



Consulting parents and carers of children with complex needs who use rehabilitation therapy services about research - what issues are important?

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Executive Summary

Engaging parents and carers of children with complex needs in research presents challenges because of the nature of their caring responsibilities (Contact a Family 2012). Studies have highlighted the importance of involving parents and carers in research, and difficulties when conducting research when parents and carers are participants (Hutton et al 2016, Woodgate 2015).

With the aim of establishing a foundation for collaboration and partnership in research, parents and carers of children with complex needs were invited through a local parent carer forum to take part in a consultation about their priorities for research, with a focus on rehabilitation therapy. Three meetings were organised where researchers and parents and carers could discuss issues and topics of importance. Potential research ideas were generated at these meetings and shared via email with other parents and carers who were unable to attend face-to-face meetings and professionals who work with children with complex need. Out of seven initial topics, three were prioritised. These were:

- relationship with therapist (parent/carer/ therapist & child/therapist)
- the burden of 'administrative care work' on parents and carers
- the value of a personalized approach

A number of researchable questions were developed, based on these topics during the time allocated to the consultation. The aim is to build on this work to develop a proposal for funded research that will make a difference to parents and carers and their families. The researchers will be consulting more widely before developing a research proposal with parents and carers. There will be provision of appropriate support and training for interested parents/carers to be involved in the conduct of the research. An aim is to undertake internally funded research with the *Kent Parent Carer Forum* to ensure that the input of our consultation group and other local parents/carers can be shared with local service providers.

Background

Engaging parents and carers of children with complex needs in research presents challenges because of the nature of their caring responsibilities (Contact a Family 2012). A previous study highlighted the importance of involving parents and carers in research about them, but reported difficulties in recruiting parents/carers as participants (Hutton et al 2016). A series of consultation meetings with parent/carers of children with complex needs were organised, with the aim of identifying research topics of importance to parent/carers and exploring potential barriers to parents' participation.

During the consultation, topics raised by parents and carers were considered alongside discussions about potential changes to the way rehabilitation therapy services are delivered and ways of working that could improve families' experiences. We sought feedback from therapists who work with children with complex needs on the ideas generated by parent/carers.

The aim was to provide a foundation for collaboration and partnership to support future research. Researchers were interested in documenting the outcomes and experience of consulting parents about their priorities for research considering practical issues that could inform future collaboration. The intended outcome of this work is the development of research proposal(s) designed with parents and carers.

'Complex need' is defined as 'a child or young person who use two or more therapy services regularly (Occupational Therapy, Physiotherapy and Speech and Language Therapy)'.

Approach to Consultation

Ethics

Ethics approval for the consultation work was granted by Canterbury Christ Church University ethics review procedures on 25th April 2017 (Ref: 16/Edu/CL118).

Identification of parents/carers

A variety of methods were used to identify parents/carers who met our inclusion criteria based on local knowledge and parent and carer networks. Parents and carers were recruited at an event organised by the *Kent Parent Carer Forum*. Researchers gave a short presentation at this event and contacted staff from two special schools, who then helped support the recruitment of other parents. The *Kent Parent Carer Forum* distributed information through their network and flyers were distributed to parents of children at two special schools and within Canterbury Christ Church University. Eight parents and carers expressed an interest in being involved. All those (parents and carers and professionals) expressing an interest in taking part in the consultation were sent an information sheet and a consent form (see Appendix). Eight professionals expressed an interest in contributing to the consultation, agreeing to provide feedback via email/telephone on ideas and themes arising from our consultation with parent/carers. Although 8 expressed an interest only 3 professionals completed consent forms and could be involved in the consultation. See Table 1 for a breakdown of parents and carers and professionals those involved in the consultation.

Table 1: Parents and Carers and Professionals involved in the consultation

	Expressed interest	Attended meeting #1	Attended meeting #2	Attended meeting #3	Fed back on meeting #1	Fed back on meetings #2 and 3
Parent/carers	9	6	3	4	3	2
Professional	8	n/a	n/a	n/a	1	1

Overview of consultation activities

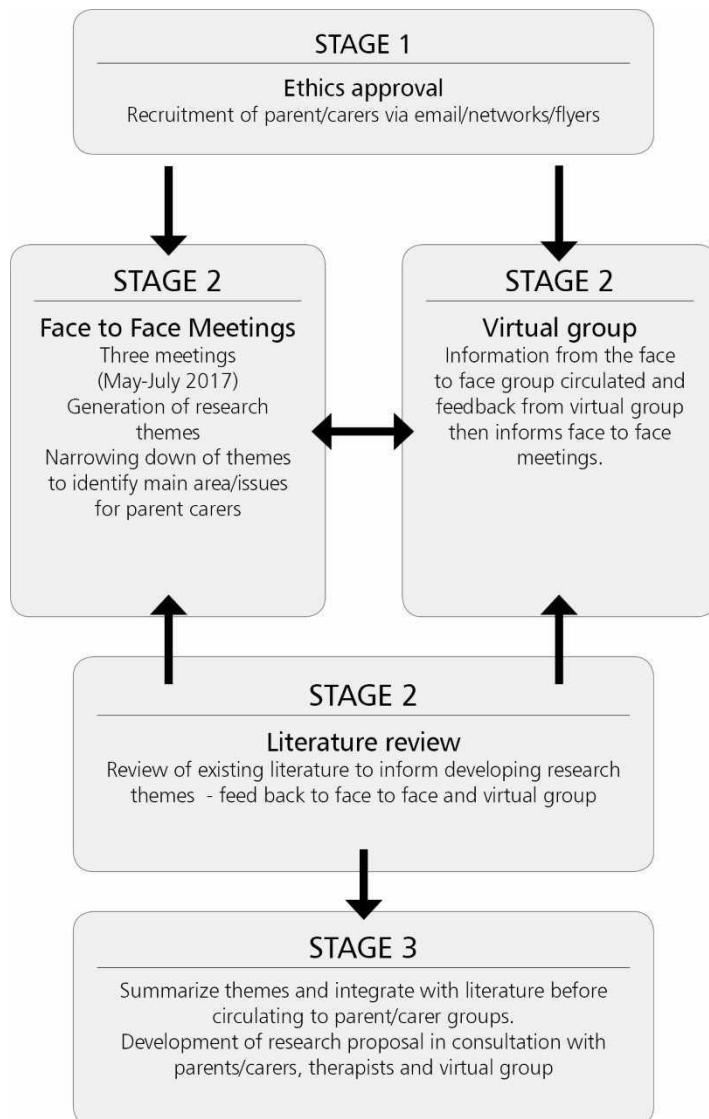
There were three stages to the consultation (Figure 1). Stage 1 followed ethics approval and the recruitment of parents and carers and professionals to the consultation. Stage 2 involved organising three consultation meetings with parents and carers. Ideas and themes generated were shared with parents and carers who were not able to attend the face-to-face meetings and professionals who provided feedback via email. Findings from a rapid review of the literature were shared with parents and carers at the final meeting. Stage 3 involved synthesising themes and ideas from the meetings, feedback and literature where topics could be considered from the perspectives of parents and carers and health professionals in the context of other research.

