

Healthy Parent Carers Family Faculty working group meeting

(Room 1.23, South Cloisters, St Lukes Campus)

10 May 2018

Meeting notes

Attendees

PenCRU – Chris, Gretchen, Katharine, Silvia

Family Faculty – Annette, Caroline, Jane, Jen, John, Julia, Julie, Lyn, Mary, Ursula

Overview

- PenCRU updated the group on the Healthy Parent Carers programme next steps.
- Family Faculty reviewed the study advert and the participant information sheet.
- The group discussed the practicalities of being allocated to receiving online materials, and reviewed how the online materials are presented on the website.
- The group considered how to ensure participants who sign up are retained until trial starts in April 2019. The issue of retaining participants throughout the study was also discussed.

- PenCRU updated the group on the Healthy Parent Carers programme next steps. We are testing the [feasibility](#) of delivering the programme in the community and feasibility of running a trial to see if the programme improves health and wellbeing. We are recruiting sites to host the group sessions, and preparing documents and materials for the [ethics committee](#) application.
- The Family Faculty reviewed the study advert and the participant information sheet, and provided feedback on how these could be improved, to make the information clearer and more relevant to parent carers.
- The group discussed the practicalities of being allocated to the arm of the study that will be receiving online materials, and reviewed how the online materials are presented on the website. The online materials should also include videos for Connect and Give.
- The online materials could be restructured to make it clearer that the videos are additional resources and not an integral part of the modules. This could be done by presenting the materials in two columns: the first column will include links to the modules, and the second column entitled “Additional/supplementary resources” should contain the video links.

- It was raised that participants recruited in October 2018 to participate in a study that started in April 2019 might either forget or lose interest in the months between signing up and starting. Regular updates, for example via newsletter, in the months between sign up and the programme starting would also help keep participants motivated. Automated messages, for example text, could be sent one week prior to the programme starting as a reminder.
- It was suggested that PenCRU should be clear about why there is a delay, explaining that researchers need to visit each participant individually to get their consent and collect baseline measures. This information will help better manage expectations.
- It needs to be clear to participants that they will need to meet one to one with a researcher prior to the programme starting. It should be described as a “face to face meeting”, as some participants might choose not to hold the meeting in their homes.
- The issue of retaining research participants was brought up. The participants should know that their participation is valued even if they stop attending the groups or do not complete the online materials. Furthermore, it’s important for the research team to know why participants drop out.