



Running a research consultation group with parents and carers of children with complex health needs who use children's rehabilitation therapy services: practical considerations and insights.

Eve Hutton and Gemma Wells, *School of Allied Health Professions, Faculty of Health and Wellbeing*
 Joanna Apps and Charmian Cowie, *Research Centre for Children, Families and Communities*

ABSTRACT

Participatory research, user involvement, consultation, co-production, and service user participation are terms and approaches that ensure the beneficiaries of research shape how it is developed and conducted.

While such approaches are accepted practice there is little guidance for researchers on how to conduct such activities with parents/carers of children with complex health needs.

Using insights from a series of consultation activities, the authors explore ways to work effectively with parents/ carers when care responsibilities and other constraints may restrict or limit their ability to participate.

We defined children with complex needs children as those who use two or more therapy services (Occupational therapy, Speech and Language Therapy and Physiotherapy) on a regular basis.

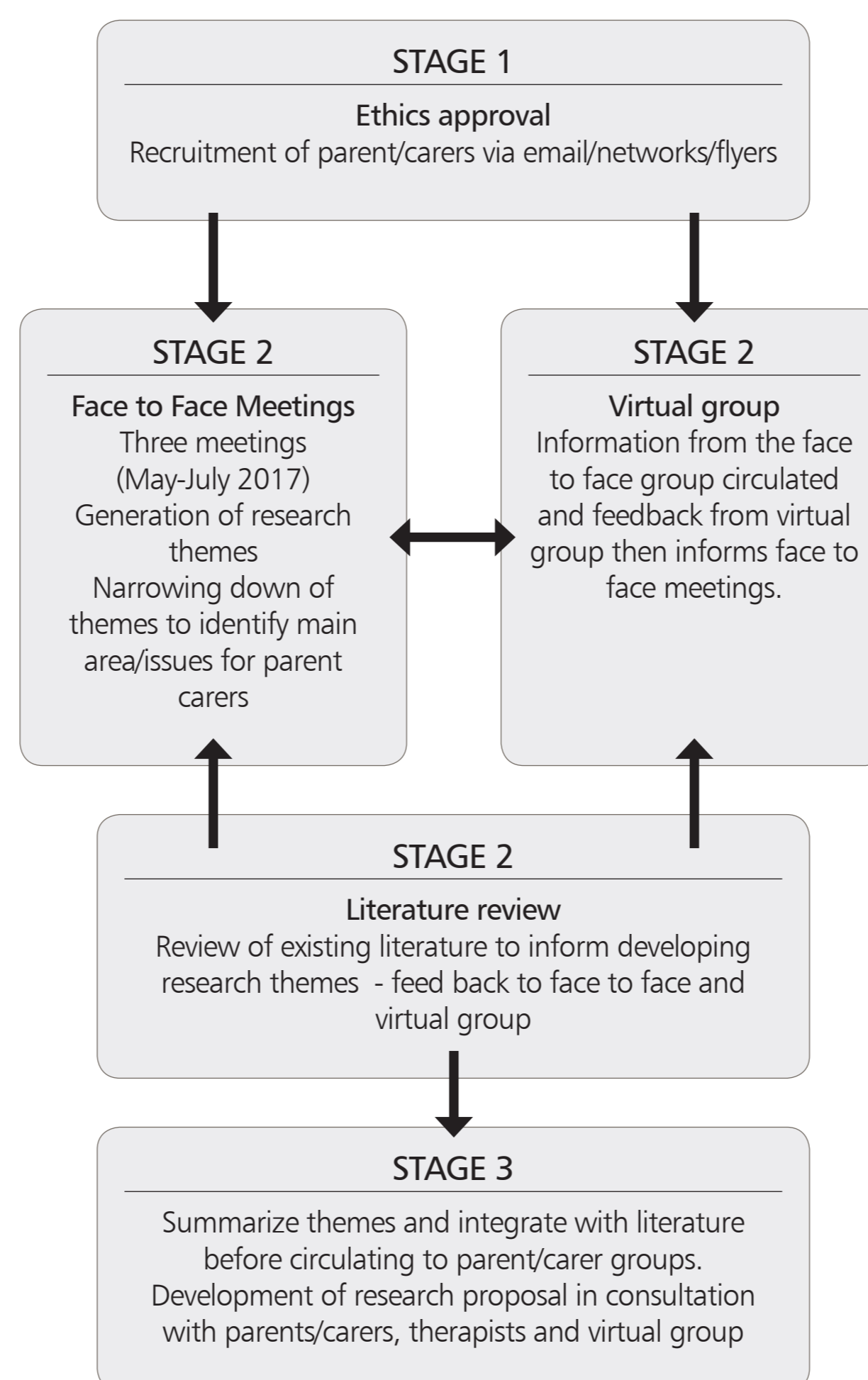
BACKGROUND

- A scoping study of the support needs of parents/ carers of children with complex needs highlighted areas for further research including; continuity of care, personalized care and the importance of simple things, for example returning phone calls, that made a big difference to parent/carer experience.
- There were challenges in recruiting parents and carers to this study. Many who initially expressed interest did not have further involvement, leading to speculation about demands on their time and practical issues that they face.

OBJECTIVES OF THE CONSULTATION

- Exploring how to engage effectively with parents/carers when developing research
- Ensuring that the views of parents shape research enquiry
- Focusing on questions and issues that are important to parents/carers
- Making a difference and improving parents experiences of care & support

METHODS



Seven emergent themes arose from our first consultation meeting

1. Flexibility of Appointments-time and location
2. Improved communication
3. Stress of home visits
4. Relationships with therapists
5. Parent/carer administrative care work to chase up services
6. Personalized approach
7. Parents/carers with additional needs/disadvantage