Methods used in the consultation activities

Recognising the sensitivities of parent/carers and discussion of potentially difficult topics, consultation meetings were informal (Involve.org.uk). An improvised 'polling table' was designed to assist parents and carers to prioritise different topics (see Appendix). Different ways of summarising and sharing information with parents and carers were used by the researchers, including creating a short YouTube video which parents and carers could access at any time convenient to them.

<https://youtu.be/8icJUS22UsU>

Figure 1: Stages of Consultation



Consultation Meetings with parent/carers

Three face-to-face consultation meetings with parents and carers were organised, one in May and two in July 2017, each meeting lasted for four hours with a break for lunch. Parents were offered a choice of venue. Lunch and refreshments were provided. Meetings ran between 10.30am – 2.30pm during term time as this was the optimum time (school time) when parents were able to attend. All parents and carers received high street vouchers. Meetings were facilitated by two academics (EH & JA) and the administrator for the Research Centre for Children Families and Communities (CC). At the final meeting the author of the literature review (GW) attended the meeting and fed back findings from the rapid review. Opportunities for parents and carers to be involved with future research were discussed.

Meeting 1

Aim of the meeting

The first meeting provided an opportunity for the parents/carers and researchers to get to know one another and for parents to 'tell their stories'. The meeting enabled the researchers to find out what parents/carers expected from the consultation - most wanted to 'make a difference', pass on their experience to others and inform services of their needs.

Format of the meeting

Topics included the purpose of the proposed consultation work, discussion of roles and ground rules. The second half of the meeting provided parents with information about the process of securing research funding, with a focus on the NHS, and began some general discussions of issues and potential themes of importance. These discussions centred on what parents and carers in the group felt they needed and wanted from therapy services and what would make a difference to them and their children. Researchers worked with parents, took notes and used flip charts to record ideas and themes. These themes were then shared with the group as a whole.

Outcomes of the meeting

Using the notes and flip charts from the day EH, JA and CC summarised the main themes - seven emergent theme areas/issues were identified which were supplemented with comments from parents and carers who were unable to attend the meeting but contributed via email (see Table 1).

- Appointments - time and location
- Communication – written and spoken
- Home visits
- Relationships with therapists
- The burden of 'administrative care work' on parent/carers – 'chasing up' services
- Personalized approach to care
- The needs of parents/carers with additional needs/disadvantage

Meeting 2

Aim of the meeting

The second meeting took place two months after the first meeting to fit with parent /carers' commitments, three parent/carers attended. The aim was to generate further discussion around the seven themes and consider potential research questions.

Format of the meeting

Feedback gained from the virtual group - about the themes - was shared with parents and carers at this second face-to-face meeting (see Table 1). The themes were explored and discussed by members of the group. Potential research questions were proposed. The researchers talked through a 'worked example' of how a topic could be developed into a researchable question using the theme of home visits (see Appendix). Parents considered the importance of each theme, what services and professionals could do differently that could make a difference and how feasible research could be from a parent/carer perspective.

Outcomes of the meeting

The three themes that were rated most highly were:

- relationship with therapist (parent/carer/ therapist & child/therapist)
- the burden of 'administrative care work' on parents and carers
- the value of a personalized approach

Meeting 3

Aim of the meeting

The third meeting followed soon after the second meeting to fit in with parents and carers commitments, 4 parents and carers attended.

Format of the meeting

For the third and final meeting the researchers shared a rapid review of the literature related to the original seven themes (see Appendix). A discussion, led by GW followed. The information gave parents a more detailed perspective of what was known already about their chosen topics and reinforced the commonality of their experiences.

Outcomes of the meeting

The group was asked to consider potential researchable issues based on the three highest rated themes. The group arrived at a number of related questions. Not all the questions linked to the identified topic areas as ideas and discussions continued to evolve. The research questions the group generated were the ones that arose in the time allowed, they provide a number of potential research questions and are not exhaustive.

Table 2 Aims and outcomes of meetings with parents and carers

	Aim	Outcome
Meeting 1	<ul style="list-style-type: none">• Parents 'tell their stories'• Get to know one another• Ground rules• Discuss issues/topics of importance	Seven theme areas/ issues identified <ul style="list-style-type: none">• Appointments - time and location• Communication – written and spoken• Home visits• Relationships with therapists• The burden of 'care work'• Personalized approach to care• The needs of parents/carers with additional needs/disadvantage
Meeting 2	<ul style="list-style-type: none">• Discussion of themes• Consider potential research questions	Three themes rated as important <ul style="list-style-type: none">• Relationship with therapist parent/carer/therapist & child/therapist)• The burden of 'care work'• the value of a personalized approach

Meeting 3

- Discuss the review of the literature on identified topics
 - Further discussion
 - Generate potential researchable questions
 - Considered 'researchable' topics based on the three highest rated themes
 - Research questions generated in the time allowed
 - Parents continue to expand on ideas and themes
 - Develop potential research questions - not exhaustive, themes from the original seven remain important
-

Potential research questions

1. Caring responsibilities

Parents felt that there was a difference in the caring responsibilities of parents whose child attended a mainstream school compared with those attending a special school. Special schools were thought to provide more support, reducing the parents and carers responsibilities, for example where the school organised dental and wheelchair appointments to take place at the school meant that parents didn't have to transport their child to these appointments. Parents whose child attended mainstream school described a more stressful and difficult encounters associated with their child's schooling. Parents felt that research that could explore the different ways schools supported parents and carers would be useful. They formulated a number of questions that considered the role of the school in providing support and ways that the caring responsibilities of parents and carers could be addressed.

