

Dentistry for Children with Autism Project - Meeting 2

13/07/2015 St Lukes

Family Faculty: Annette, John, Maureen, Maria, Karen, Carly, Ruth, Lyndon **PenCRU:** Nicole, Chris, Kath, Sharon, David (Plymouth University)

Apologies: Josie, Lisa, Ian (Family Faculty)

Overview

- We considered the draft research documents (information sheet, invitation letter, consent form and interview questions)
- We discussed the use of video to recruit participants (content/delivery/setting)

What next?

- Research documents will be refined and an application for ethical approval made.
- The next meeting is likely to be towards the end of 2015 to discuss how the recruitment is going/initial themes arising but a meeting may be arranged sooner if problems arise in the ethics application or recruitment.
- If you have any comments or come across any information or resources relevant to the programme, please contact us pencru@exeter.ac.uk or phone (01392 722968).

Update from previous meeting

Nicole updated the group with the progress made since the last meeting.

A protocol has been written and decisions taken on the specific focus for this research;

- Preventative dental care – this research will focus on the experiences of families of children with autism going to non-specialist dental services.
- 20 – 30 parents of children with an official autism diagnosis aged between 4 – 10 will be recruited who live either in Devon or Somerset

Nicole also described the recruitment process. Initially a link to a video on the PenCRU Dentistry project page will be sent out to identified support groups. The brief video will feature Nicole introducing herself and explaining the research, who she is looking to interview and how people who are interested can find out more information. Those that contact PenCRU to ask for further info will be sent an information leaflet and an invitation letter. Anyone who would then like to take part can complete a reply slip and Nicole will then call to arrange an interview date/time.

The group discussed other possible organisations in the South West who Nicole could send the video link to: including Auchid, Auty not naughty, Early birds, CBC Plymouth, John Parkers Unit, Dame Hannahs. Recruitment via the video and website is the first stage of the recruitment. If this didn't work, we would consider other ways to advertise the opportunity.

Discussion 1: Information Sheets and Invitation letters

In small groups we each discussed the invitation letter and the information that will be sent to people who are interested in hearing more about the research after they watch the video.

Feedback included:

- Discussion on terminology. The term 'autism' is preferred on its own rather than ASD or ASC. High street dentist is preferred over non-specialist dentist. The term 'interview' is to be avoided as it has threatening/negative connotations eg job interview, benefit interview. Particularly when referenced to 'recorded'. Instead use 'meet you and ask you about your experiences'.
- Jargon to be avoided including 'family focussed' – replace with family's experience.
- Information about the research could take a 'what/why/who' structure – eg 'this research is looking at experiences of children with autism.... Because there is little research from a family perspective and it will inform dental practice....we would like to ask parents of children aged 4 -10 with an autism diagnosis
- Needs explanation as to why we are recording the information given. Emphasise what will be reported will not be personally identifiable.
- Important to mention gift voucher for taking part as an incentive and that all participants can receive a summary of the findings from the research.
- While Colgate are not looking for branding or marketing from funding this research, it was felt best not to mention the company on the research documents.
- Title was felt to be long – could look at using acronym
- It was felt that with the headers on the top of the letter giving it authority; the invitation letter could be more personal, including being signed by Nicole/referring to Nicole directly.
- It was suggested that the web link needs to be direct to the project page rather than expect respondents to navigate the website. If this is a long address, a short link eg bit ly
- Parents would like a choice re completing the reply slip by post or online. It was suggested that the request for further information could be a brief online form posted next to the video on the webpage so that parents could just complete this to receive further information, either by post or by email. Telephone number to also be clear at all stages.
- Text on reply slip needs to be changed to reflect that at this point of the process, when completing it; individuals are expressing an interest in being interviewed.

Discussion 2: Video Feedback

Nicole played the video that we had put together as an example of what we would produce for the recruitment process. The group gave the following feedback:

- Nicole to speak more slowly, to pause and breathe more!
- Good that Nicole wasn't sitting behind a desk.
- Plant was too distracting! Plain background was preferred, not white but also not too bright like the red used in the example video.
- Initial screen looks like blank headed paper – needs to start with title and shorten transition time between the slides with text.
- Preference for camera angle to be face on as if speaking to the person watching the video
- Wearing hair down was thought to be more informal
- Avoid terms as discussed above eg nonspecialist, understanding rather than capturing views, working with rather than collaborating.

- Discussion was had regarding need to interview parents of children who had 'challenging or fearful' dental experiences. Parents may not think that their child's experiences met this criteria. Could use difficult or stressful instead. Agreed important to capture experiences of families whose children hadn't had bad experiences. Nicole to be clearer in the video to explain that she is interested in hearing about positive and negative outcomes, but where it has been stressful or parents have put strategies in place to minimise stress. Parents need to think that they can give valuable information.
- Emphasise it is the parent carers views that are valuable/no-one knows their child better.
- Take out 'I need you'.
- Explain that parents can live in Somerset OR Devon including Plymouth and Torbay.
- Don't mention you are looking for 20 – 30 parents – those that are unsure may think that as it is such a low number that you will have plenty and so won't volunteer.
- As above ensure use a specific link to project page rather than to PenCRU homepage.
- Remove the lines going vertically across the screen and ensure the ones going horizontally across do not block the text.
- Change University of Plymouth to Plymouth University.

Discussion 3: Consent form

The group gave feedback on the draft consent form:

- Needs consistent title – suggested 'parent experiences of high street dentists for children with autism' (PEXDCA)
- Take out version number from sub-title
- Change the ethics committee
- Text not really plain language – better to say 'I have read and understood', 'I can withdraw without giving a reason'
- Difficult to circle yes or no
- As Nicole will be going through this form in person at the start of the interview and details, such as how the data will be stored will be provided in information leaflets, attendees were happy with the brevity.

Discussion 4: Draft Interview Questions

The proposed interview questions were circulated amongst the group for their comments and feedback. This has been collated as follows:

Question 1:

- Changing ASD to autism
- Query over "What are his/her strengths? Challenges" question – is it relevant/needed?
- Reword "Does s/he comply with simple instructions?" question
- Include a question about routine/flexibility

Question 2:

- Change 'dental history' to 'dental experience'.
- Substitute the word 'problems' with 'issues'.

Question 3:

- Query over “Have you tried other things? What happened?” question – may need more clarity.

Question 4:

- Rephrase ‘dentist’ to ‘dental practice’ as it is a team effort in preparing for a child’s visit.
- Change ‘collect’ to ‘ask/do’.

Next Meeting: [To be arranged \(likely Nov/Dec 2015\).](#)