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Young People's Newsletter

Issue 4, September 2015

THANK YOU!

Over 80% of you have stayed involved in the study.

It is great to hear about your experiences of transition as many of you are moving into adult services.

121 (32%) of you have left children's services;

- ⇒ 67 are now being seen in adult services for their condition
- ⇒ 33 are receiving care from their GP

Inside this issue:

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- Overview of the Transition Programme
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**Look out for our new website
COMING SOON!**

If you'd like to contact us, please do:

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

UP Group's research on health passports



In July the Transition Programme young people's working group, UP, held a celebration event to present all that they have achieved over the last 3 years. The event was a great success and the UP group can be very proud of everything they have contributed so far.

One of their achievements is their own research looking at the use of health passports.



A health passport is a document you might carry with you when attending healthcare appointments. It contains information about you, your medical history and how you want people to communicate with you and support you.

There are several versions of health passports being used in different hospitals. The UP group have been evaluating the health passports currently used. For this research the young people:

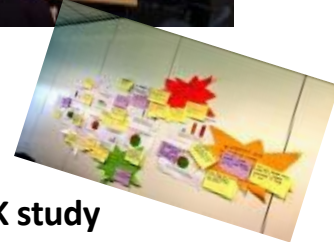
- had a conference call with some clinicians who work with young people and use health passports

“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” - UP member

- designed their own questionnaires about using health passports

“ We struggled to word the questions in the right way. BUT... we aren't afraid to ask for help!” - UP group

- analysed results of the first set of questionnaires filled in by young people who attend a hospital which uses a health passport system.
- drew on their own experiences of transition and how a health passport might have helped them when they were transferring to adult services.



Some 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 perspective.

What next? The UP group are working on refining their results, including young people from a second hospital, and thinking about what other information they want to collect about health passports.

Do you have any experiences of using health passports? Do you think they would be helpful when planning your move to adult services?

How the longitudinal study fits in to the overall Transition Research Programme

This 3-year longitudinal study is part of a much bigger 5-year research programme looking at transition from children's to adult healthcare services. Below is an outline of the programme and how this longitudinal study fits in to the overall programme.

OBJECTIVE 1: To work with young people with complex health needs to determine what successful transition means to them and what is important in their transition.

- UP group was formed and they have led on a study evaluating the use of "health passports" as well as advising the Programme Management Board throughout the study.

UP also designed the certificates you receive at each visit



- Q-Sort study to explore the importance young people attach to the different components of good transition service. These findings were described in the previous newsletter.

This study helped with the design of the "Preferences for transition services" questionnaire you have been completing at visit 3

OBJECTIVE 2: To identify the features of transitional care that are effective and efficient

- The longitudinal study you are involved in is addressing this objective.

15 young people from this study also took part in the YETI study

- **YETI Study:** This is a more in-depth study that involves being interviewed and having someone observe some of your appointments.
- The information you give us about what happens in your appointments and how you travel to and from your appointments is being used to evaluate the costs of services and to illustrate the different models of transition support offered by services.

OBJECTIVE 3: To determine how transitional care should be organised, provided and commissioned

- Research looking at what three NHS Trusts think about "developmentally appropriate healthcare" and how they put it into action.
- A study of commissioning (i.e. deciding what services should be developed and paid for by the NHS): the current arrangements, barriers and facilitators, and looking at how transition services could be commissioned better.

All these research findings will be brought together in our final report where we will make recommendations on WHAT and HOW to commission services for young people.

Research Assistants' FINAL training day in Newcastle!

In July the research assistants all came together in Newcastle to receive their training for the final visits that started in August.

It was a great opportunity for us all to come together and share our ideas and experiences and prepare for the study coming to an end.

The research assistants heard about the results of the study so far and results from other parts of the programme.



Top row: Allan Colver, Helen McConachie, Alison Mulvenna, Jeremy Parr, Holly Roper, Ann Le Couteur
Bottom Row: Louise Ting, Sarah Nolan, Rose Watson, Hannah Merrick, Guilomar García Jalon, Shaunak Deshpande



Hi, I'm Shaunak!

I work as a research assistant on the Transition Study in the North East of England. I have been visiting young people, who have ASD or Diabetes. I took up the role just before Christmas 2014 and I have enjoyed completing the visits with the young people and touring around this lovely region.

I used to work as a Business Analyst, but I then decided to go back to university, where I completed a postgraduate degree in Psychology. I have previously worked with young people with ASD, Epilepsy, Schizophrenia and Multiple Sclerosis.

In my spare time I regularly run with a local running group and I dance Salsa.

USEFUL LINKS:

- ⇒ It was **International Youth Day** on the 12th August 2015– this year's theme was Youth Civic Engagement:



<http://undesadspd.org/Youth/InternationalYouthDay/2015/Campaign.aspx>

- ⇒ Have you seen BBC Three's **Defying the Label** Series? See the programmes, blogs and videos here:

<http://www.bbc.co.uk/programmes/p02w3q4c>

- ⇒ See UP group's video '**Transitions Got Talent**', which takes a fun look at an important issue - how health professionals interact with and treat young people:

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