What could/could mainstream schools learn from special schools in supporting parents of complex needs?

How do/do mainstream and special schools work together to support parents of children with complex needs in the same localities?

Are there (preventative) approaches that services/therapists/schools could adopt that would help reduce or lessen parent/carer responsibilities?

2. Personalised care

The group discussed whether there were applications or technologies that could help with their caring responsibilities, lessening the burden of care and make organising and coordinating services for their child easier. Issues about equipment provision were raised as a particular area of difficulty for parents and carers that took up time and led to frustrations. These were often problems linked to the incorrect ordering or prescription of equipment and also issues with the delivery and maintenance of equipment in the home.

What is/is there potential of using technology to address issues/problems with (ordering and prescription, delivery and maintenance) of specialist equipment? How acceptable would this be to therapists and carers?

3. Relationships with therapists

There were several aspects to this topic, including the nature of the relationship between the therapist and the child and therapist and parents and carers. An issue that arose was how relationships with therapists may be influenced by the gender, class, ethnicity and learning needs of the parents and carers and the extent to which therapists receive training in how best to work with families with differing needs.

Does/how does gender/social class of the parent/carer affect interactions/outcomes with therapists? Are therapists able to respond to parent carer needs?

Do therapists receive training around the needs of parents and carers (class, gender, ethnicity, special needs)?

Feedback from professionals

A summary of the second and third meetings, including the research questions that the parents and carers had identified, was shared with therapists via email. Two therapists responded with comments. We asked professionals to consider the value of the questions to the NHS. The theme of education and school was highlighted as important. Professionals raised the issue of services offered by NHS therapists to schools, the associated resourcing issues particularly services being stretched, the impact of these services in terms of outcomes for the child, potential differences between types of school (mainstream/special) environment and parental expectations.

“The issue of the support/services from schools has real implications for the NHS in terms of the services offered and the effects of these services on the outcomes for the child and family. I think one starting point would be to discuss and define what people mean by therapy services [in school].”
(Professional 1)

“There are differences in supporting children in special schools and mainstream schools so it would be valuable to see whether the differences could be identified. This may link into parental expectations of the benefits of the different types of schooling and expectations of their children. From a therapy point of view the increasing number of children in different mainstream schools can stretch resources.”
(Professional 2)

Questions about personalised care and relationships with therapists indicate an openness to further enquiry in these areas.

“Parents and equipment, may need to be looked at in line with resilience.” (Professional 2)

“There are different initiatives being developed to use technology that can be useful but I have not thought about it in respect to being able to visualise the environment instead.” (Professional 2)

“The relationship between therapists and parents may also depend on the level of experience. Training is variable.” (Professional 2)

We asked professionals to consider whether, if research was undertaken, there would be any issues affecting feasibility e.g. recruitment of participants, access to resources. Both professionals thought that recruiting participants could be challenging. A point was made about ‘hard to reach’ families and the need to be comprehensive in terms of accessing participants from all social classes. They highlighted the importance of taking a broader view to include stakeholders from education as well as health.

“Recruitment will be an issue if done in isolation i.e. just the NHS, including education and social services is essential to gather as much information as possible as to what is important and useful to all involved. There also needs to be clear benefit demonstrated as there is so much feedback/user views sought.” (Professional 1).

“I think it would be challenging to try to recruit a cross section as there are some hard to reach families whose responses may provide insight into the research. But if parents can see that their maybe some benefit from the research even in the longer term.” (Professional 2)

We also asked them to consider national or local changes in the NHS and whether there was any research ongoing that was addressing some of these areas.

“There are studies ongoing via charities into families’ views, including some about outcomes.” (Professional 1)

“The idea of family approach is central to a lot of the new developments of ways of working.” (Professional 2)

“There is an environment of change at the moment where local services are being commissioned in different ways potentially impacting on different service designs. The context of service provision needs to be considered.” (Professional 2)

Rapid Literature Review

A rapid review of the literature (see Appendix) was undertaken prior to the final meeting with parents and carers. The aim was to uncover whether there was existing research that had been undertaken in the topic areas parents and carers had identified. The information gave parents a more detailed perspective of what was known already about their chosen topics and reinforced the commonality of their experiences with other parent/carers. Parents and carers were interested to learn that the issues raised and experiences of other parents were so similar to their own. The review confirmed that the issues and topics remained relevant.

Practical considerations and insights

In undertaking this consultation researchers learnt valuable lessons from parents and carers that can inform future collaboration and partnership with parent/carers. (See Appendix Poster).

Use multiple routes when recruiting

- Use national networks to contact parents (e.g. 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 social media/email to engage parent/carers.

Offer 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.

Consider child care issues

- 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.

Allow sufficient time for parent/carers to tell their story

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

Explore alternative forms of communication with parent/carers.

- 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.

Next Steps

The aim is to build on this work to develop a proposal for funded research that will make a difference to parents and carers and their families. The consultation has resulted in a poster presentation at the Canterbury Christ Church University, Special Needs Inclusion Community Conference (SNIPCC; 14th October 2017). There are further planned publications from the work and conference presentations. The researchers will be consulting more widely before developing a research proposal with parents and carers. There will be provision of appropriate support and training for interested parents and carers to be involved in the conduct of the research. An aim is to undertake internally funded research with the *Kent Parent Carer Forum* to ensure that the input of our consultation group and other local parents/carers can be shared with local service providers.

