



## Healthy Parent Carers project Working Group

### Meeting 13

Monday 13 November, South Cloisters, St. Luke's Campus

#### Family Faculty:

Anna, Annette, Bel, Jane, Jen, John, Julia, Lisa, Lynn, Mary, Mirtha, Ursula

#### Family Faculty apologies:

Ruth

**PenCRU:** Chris, Gretchen, Silvia

#### **Overview**

- PenCRU staff and Family Faculty discussed key points of the proposed feasibility study now shortlisted for Stage 2 of the NIHR Research for Patient Benefit programme.
- The group agreed that the control group participants should access the booklet online, rather than receiving a hard copy, and that this should be split into weekly chapters.
- Most Family Faculty members strongly felt that the child's condition is not the only factor affecting programme outcomes.
- The group did not reach an agreement on whether randomisation should be balanced for factors such as child age or particular symptoms.
- The group agreed that potential expectations of additional support post-study can be managed if the research team is clear at the consent stage that additional support will not be provided post-survey and able to signpost parents to relevant support services.

#### **What next?**

- The deadline for Stage 2 application submission is 29 November 2017. PenCRU will learn the outcome around March/April 2018.
- If you have any comments or come across any information or resources relevant to the programme, please email [PenCRU@exeter.ac.uk](mailto:PenCRU@exeter.ac.uk)

#### **Background to the project and feasibility study**

---

- PenCRU introduced the [Healthy Parent Carers \(HPC\) project](#) and progress made so far.
- The next stage of the process is a [feasibility study](#) to test whether the HPC programme can be delivered in the community and evaluated in a randomised controlled trial. The facilitators will be selected by the Council for Disabled Children, who have an existing group of experienced facilitators as part of their Expert Parents programme. The facilitators will be trained by PenCRU staff and Bel and Mary from the Family Faculty who delivered the training previously. Local assistant facilitators will need to be identified; these will be individuals from the community.

## ***Research processes***

---

- Research process:
  - Study advertising
  - Volunteers contact researchers/ telephone screening
  - Consent taken by researchers face to face and forms completed
  - Randomisation to HPC group or Control group
  - Group participants are contacted by facilitator
  - Control group receive the HPC materials
- We should make sure that volunteers can get in touch with the research team to express their interest to take part in the study via phone and email.

## ***Control group***

---

- It was suggested that to make the booklet easier to go through, control group participants could receive weekly booklet sections. This, however, could be costly and complex to do.
- The group discussed clarity of instructions for the control group to use the booklet.
- The group agreed that if the booklet is given to the control group online, rather than hard copy, in the future, it should be given online to the feasibility study control group as well. If the feasibility study control group were given a hard copy, outcomes for this group may not reflect outcomes for future real-world dissemination.
- The webpage with the online booklet could be password protected.
- One Family Faculty member noted that not all rural areas get internet connection, and thus may cause problems for participants to access the online booklet.
- The booklet could be split up into chapters on the online webpage. In this way the research team could monitor who accesses which section when.
- The booklet could be available online throughout the group programme, with the option of receiving a hard copy once the study ends.

## ***Randomisation***

---

- Randomisation by child age could be useful as parent experiences at different child ages are different; the older the child gets, the more experience the parent has of caring for their child.
- The research team would need to have a rationale for adjusting randomisation.
- Some parents felt that if the word 'randomisation' is used, they would expect the process to be truly random and without any adjustments.
- Being able to tell control group participants that they have been allocated to that group due to randomisation may help with potential disappointment. When talking about two options it was suggested to use language similar to: "We are testing support by comparing a group intervention to a booklet"; don't mention 'control' or that the group sessions are the main focus of the study.

## ***Feedback relating to child condition being an important factor***

---

- Most Family Faculty members strongly felt that the child's condition is not the only factor affecting programme outcomes. The programme focuses on the parent as an individual,

independently of their child's condition. Parents also noted that there are many different variables which could affect programme outcomes for parents that don't relate to their child, for example whether they work, how much support they have from family etc. Additionally, it was noted that children's disabilities change as they grow up, influenced by other external factors such as bullying. The parents disagreed with the concept of disability 'hierarchy'.

- The group considered specifically whether parents of children with life limiting conditions may indeed have different experiences.

#### ***Feedback relating to potential expectations of additional support post-study***

---

- The group agreed that any expectations of additional support post-study can be managed if the research team is clear at the consent stage that additional support will not be provided post-study and able to signpost parents to relevant support services. The information sheet given to participants at consent stage should clearly delineate these boundaries, and explain what the study is not as much as what it is. Participants should be clear of the study end date, and be reminded of this date as it approaches.
- Family Faculty members noted that it is naturally likely for participants to stay in touch socially after the study without the coordination of the research team.

#### ***Family Faculty involvement***

---

- The group agreed that termly meetings would be sufficient, with an understanding that more meetings may be required in the initial stages.
- The study advertisement, the measures, and the participant information sheets can be reviewed remotely.

#### ***Other discussion points***

---

- The study advertisement should mention that places are limited to manage expectations.