



**Involving Children and Young People in PenCRU**

**Tuesday 29 April 2014**

**Veysey, Room 112**

**Present**: 6 x Family Faculty **-***Tricia, Julia, Kirstin, Mirtha, Alan, Mike,*

3 x PenCRU *- Chris, Meghan, Anna*

*Helen (Project Manager, Exeter Catalyst)*

**Apologies:** 3 x Family Faculty *- Antonia, Alan, Pat*

Introduction

As there were attendees that had not been involved with the project previously, Meghan gave a brief summary of the project to involve Children and Young People (C&YP) in PenCRU activities.

* Should we set up our own group of C&YP to consult, similar to the adult Family Faculty, or should we focus on existing groups and schools?
* Should siblings be included or just C&YP with disabilities themselves?
* Should we look at C&YP based just in special schools or should we look at affected C&YP in mainstream education as well?
* What age range and diagnoses can we include?

It was decided to trial some options based around the topic of oral health and dentistry as this was a current interest for PenCRU, as well as allowing us to learn about involving C&YP in research generally.

Feedback from case study 1 – One to one interviews

Meghan visited Southbrook, a secondary special school for pupils, aged between 11 and 16. She worked on a one to one basis with around 20 children across age and ability levels that had been selected by school staff as likely to be interested in the topic of oral health and dentistry.

Strengths of this method:

* 1 to 1 interviews allowed Meghan to differentiate the phrasing of questions and introduction to the subject to meet each child’s own abilities.
* Less outgoing C&YP were not overshadowed or swayed by more vocal peers, and this method could be applied for C&YP with communication difficulties.
* This method works well to identify C&YP who may be interested in becoming more involved with a topic on an ongoing basis.

Limitations of this method:

* C&YP are not able to interact with each other and build of each other’s’ suggestions and comments, which could spark relevant discussion and debate.
* It is possible that the C&YP might say what they believe the interviewer wants to hear, rather than giving their own opinions.

It was suggested that after one to one interviews had been held those C&YP involved could be allowed to discuss the topic further together, allowing us to see if there is consistency to their opinions, and see how each other’s views may influence and/or alter their thoughts.

Practical considerations:

* Should parents be asked to consent to their C&YP being involved? It was suggested this is not usually necessary as the C&YP are not research subjects, and that it was not significantly different to the normal school programme decided by the school staff; parents in the Family Faculty present agreed.
* We should provide recognition for the C&YP involved – acknowledgement for their time/certificates/badges/etc. Those who work on a longer term project could have it noted in their school achievement record or similar with agreement from a school.

Feedback from case study 2 – Distance method

A group of 8 pupils from Ellen Tinkham, another special school, were involved in a discussion session also around the topic of dentistry. Those involved were aged 10-19 years, with a range of ability levels.

With consultation from the school, Meghan provided a planned session, including discussion prompts and differentiated levels for C&YP with different abilities, to be delivered by a school-based Teaching Assistant (TA).

Strengths of this method:

* The C&YP already knew the person delivering the session and had a rapport with them.
* Relatively low resources required from PenCRU.

Limitations of this method:

* The TA felt that collecting participants opinions individually, before working together in a group may have allowed all participants to contribute more equally

General issues raised for future activities

* Overall, the responses and ideas from the C&YP in both case studies were very similar, suggesting that both one to one interviews and group sessions can be meaningful, and that it may not always be necessary for a researcher to be directly involved in working with C&YP themselves.
* Wherever possible a range of schools and/or other groups should be consulted, as the results you are likely to differ depending on the C&YP’s previous experiences and abilities.
* Specific groups of C&YP could be targeted, e.g. those likely to have particular interests and experiences relating to a topic.
* The same group of C&YP could be consulted on an ongoing basis or new groups could be consulted each time. If the same group is used they can develop rapport, knowledge and experience, but then a smaller number of C&YP are represented overall.
* We should identify the different options for involvement of C&YP in the research cycle:
  + Question generation
  + Formulating methodology
  + Analysing research findings
  + Disseminating findings

Possible challenges

* C&YP with communication difficulties have not had an opportunity to be involved so far. However, there is no reason why they should not be included in future when we have fuller resources and time available. With adequate planning talking mats, etc. can be prepared. However, there was some discussion around the bias that may be applied to their answers through the facilitators, either parents or others. It was suggested setting a questionnaire for facilitators around the topic under discussion too to try to assess their views on the subject which may affect the C&YP’s recorded ‘translation’.
* Will disabled C&YP provide consistent answers to the same questions over time? This could be checked by repeating the same exercises but would be very time consuming.
* Will C&YP try to impress or appease either an outside visitor or a person from their school who they consider an authority figure who is directing the session and give opinions on this basis rather than expressing their true views? It was agreed that either the researcher or school staff taking the session with C&YP must be able to build a rapport with the participants and put them at ease while validating all their inputs.

What next

* PenCRU are producing a Plain English summary of what we have found out about involving C&YP in research so far. During this meeting comments were collected on a draft version of this which will inform the final publication.
* Planning and identification of resources are required before deciding on next steps.
* PenCRU will continue to liaise with Southbrook and EllenTinkham, and look to investigate opportunities with other special schools/C&YP’s disability groups/ SEN teams at mainstream schools. It was suggested that we offer ‘affiliation’ to the Family Faculty to participating schools.
* The Catalyst funding for this project will end in July 2014. Helen Featherstone advised that we submit suggestions for future activities for any unspent funding, although the Catalyst project itself comes to a close in May 2015.