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Appendix

Appendix 1: Literature Review

1. What access do children with complex needs have to therapy in (different types of) schools?

The access that children with complex needs have to therapy in different types of schools appears to be variable although not necessarily due to the nature of the school that they attend. It may be assumed that attendance at a special school would result in better access to specialist therapy input and indeed there is evidence to support this notion. Qu (2015) observed and conducted semi-structured interviews with 6 educators from a single special school. He discovered that the environment in a special school is more likely to include additional areas such as therapy rooms and quiet spaces. He also suggested that there is less financial support for specialist services in mainstream schools, with less money allocated for each student. However, Northern Lincolnshire and Goole NHS Foundation Trust (2014) conducted a review of therapy services that they provided to special schools. Opinions were sought from staff (n=22) and parents (n=38) associated with two different special schools. The key concerns raised by both staff and parents focused on the quality of communication, methods of communication, the desire for improved joint working between staff, parents and therapists, and timely access to equipment. This suggests that challenges still exist in effective implementation of specialist services in schools that exist to meet the needs of children with complex needs.

Magnusson et al (2016) found that parents were more likely to report that their child with developmental delay had unmet therapy needs if they were in mainstream schools. In contrast Alsem et al (2016) conducted a study in the Netherlands which explored parent's perceptions of the services received by their child with cerebral palsy in their transition from pre-school to school-based services. They found that the type of school attended by a child did not influence the therapy that was received. However, differences were identified between pre-school therapy services and school-based services, where pre-school services were more family centred and facilitated by enhanced levels of communication.

Qu (2015) concluded that overall there is a lack of consensus about whether mainstream or special schools are better for children with severe learning difficulties; this appears to reflect the literature exploring this issue.

2. Are there preventative approaches that services could provide to help avoid or reduce family breakdown/ issues?

It is widely accepted that caring for a child with complex needs is not without its challenges. The roles and responsibilities of mothers of children with complex needs are extensive, time consuming and frequently challenging (e.g. Green 2006; Nicholl and Begley 2012; Ziviani et al 2013). They include advocating for their child to ensure their needs are met by a variety of services (Green 2006), caregiving, paperwork and administration, carrying out the roles of professionals (Nicholl and Begley 2012), providing daily support and preparing for the future (Ziviani et al 2013). Bourke-Taylor et al (2009) discussed the increased prevalence of depression in mothers of children with complex needs but acknowledged that there were vast differences in how mothers dealt with the challenges that they faced. The 9 participants in this Australian study (a combination of mothers and professionals) engaged in semi structured interviews which resulted in many challenges being identified. These

were seen to relate to the child, the family, the mother herself, services, and environmental challenges.

McCann et al (2016) conducted a pilot cross sectional study as an extension to a piece of work that had focused on the time use of mothers. 10 mothers were involved in this study and they identified 156 activities that they performed as a consequence of having a child with complex needs. Whilst the women all felt competent in the health care procedures that they were required to complete they did not enjoy doing so as they considered them to challenge their responsibilities as a parent to protect their child from pain and harm. McCann et al (2016) described the women as experiencing 'role tensions' and suggested that exploring these could help professionals to understand the best way to support parents of children with complex needs.

Few studies have concerned themselves with understanding how parental stress can be reduced when they are caring for their child with complex needs (Krakovich et al 2016). Studies which have been conducted suggest trying parent focused interventions (e.g. Koegel et al 1996), parent education (Tonge et al 2006), peer led interventions (e.g. Dykins et al 2014), and exploring how the role of the teacher in special education may benefit parents.

Bourke-Taylor et al (2009) suggest that occupational therapists need to ensure effective communication with mothers of children with complex needs and that they would benefit from using 'occupational performance coaching' (Graham et al 2009). Occupational performance coaching is concerned with enabling parents to identify issues and barriers to their parenting role and is said to facilitate problem solving which can lead to performance improvement. However Graham et al (2009) acknowledge that this approach to practice may not be suitable for everyone as it requires "sufficient cognitive and language skills, stable mental health and adequate physical health to enable them to implement collaboratively developed interventions".

In a longitudinal study conducted in Canada by Woodgate et al (2012), the opportunities that families which contains a child with complex needs had to participate or 'have a life' were found to be dependent upon the physical, mental, psychological and spiritual work undertaken by the parents. Much of this work required parents to have the ability to identify and harness the resources required. Without this active engagement of the parents it is suggested that there are likely to be consequences for the wellbeing of the whole family (Raina et al 2004). For those families where parents find it difficult to access a full and rewarding level of participation for the whole family, engagement with projects as those identified by Maras et al (2008) may be beneficial in enabling them to develop the skills required to ensure family issues are avoided.

Maras et al (2008) identified the need for families to become more independent in order to decrease the cost of ongoing/ long term input from many different services. Whilst they do not refer specifically to families that contain children with complex needs, the 'mini projects' which are suggested clearly hold relevance to all families for whom input from services is often the norm. The 'mini projects' were provided by voluntary and community organisations and the content was defined by the needs of the parents accessing them. Examples of the sessions provided included parenting classes, personal development training, pamper days, anger management, and employment and training days. The parents who attended these sessions reported that they helped them psychologically, felt that they were constructive, appreciated the 'choice' that they were able to make, and identified a need for this input to be ongoing. Maras et al (2008) identified 5 lessons to learn from this piece of work. These were the need to make sure that everyone has a shared understanding of the project; the importance of establishing the roles of individuals and the

responsibilities they are expected to fulfil; how best to record the outcomes; the need for good communication between agencies, and the importance of seeing the families as experts.

