

## 2nd Progress Report for the Burdett Trust for Nursing

**Project Title:** Transition: understanding it and making it work

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## Progress Report

### 1. Background

More and more children with chronic health conditions are surviving into adulthood and need ongoing specialized care. As these children get older they need to be transferred from child health services to adult services. This process of planning and moving on from child to adult care is known as 'transition'. It is clear from previous research that moving on from child services can be problematic and how young people are transitioned could be improved. However, it is not clear what needs to be done or how any changes should be carried out.

### 2. Project aims

The purpose of this study is to increase our understanding of the complexities of care for young people as they move from child to adult services, to find out what works well in order to develop a clinical practice-benchmarking tool.

This study aims to:

1. Explore young people's and parents'/guardians' views on how best to achieve continuity during transition from child to adult services.
2. Explore the views of health care professionals working with a range of childhood chronic conditions on how best transition can be introduced and sustained.
3. Detail a range of transitional models that best describe approaches to finding solutions to organisational barriers.
4. Describe and inform client focused best practice that will facilitate the transition of young people from child to adult services.
5. Develop and nationally disseminate a clinical practice benchmarking tool to support the structured comparison and sharing of good practice in the transition of young people from child to adult services.

### 3. Methods

Although described here as a linear process, the searching for evidence, data collection and data analysis that will lead to the development of the benchmark tool will be undertaken concurrently.

This study has three planned phases:

In the first phase, a literature review will be carried out. Workshops and meetings will be held with young people, their parents/guardians, health professionals and experts in transition to find out about the process of transition from their viewpoint. Young people

aged 13 to 21 years with chronic health conditions (e.g. diabetes, cancer, cystic fibrosis) and their parents/guardians will be recruited to take part from hospital clinics in London.

The second phase involves using information collected in Phase 1 to describe the key components of a transition programme and how it would work in practice. A transition benchmark tool will be developed.

The final Phase will involve sharing our findings throughout children's services in England. Links will be made with the Department of Health regarding the inclusion of our work in the Essence of Care benchmarks (Department of Health, 2010).

#### **4. Progress to Date**

Phase one of the study, is now well underway. The original protocol is being followed with a few changes primarily relating to the recruitment of young people. These changes and the reasons for them will be discussed within this update on the progress of the study.

##### **(i) Literature review**

We were fortunate at the start of our project to make links with a team about to embark on a Cochrane Review of Transition. We therefore joined this team, with Susie Aldiss participating fully in the review process. Susie Aldiss is therefore linked with the team led by Fiona Campbell at the University of Sheffield who are completing the Cochrane review. The review will include both qualitative and quantitative research papers. Over the past year, Susie has had regular, monthly telephone conferences with the team working on the review. Initially, approximately 8000 references were identified which were sifted by title/abstract. The full papers for the remaining references were then retrieved to check whether they were relevant and fitted the inclusion criteria for the review. All exclusions and inclusions have been double-checked by two reviewers. The quantitative publications of the review is almost complete and due to go out to the co-authors for comment. Only one paper was identified that fitted the inclusion criteria in this part of the review (due to Cochrane having very strict inclusion criteria about data collection for interventions). Around 40 papers have been identified for inclusion in the qualitative element and the team are beginning to extract the data from these papers. The qualitative section will be added into the review next year.

We have also added into our protocol a review of policy documents. Laura Rose has collated the UK policy documents (to date) relating to transition and has reviewed the content of these policies and produced a summary. We plan to include this policy document review in a paper that also includes the data collected with stakeholders.

Outside of the Cochrane review we continue to collect recent publications, and maintain an updated managed system to help retrieve publications for future reporting and to inform data collection through our study.

## (ii) Data collection with stakeholders

Data collection with stakeholders took place in 2012. Three focus groups were carried out between May and September, which were attended by twenty stakeholders in total. In addition, one telephone interview was carried out with a stakeholder who was unable to attend any of the focus group meeting dates. The stakeholders represented various professional roles within health care and social care including: consultants, clinical nurse specialists, psychologists, occupational therapists and researchers. They had expertise in working with young people with many different health conditions and disabilities.

Three members of the research team (SA, LR and FG) worked on the analysis of the transcripts from the focus groups and interview. Qualitative content analysis was used and asked two questions of the data:

- 1) What are the current challenges and barriers of transitioning young people from child health to adult health care?
- 2) What strategies or approaches do professionals feel should be implemented to facilitate the transition from child health to adult care?

The research team applied the findings to the theoretical model for the study as detailed by While et al (2004). The model is described as a 'sequential model of transition' which recognizes that young people's needs are changing and that they require some preparation if they are to adjust to adult care successfully (While et al, 2004). Adding our analysis of the data to the model allowed us to examine key practice components and core principles (i.e. recurring themes) which related to the way services should work with parents and young people to promote greater continuity in the transition from child to adult care. The research team are in the final stages of writing up the discussion of the focus group findings for an early dissemination publication.

## (iii) Site approvals

Approval from the NHS Research Ethics Committee took much longer than expected and approval was given for all parts of the study on 12<sup>th</sup> November 2012. Meetings with local sites began to take place from January 2013. For each site, a local Principal Investigator needed to be identified and the study paperwork then had to be submitted and approved by R&D. Box 1 details the dates the approval paperwork was submitted and when approval was granted for each of the four sites. Obtaining research passports and honorary contracts for the team significantly slowed the progress with the study as it involved all members of the team who will have contact with patients obtaining up-to-date Disclosure and Barring Service certificates (Criminal Records Checks) and evidence of Occupational Health clearance. It also took some time to identify Principal Investigators at two of the sites and the team met with several professionals at each site before someone took on this role.