We explored the seven themes in more detail and began to develop potential research questions from each. The group rated each theme on importance to families of children with complex needs and feasibility of conducting research in that area. Three themes stood out:

1. Relationship with therapists
2. Parent/carer administrative care work to chase up services
3. Personalized approach

INSIGHTS

MULTIPLE ROUTES TO RECRUITMENT

- Use national networks to make contact with parents (Kent Parents Carers Forum).
- Attend events where parents are likely to be present and use the opportunity to network with representatives from a variety of organisations (statutory and non-statutory). Distribute flyers and use email to engage parent/carers.

OFFERING PARENT/CARERS CHOICES IN THEIR PARTICIPATION

- Listen to parent/carers views about date/time/location and format of events.
- Offer options for both face to face and/or virtual involvement.
- Recognise that parents/carers required flexibility to fit around caring commitments.
- Offer the choice of a phone call with a researcher at a time convenient to them.

PROVISION OF CHILD CARE

- The majority of parents in the group had school age children and were able to participate during the school day but lack of facilities and/or resources to provide on-site or alternative childcare restricted the face-to-face participation of parents of younger children.

ALLOWING ENOUGH TIME FOR PARENTS TO TELL THEIR STORY AND EXPRESS THEIR FEELINGS

- Allow plenty of time for parents/carers to tell their story and avoid overly structured activities. Acknowledge the need for parents/carers to vent strong feelings of frustration and sometimes anger.

FINDING ALTERNATIVE WAYS OF PRESENTING INFORMATION

- Offer alternatives to written documents and consider quicker and less burdensome ways of providing information to participants with very limited, and precious, free time, e.g. audio and video based information.

CONCLUSION

The next stages of this project are to:

- Consult with therapists to gain their perspective before developing a research proposal with parents/carers.
- Provide appropriate support and training for interested parents/carers to be involved in the conduct of the research.
- Undertake internally funded research with the Kent Parent Carer Network to ensure that the input of our consultation group and other local parents/carers can be shared with local service providers.

ACKNOWLEDGEMENTS

We would like to thank all the participants in our face to face and virtual groups, the Kent Parents Carer Forum and all other individuals and organizations who have assisted and continue to assist with this engagement work.