This notion of seeing families as experts was also apparent in work conducted by Nightingale et al (2015). They suggest that the most reliable way for professionals to support parents of children with chronic conditions is to ask them directly about what they feel they need to learn and how they would prefer for this learning to occur. However, they observed that there was no validated method of achieving this. As a consequence Nightingale et al (2017) set about designing a tool that could be used to facilitate the communication of this information and consequently enable a collaborative relationship to be established between the parent and professionals. There were two stages to their work, the first involved 7 parents and 9 professionals who had links to one of 11 children's kidney units and focused on constructing questions that could be included in a questionnaire. Information was gathered through focus groups and individual interviews. Secondly the professionals trialled the questionnaire with the parents in the study. Participants in this study concluded that this questionnaire could be advantageous for those who were less confident with communicating their concerns, learning needs and preferences, and that it could facilitate a consistent approach by all professionals. There were also a number of issues that were raised as requiring attention prior to the introduction of such a tool, these included; providing the parents with the opportunity to choose when and where they completed the questionnaire, when the best time for completion would be, and whether professionals would be willing to adjust their practice to accommodate the introduction of this new tool.

Kruijzen-Trpstra et al (2016) highlight that it is important to consider the personal preferences of parents when considering how they can be best empowered in their role as a parent of a child with an ongoing condition. They conducted semi-structured interviews with 21 parents of children who were aged 2-4years and had a diagnosis of cerebral palsy. They found that the parents wanted to be listened to and have their opinions valued, and appreciated honest discussions with professionals. However, this study found that the exact nature of the partnership working between parent and professional varied for each of the parents. Some parents preferred goals to be set by the Therapist so that they could fulfil their role as a parent, others wanted to be actively involved in the process of therapy for their child but did not feel capable of doing so. Kruijzen-Trpstra et al (2016) concluded that the empowerment of parents whose children are engaged with therapy services was complex and different for each parent. They suggested that professionals require additional education in how to empower parents in a way that takes into consideration their preferences for their level of involvement.

Stephensen and Chesson (2008) explored the long term impact of developmental co-ordination disorder and found that 80% of children 6 years post screening were having ongoing issues in three or more of the following areas: motor performance, academic performance, emotional/ behavioural responses, and social interaction. This had consequences for the whole family. Stephensen and Chesson (2008) suggest that there is value in pursuing a new direction in service provision where intervention is provided to a large number of parents rather than a small number of children.

Barfoot et al (2016) recommends that a key worker or care-coordinator approach should be taken to support families who have children with complex needs. Looman et al (2013) suggest that a care-coordinator who assists in navigating systems and takes a relationship-based approach to problem solving is advantageous in the provision of services to children who have complex needs. However they acknowledge at the outset that there is a lack of clarification regarding the preparation and implementation of this role. They conducted a randomised trial and found that families who were allocated a care-coordinator were less likely to experience fragmentation in service provision and

more likely to receive efficient care. The care-coordinator communicated with the families for which they held responsibility through the use of a web cam (video conferencing) and provided a direct route of contact to themselves. As a result parents reported increased levels of satisfaction, trust and confidence with the services that they and their child received.

There seems to be a theme in the literature that there is a need to empower parents of children with complex needs but no real consensus about how this could be achieved.

3. What is the potential in terms of savings in cost/ time of using telecare (videos/ skype) to address issues with equipment? How acceptable is this to Therapists and carers?

It is reported that there are 5.5 million missed NHS appointments in England (Hallsworth 2015). Numerous facilities have trialled or permanently implemented the use of SMS messaging to remind people of their upcoming appointments (e.g. Gurol-Urganci et al 2013; McClean et al 2016). This method has been observed to reduce non-attendance, however the level to which this has been achieved is not considered to be optimal (McClean et al 2016).

This study is concerned with understanding whether telecare in children's services can result in cost and time savings whilst also maintaining a level of service that is deemed effective for both parents and professionals. Cason (2014) explain that video conferencing is the most commonly used format of telehealth in the United States and has been shown to prevent delays in receiving input (Cason and Cohn 2012) and improves interprofessional working (Cason 2012). Cason (2014) cites an example of how video-conferencing was successfully used in a study of children with complex feeding needs. Both professionals and parents reported a high level of satisfaction with this new means of communication which facilitated prompt communication, assessment and intervention.

The American Occupational Therapy Association (AOTA 2013) produced a position paper that stated that there is evidence for the use of telehealth in many areas of practice. Examples include, wheelchair prescription, ergonomic assessment, home modification, adaptive equipment provision, and neurological assessment.

4. Does/ how does the gender/ social class of the parent/ carer affect the interactions/ outcomes with therapists? Are Therapists aware of any of these differences? Do Therapists get any specific training around interactions with different groups of parents and carers?

An American study conducted by Fingerhut et al (2013) which involved individual semi-structured interviews with 28 Occupational Therapists who worked in three different settings (home, clinic, school) found that there was a preference held by these professionals for a family centred approach to practice. However they acknowledge that family characteristics such as language, socioeconomic status, and culture, negatively impact upon the successful implementation of family centred practice. Fingerhut et al (2013) conclude that professionals working with families need to learn about cultural awareness, how to access interpreters and translate materials to facilitate communication, and how to use flexible and creative means of communication with parents. Jansen et al (2017) concur that there is a need to acknowledge and work with the unique nature of each family; an observation they made after compiling 4 case studies over the period of 12 months. However, neither of these studies specify how or when this learning should occur.

Magnusson et al (2016) drew upon data captured by a national survey to establish the degree to which young children with developmental delay had unmet therapy needs in the United States of America. They established that of 5349 children aged 0 – 4 years, 50.2% met the criteria for a diagnosis of developmental delay to be assigned. Of those who were considered to have developmental delay, 21.6% were considered to have unmet therapy needs. However, only 6.2% reported that their child had unmet therapy needs. Magnusson et al (2016) identified a higher representation of children from non-white children in the statistics and argued that the racial, ethnic, and socioeconomic factors which characterised this group had an underlying impact. This impact had consequences for whether parents are likely to seek out or access therapy services for children with developmental delay. Magnusson et al (2016) concluded that there is a need to develop and provide interventions that focus on improving communication between the service provider and the parent/ carer, and to encourage shared decision making in order to address the differences that appear to exist in which children experience unmet therapy needs.

