



## Contenance Project Working Group

### Meeting 2

Thursday 19 October 2017, South Cloisters, St. Luke's Campus

**Family Faculty attendees:** Anna, Anna-Louise, Annette, John, Julia, Lisa

**Family Faculty apologies:** Dee, Lynn, Ursula

**PenCRU:** Chris, Silvia

#### **Overview**

- Chris introduced the research project to the Family Faculty working group.
- The working group discussed how to best recruit parent carers for the survey, and suggested key organisations and roles which can help advertise the survey.
- The working group compiled detailed lists of what information the survey should collect on the parent carer and their child.
- The survey should take no longer than 20 minutes, and mainly tickbox responses so quick to complete. Usual considerations: ensure time estimate realistic, save and go back and include a progress bar.
- The group agreed that at least 500 survey responses from parent carer should be targeted and over 1000 would be deemed an impressive response. The group identified key factors that will help ensure high number of survey responses.
- The working group identified the key stages in the research process which will require meetings, and discussed how to best involve remote working group members.

#### **What next?**

- Chris will continue working on the funding application with our co-applicants for this research project. A decision is expected from NIHR in March 2018.

#### **Update on project so far**

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- Chris introduced the research project to the Family Faculty working group. The research question is: "What is the available evidence for interventions relating to improving continence for children and young people with neurodisability?" This research was commissioned by NIHR and we are competing to carry it out. We have a team of co-applicants with topic and research methods expertise. During the summer PenCRU submitted an 'Expression of Interest', we have now been invited to submit a full application as next stage in process. This means completing a more detailed funding application document and producing a full plan/protocol document.

**Parent carer recruitment for survey**

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- The working group agreed that parent carer survey respondents need to have experience of interventions relating to improving continence; this will ensure that their responses add knowledge that other parent carers wouldn't had they no experience of interventions.
- Parent carer survey respondents should draw on experiences from the last 3/5 years at most. Survey respondents should be able to say in the survey how current their experience of interventions relating to improving continence are.
- One working group member noted that we can expect two 'cohorts' of parent carer survey respondents: families whose experience of interventions led to the child achieving continence, and other families who are still experiencing continence problems despite interventions.
- Working group members suggested we advertise the survey through the following channels: school nursing teams; health visitors; special schools; learning disability teams; NHS continence teams; parent carer forums; Facebook groups, including local and national; ERIC, the Children's Bowel and Bladder Charity.

**Parent and child information to collect in survey**

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- One working group member noted that if the survey asks questions that respondents deem too personal, this may be off-putting and may interrupt completion of survey. Some working group members felt that asking for full post-code would be perceived as off-putting, however they also commented that if the survey explains why we collect that information respondents may be more willing to provide this information.
- We should make it clear to survey respondents that we will not share their information, and they will not be identified.

Parent information	Child information
<ul style="list-style-type: none"> <li>• Ethnicity</li> <li>• Relationship with child</li> <li>• Age</li> <li>• Expectations and motivation to improve their child's continence problems</li> <li>• Ideal world solution to child's continence problems</li> <li>• Family history of continence problems</li> <li>• How did you hear about the survey?</li> <li>• Do you want to be made aware of survey results?</li> </ul>	<ul style="list-style-type: none"> <li>• Type of disability (drop down, with "other" option free text; option of selecting multiple disabilities)</li> <li>• When is the child incontinent: daytime, night time or both</li> <li>• Primacy/ siblings</li> <li>• Type of school attended</li> <li>• Age &amp; Gender</li> <li>• Type of interventions/ treatments received, including alternative therapies or homeopathic therapies</li> <li>• Mobility</li> <li>• When did continence problems start</li> <li>• What professionals are involved in the child's care</li> <li>• Does the child have access to a dedicated toilet at home</li> <li>• Communication</li> <li>• Bladder problems, bowel problems, or both</li> </ul>

### ***Group discussion on parent carer survey***

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- A general question asking what interventions families have tried and whether they've worked (rating question format) should be asked.
- The working group suggested that a minimum of 500 survey respondents would be required.
- The working group asked whether the research team should have target numbers of different types of disabilities in the survey responses to allow representativeness.
- One working group member said the survey should ask whether a family have tried to toilet train their child because of no diagnosis at the time, or whether the family didn't try toilet training because the child was diagnosed at birth.
- One working group member thought it would be useful to ask parent carer survey respondents how well they think the professionals involved in their child's care know their child.
- The group discussed whether it would be advantageous to offer the option of having the survey translated for parent carers whose first language isn't English. Silvia explained that she had previously known of [LanguageLine](#), an organisation which offers translation and interpreting services.
- The group discussed how to ensure high survey response rates: send out reminders; send out survey advertisements at different times of the day; make sure the blurb explaining the survey is interesting and attracts attention; have an easy option to share the survey link with friends; include survey progress bar; include the options to save the survey, and go between pages without losing your responses; be clear and honest on how long it will take to complete the survey, for example including a sentence like "other people who have completed the survey have taken 10-15mins".
- The working group suggested that the survey should take 20mins max to complete, and ideally 10-15mins.
- The working group felt that a financial reward for completing the survey was not necessary in this context.
- It was suggested that the research team test out how the survey advertisement looks like on computer email, tablet or phone to make sure all information is visible and links are easily accessible.

### ***Working group processes***

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- The group identified the following stages in the research process that will require meetings: meeting to develop parent carer survey and review professionals survey; meeting on ethics; meeting to interpret survey results; meeting to look at systematic review findings; meeting to bring together results of surveys and systematic review.
- The working group attendees suggested the following ways to effectively involve remote working group members: test out the survey, including timings; continue to receive meeting agendas and minutes; reward them for their remote work.