delivery and management of the Transition programme.

The conference is organised by the NIHR PenCLAHRC (Collaborations for Leadership in Applied Health Research and Care for the South West Peninsula)

Publication of the Chief Medical Officer's (CMO) Report

Chief Medical Officer, Professor Dame Sally Davies, has used the second volume of her annual report to highlight the shortcomings and inconsistencies in the care of children and young people in England and Wales.

Whilst volume 1 of the report is a compendium of data and information used to describe the health of the nation, the CMO has dedicated the entire narrative section of the report to young people. She makes the argument for doing more, sooner to safeguard child health. According to the report this makes economic sense and could lead to savings of **£1billion** each year, "The evidence is crystal clear and the opportunity is huge – investing in children is a certain way of improving the economic health of our nation, as well as our children's well-being."

Included in the report is a chapter on children and young people with complex health conditions, and how many aspects of their care (including transition) need to be improved. It is expected that this will lead to a themed call from NIHR for research to improve health outcomes for long-term conditions in childhood.

The press release which offers a summary of the reports key findings and recommendations can be found here: <https://www.gov.uk/government/news/chief-medical-officer-prevention-pays-our-children-deserve-better>

Or for the full report, see here:

<https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays>

Events of Interest

- **Nov 18- 20th 2013 and 10-11th April 2014 —Transition: Closing the Gap between Child and Adult Services**
York
<http://www.york.ac.uk/healthsciences/cpd/modules-courses/transition-closing-the-gap/#tab-5>
- **January 16th 2013 — Transitions for children and young adults with autism**
<http://www.rsvpbook.com/event.php?404136>
- **March 18th 2014 Westminster eForum — Keynote Seminar**
Next steps for improving children and young people's health
<http://www.westminsterforumprojects.co.uk/>
- **March 23-26th 2014— Society of Adolescent Medicine**
Austin, Texas
www.adolescenthealth.org