Kvarme et al (2016) conducted individual and focus group interviews with 27 parents (18 of whom were mothers) who were caring for a child with complex health needs. The parents originated from Poland, Pakistan, and Vietnam but were currently residing in Norway. Kvarme et al (2016) suggest that the health and quality of life of these parents was negatively affected by their limited knowledge of the Norwegian language, health, social and welfare systems available, and their rights to access certain resources. They concluded that these parents needed to be provided with more information to enable them to obtain the necessary support to help them to care for their child with complex health needs.

Studies that explore the experience of parents who have a child with complex needs predominantly capture the opinions and experiences of the mother. This could be because women are more likely to take on the role of carer for a child with complex needs; giving up their career, accepting that they will miss out on certain life experiences, and finding it difficult to be separated from their child (Bourke-Taylor et al 2009).

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25th April 2017

Ref: 16/Edu/CL118

Joanna Apps
c/o Research Centre for Children, Families and Communities
Faculty of Education

Dear Joanna

Confirmation of ethics compliance for your study “Parents and Carers of Children with Complex Needs Consultation Group”

I have received your Ethics Review Checklist and appropriate supporting documentation for proportionate review of the above project. Your application complies fully with the requirements for proportionate ethical review as set out in this University’s Research Ethics and Governance Procedures.

In confirming compliance for your study, I must remind you that it is your responsibility to follow, as appropriate, the policies and procedures set out in the *Research Governance Framework* (<http://www.canterbury.ac.uk/research-and-consultancy/governance-and-ethics/governance-and-ethics.aspx>) and any relevant academic or professional guidelines. This includes providing, if appropriate, information sheets and consent forms, and ensuring confidentiality in the storage and use of data. Any significant change in the question, design or conduct of the study over its course should be notified via email to red.resgov@canterbury.ac.uk and may require a new application for ethics approval. It is a condition of compliance that you must inform me once your research has been completed.

Wishing you every success with your research.

Yours sincerely

Carol Clewlow
RKE Co-Ordinator
Tel: +44 (0)1227 922893 (direct line)
Email: red.resgov@canterbury.ac.uk

Appendix 4: Theme Tables

Theme	Significance to parents/carers
<ul style="list-style-type: none"> • Appointments • Problems of late changes to appts • Appts in London • Facilities-privacy, space 	<ul style="list-style-type: none"> • “Time has been a massive issue for us. Mostly the length of time it takes to get appointments or equipment but also to travel to and attend appointments, plus coordinating people to deal with our other son.” Parent #1 • Rated high importance by two parents • “A late change of venue can cause problems for parents who either don't drive or for those whose children have learning problems, as change can be hard.” Parent #1 • “I feel the piece about London visits needs more clarity. I am also conscious that the following just reflects my views. I think I am in agreement that the children with most complex needs seek medical input from centres of excellence, which for this part of the country tends to be London. The expertise and facilities are far superior and for the large part the care and attention supercedes

that you would get locally. However, the concept of sending our sickest and most extensive users of healthcare resources the furthest and most frequent is difficult to comprehend, especially when a child is too sick to make the journey for their medical care. I believe that this migration was only intended as a support to local teams who continue to take the lead in the child's care. However, in practice it has been very much viewed locally as a relinquish of responsibility with the view 'London takes care of them now!'

Parent # 2

- Having to keep **checking and rechecking** appointments and other things to ensure they were in place-Parent # 3
- Sometimes structural constraints like hospital parking restrictions could lead to missing appointments and the cost of parking was expensive with so many appointments. There could also be a knock on effect if a therapist was late for an appointment as parents could then get a parking ticket in the hospital car park. This added to the stress of the appointment. Parent # 3
- After much thought and many years of usage I would still like my child to be cared for out of a centre of excellence despite the distance, inconvenience and cost to the family associated with this

model. However, there are many ways in which this could be made easier for the patient and family:

- Facilities on arrival (changing places with hoists, a bed for rest and stretching out from the wheelchair, quiet space, kitchenette to prepare specialist feeds and medications, privacy to undertake daily clinical procedures, play area, enough space to accommodate siblings and other family members or carers that travel with you)
- The option to attend several clinics on one day to avoid frequent journeys
- Consideration as to what appointments and when to ensure maximum benefit to the patient and family with regard to their care pathway.
- Flexibility with regards to the time of the appointments to allow for travelling, traffic problems and catering for medical interventions and cares on route.
- Expenses. More consideration needs to be taken here it is not just travel expenses, you also need to consider loss of earnings of the parent to attend the appointment, childcare costs for siblings, food

	<p>costs, congestion charge, parking, additional equipment required to travel (cool boxes to refrigerate feed and medications, portable sats monitors, oxygen cylinders, suction pumps etc.)</p> <ul style="list-style-type: none"> • The ability to undertake routine procedures locally, such as pre-op tests, infection control swabs, blood tests, scans and some X-Rays with the information shared in a secure and timely manner. This will avoid 6 hour round trips for basic procedures. • More telephone or skype consultations where appropriate. Possibly organised at local 'virtual' clinics for those technically adverse or where it is not available in the home. • Centres of excellence i.e. long trips to London managed better.
<ul style="list-style-type: none"> • Improved communication 	<ul style="list-style-type: none"> • "With regard to communication, some clarity is needed. I just write things down if I've not heard them before and google them later. I'd rank this lower as I'm comfortable asking for clarification and we have challenged some things." Parent # 1 • "When we first started getting letters for our son I kept getting annoyed that they were addressed to 'parent or carer' as I thought

they should know we are his parents. This is not a big issue though as there are so many things to deal with.” Parent # 1