## Box 1 Dates of site approvals

### **University College London Hospitals NHS Foundation Trust**

22<sup>nd</sup> January 2013 - Study paperwork submitted to R&D for site approval.

25<sup>th</sup> February 2013 - Site approval given (pending research passports being issued).

### **Great Ormond Street Hospital NHS Foundation Trust**

17<sup>th</sup> February 2013 – Study paperwork submitted to R&D for site approval (with research passport documents to follow).

2<sup>nd</sup> May 2013 – Site approval given (delay due to waiting for SA's research passport to be issued by UCLH).

### **Chelsea and Westminster Hospital NHS Foundation Trust**

17<sup>th</sup> June 2013 - paperwork submitted to R&D for site approval.

19<sup>th</sup> July 2013 - site approval given.

### **Guys and St Thomas' NHS Foundation Trust**

12<sup>th</sup> August 2013 - paperwork submitted to R&D for site approval.

31<sup>st</sup> October 2013 - site approval given.

## (iv) Local professionals' focus groups

Phase one data collection involves also seeking the views of professionals working at the four sites involved in the study. On August 15<sup>th</sup> 2013 the first local professional's focus group was held and was attended by ten clinical nurse specialists. The aim of the session was to gain further insight and understanding and insight into how transition is facilitated within a range of specialities. Groups at the remaining three sites are currently being set up.

## (v) Data collection with young people and parents

The first workshop was held on Saturday 21<sup>st</sup> September 2013, young people from Great Ormond Street Hospital and University College London Hospital were invited to attend. Nine young people and their parents were planning to come, however on the day five were not able to (due to illness and travel problems). Four young people and four parents attended. The day involved a focus group for parents, paired and group discussions for young people

and both groups came up with a 'checklist of good transition'. Even though the group was smaller than expected, the team felt the data collected was very valuable and the families appeared to enjoy attending and giving their views. All of the participants in the workshop were given information about joining the 'co-design group' for this work and continuing to work with the research team into phase 2 of the study, two families have said they would like to do this. Another workshop is planned for 7<sup>th</sup> December 2013 and it is likely that one final workshop will take place in early 2014.

#### (vi) Web-site development

The study website is now live and can be viewed at: [www.transitionstudy.co.uk](http://www.transitionstudy.co.uk)

The website features information and updates about the study, links to key transition documents and the outputs of the study. We are also planning to include Podcasts of young people and their families talking about the transition process.

The research team are able to update the website to ensure the information remains current, disseminating findings as soon as we are able.

#### 5. Amendments to the study protocol

To try to increase recruitment of families, two substantial amendments have been made to the study protocol (Box 2).

#### Box 2 Amendments to the study protocol.

**Substantial amendment 1** – to increase the age range of young people approached to participate in the study from 18 years old to 21 years old (following feedback from the sites that young people in some services transition to adult care when they are over 18 years old).

28<sup>th</sup> January 2013 – Paperwork for amendment 1 submitted.

30<sup>th</sup> January 2013 - Amendment 1 approved by the NHS REC.

**Substantial amendment 2** – for professionals to be able to post/email information about the study to young people/parents (following feedback from the sites that some young people attend clinic infrequently and therefore would not have to opportunity to take part in the study as recruitment was originally only through face to face contact).

17<sup>th</sup> June 2013 - Paperwork for amendment 2 submitted.

24<sup>th</sup> June 2013 - Amendment 2 approved by the NHS REC.

## 6. Explanation of any Delays on the Project

Gaining NHS Research Ethics Committee approval took much longer than expected. The delay with beginning data collection with young people and parents however enabled us to carry out more focus groups with stakeholders, which the team feel has been valuable. The difficulties the research team faced when trying identifying a local investigator at two of the sites, also resulted in the delays from R&D and subsequent recruitment to the initial workshop. Recruitment to the study has been slow; the team are reliant on local professionals working with young people to give out the study information. Susie and Laura have been to the sites to meet the local teams and are in regular contact via phone/email with them. Recruitment is starting to pick up and we are hopeful that more young people and parents will attend the next workshop. Recruitment, which relies on clinical staff, is always fraught with delays, research teams have no other route to recruit, therefore 'sensitive' but frequent contact is required to keep our study 'in their sights'. We are hopeful that future groups will be better attended, however this still depends on families on the day being able to come. Recruitment and working with sites continues to require much of the researchers time.

## 7. Patient and Public Involvement

The team were contacted by a young person, Tanya who is keen to improve transitional care following her own experiences of moving to adult health care. Tanya is going to join the team as a 'Patient and Public Involvement Representative' and work with us on the data analysis.

## 8. Early dissemination plans

1. To submit a paper on the stakeholders' views of transition by the end of 2013.
2. An abstract has been submitted to present stakeholder data at the RCN Research Conference in April 2014.

## 9. References

Department of Health (2010). *Essence of Care*. Department of Health.

While A. et al. (2004). Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health & Development*, 30, (5), p.439–452.

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