- Better information sharing that was not just tick boxing but holistic to the child and family, a recognition of the emotional impact on parents of having a child with disability (e.g. she said that it's not so much about the problem for example of a letter sounding punitive- parents can deal with that in itself -but about the difficulty of dealing with that when there are so many other emotional strains).Parent # 3
- She would also like more accessible reports and particularly had a problem with understanding audiology reports and now always asks for audiograms. Parent # 3
- Not being signposted to support services. Finding your own way to support in the voluntary sector (2 parents)
- Gaps between services and lack of communication between services. Services are not joined up and/or information sharing is not on a level that is useful-just ticking boxes Parent # 3

	<ul style="list-style-type: none"> Letters could seem very formulaic and looked like they had been written using 'a template'. Not necessarily punitive but feels like they are 'one size'. Parent# 3
<ul style="list-style-type: none"> Taking the stress out of home visits 	<ul style="list-style-type: none"> "I don't like home visits much" Parent# 1 Did not find home visits intrusive but could understand that some parents might feel this way Parent# 3
<ul style="list-style-type: none"> The importance of the relationship with therapists 	<ul style="list-style-type: none"> Relationships with therapists are very important Parent # 1 The relationship between the therapist and her child was very important to this parent. She said that one therapist had a 'lovely' relationship with her child and she felt she wanted to give her a hug but couldn't. The relationship between therapists and children is quite intimate because of touch and the kinds of support they give. The parent felt sorry for this therapist being unable to express her feelings towards her child. Parent # 3 Relationship of therapist and child is important. Parent # 3 Theme Rated high importance by two parents

<ul style="list-style-type: none">• Parent/carer undertaking 'caring work' to chase up services	<ul style="list-style-type: none">• “This week, I've chased a lycra suit as clinic is only once a month (although I know DMO, the company that makes the suits, turns them around quicker than this) and I realised it should be back from repairs before anyone contacted me. Last week we had an apologetic phone call to say that a much needed piece of equipment could not be delivered, on the day it was due to be delivered. It had been tricky to find a day when I was in but someone had simply ordered the wrong size so now we have to wait weeks again. Our son has been injuring himself on the current shower / toilet chair. Companies that take orders from the public rather than the NHS cannot get away with this.” Parent # 1• “Being reasonable and a bit desperate sometimes gets results. Yet again my son broke something on Monday and I actually got a call on Tuesday from someone in wheelchair services who knows my son and made an appointment for next month. Not bad when I'd rung after school on Monday. Once I had to complain to get any appointment and we still had to wait a couple of months.” Parent # 1
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- “I've said 'I just want to be a mum' before. It takes a lot of energy to deal with everything that comes with having a disabled child.”
Parent # 1
- “Things have to be right for our son as he is physically 'extreme'. Time is more of a problem [than communication], last Tuesday we finally found a toilet sling that is to be ordered, about 18 months after getting a ceiling track hoist into the wetroom.” Parent # 1
- Main issues were around the chasing up that needs to be done.
Attributed Parent # 3
- Parent #3 said she had to keep checking and rechecking appointments and other things to ensure they were in place.
- Parent # 3: Having to ask for things her child needed and this not happening automatically (because she met other ‘tick boxes’ around cognitive development-“she’s doing this so she’s OK”) had been an issue for this parent.
- “the term 'therapists' does apply to us as parents as we need to coordinate and do therapy with our children but I would describe

myself more as a secretary or personal assistant when chasing equipment or services for our son as a lot of time is spent on paperwork” Parent # 1

- “With regard to mainstream versus secondary schools, parents need to help school staff as therapists cannot be relied upon. Our son passed his year 6 SATS but there is now a further complaint about equipment as therapists have yet to sort out a toileting chair that he should have had before July for year 6 residential (requested October 2016 for end of June 2017 and still not correct despite a formal complaint in August, although he's started at mainstream secondary where they have never had anyone as disabled). The occupational therapist and physiotherapist have scheduled a meeting at school for tomorrow, 19th September, to meet at school but term started for children on 4th September and everything needed to be in place by then. I spent the first week our son was at school trying to sort out issues and putting in a complaint to services. Special schools would have known the equipment was not correct / been able to use an alternative and need less guidance. It doesn't help that we've been told they will learn from our experience as you cannot repeat the first week - I repeatedly chased everything but it was still wrong.” Parent # 1

<ul style="list-style-type: none"> • The value of a personalized approach 	<ul style="list-style-type: none"> • “More bespoke approach to care ditch the ‘one size fits all’. Less emphasis on box ticking and time taken to file targets and more focus on understanding the situation, taking ownership and finding a solution.” Parent # 2 • “Having attended a 'tea and talk' morning with MCH (Medway community healthcare) on 19th June, the physio chairing the meeting admitted that children are categorised. Following this they get a certain amount of contact from the therapy team each year. Either 3 per year, approx 1 a month, or 20 contacts a year, usually in intensive blocks. Children do go from one category to another but as therapy time is so limited, we like many other parents, have more contact with charities. For example, our son gets a horse riding lesson every fortnight.” Parent #1 • With regard to personalisation, communication and letters, I noticed on a facebook group that some parents had been sent a generic letter about CAMHS. Many were left confused or fed up as they had more than one child with special needs and did not know which child the letter referred to. Parent #1
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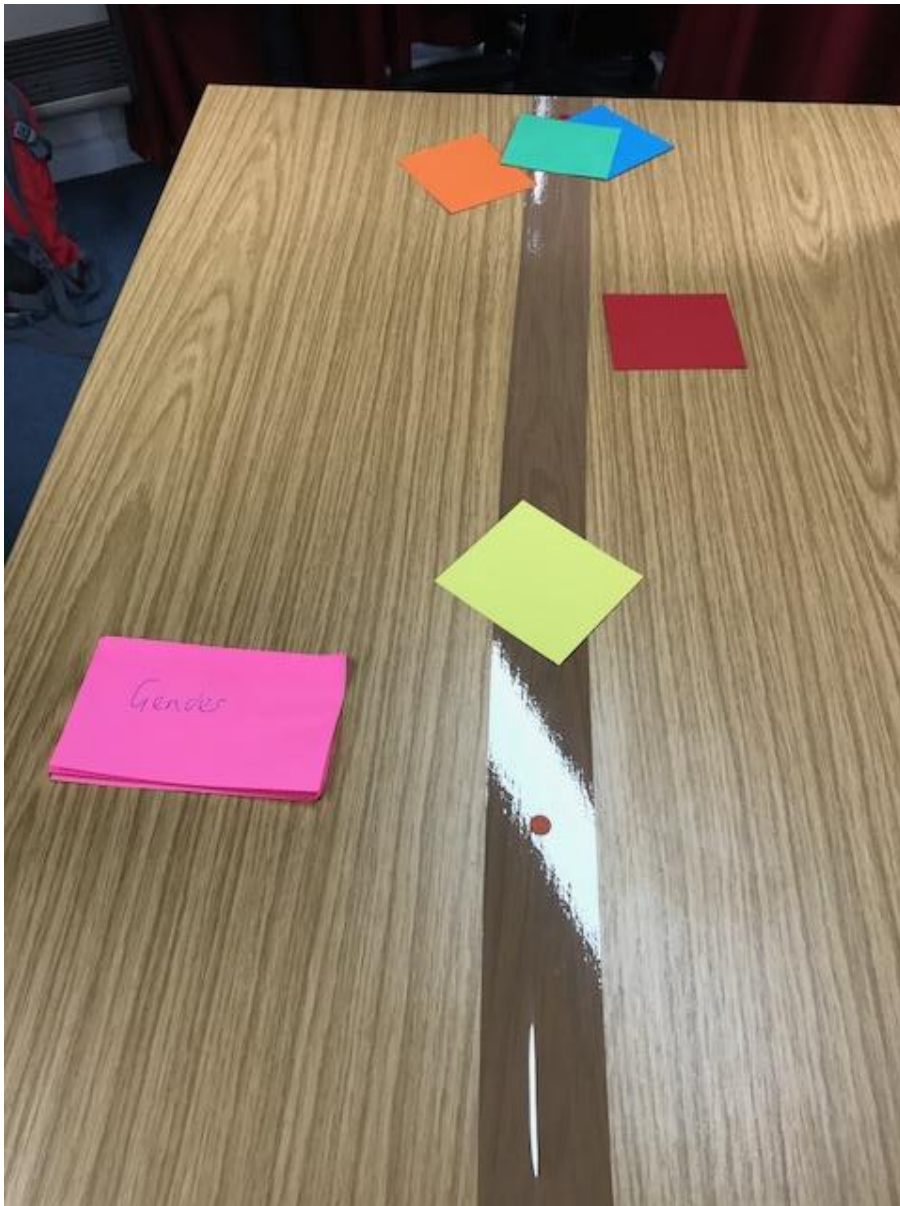
- Better information sharing that was not just tick boxing but holistic to the child and family, a recognition of the emotional impact on parents of having a child with disability (e.g. she said that it's not so much about the problem for example of a letter sounding punitive- parents can deal with that in itself -but about the difficulty of dealing with that when there are so many other emotional strains).Parent #3
- Parent #3: Having to ask for things her child needed and this not happening automatically (because she met other 'tick boxes' around cognitive development-"she's doing this so she's OK") had been an issue for this parent. This related to professionals not seeing her child's needs holistically. She said in particular that there was not enough thinking about the social/emotional/stigma impact of how different services and aids were provided.
- Parents need to be confident enough to 'push' for services. 'Taking on a crusade' to liaise with lots of organisations and services to get child the support she needed. Parent # 3
- Rated high importance by two parents

	<ul style="list-style-type: none"> • Rated most important theme by one parent (Parent #3)
<ul style="list-style-type: none"> • Parents/carers with additional needs/disadvantage 	<ul style="list-style-type: none"> • We neither have special needs or (currently) low income. When we lost jobs we had a very small mortgage so did not have problems. I've not been able to work since being made redundant though. Parent # 1 • Parents need to be confident enough to 'push' for services. 'Taking on a crusade' to liaise with lots of organisations and services to get child the support she needed. Parent # 3. • Rated high importance by one parent
<ul style="list-style-type: none"> • Other issues 	<ul style="list-style-type: none"> • The service providers need to accept its not working, it's not as good as it or they could be, it's not just about lack of resource it's also about culture, individual mind set and a willingness to succeed. Parent # 2 • Gaps between services and lack of communication between services resonated with this parent whose child had stopped being able to access some services when they started school. This parent had to rely on school to refer for certain services and this was not

always happening, with the SENCO taking a lot of time to get things in place. Services were not joined up and/or information sharing was not on a level that was useful-just ticking boxes. Parent #3

- This parent had **not been signposted** to support services at the time of her child's diagnosis and was very depressed at that time but then by chance found a national charity that works with children and parents with the same disability her child had and they had been very helpful: 'the help from the voluntary sector-it changed my world.' Parent # 3
- [talking about with the way children are transferred from the old statement of special educational needs to an EHCP]: We can confirm that the transfer process is drawn out and traumatic, having had to apply for a tribunal date and submit documents to be used in court before being awarded transport to secondary school. Parent # 1

Appendix 5: Polling Table Illustration





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.

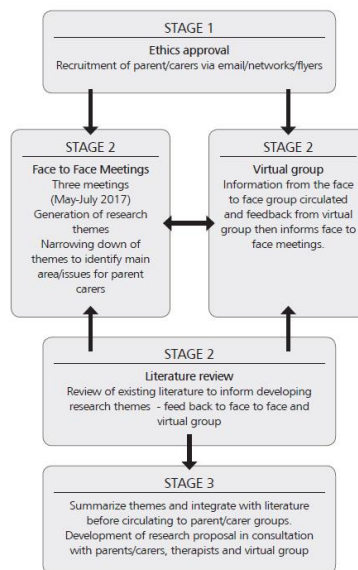
BACKGROUND

- 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.

