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Involving Children and Young People in Supportive Cancer Care Research: The Value of FDS Grant Funding & Charitable Partnerships

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Abstract (250 words)

Introduction

Involvement of children and young people in research has a multitude of benefits for children, researchers, and the quality of the research in itself. Despite the benefits of involvement, this is not always completed or reported in practice.

Aim

This article explores the involvement of children and young people during a research study exploring the acceptability of photobiomodulation for mucositis management. It considers the importance of costing involvement into grant funding and the value of charitable partnerships in conducting patient and public involvement.

Results

Children and young people with experience of cancer, and their parents, were involved at the stages of grant application, research design, data analysis, and dissemination. Involvement of families resulted in changes to inclusion criteria, plain language summaries, and participant information documents. They provided insight into data analysis and designed and filmed co-created video outputs to support acceptability of the treatment, dissemination of the research, and research involvement of other children. Involvement was supported both practically and financially by charitable partnership with Candlelighters children's cancer charity, and research grant funding from the Royal College of Surgeons Faculty of Dental Surgery.

Conclusion

Child and parent contributors shaped the research project resulting in changes to the study design, data analysis, and co-creation of video resources. Charitable partnership and flexibility of involvement supported diversity in the context of paediatric cancer research. Researchers should consider what they can contribute in return to child contributors and charities who provide support.

3-6 key words

Paediatric, cancer, patient and public involvement, child involvement

Introduction

Historically, research has been conducted *on* children and young people as participants, rather than *with* them as collaborators and contributors.(1) Involvement of children and young people in research has a wide variety of benefits; effective involvement supports quality research design, delivery and dissemination, whilst also benefiting young people and researchers' personal development and understanding of different perspectives.(2)

The National Institute of Health and Care Research define five key stages of the research process for active involvement: research design, development of grant applications, undertaking the research, data analysis, and dissemination of findings.(3) Additionally, children and young people should be involved with research priority setting, prior to the point of research design, to ensure that research resources are being utilised in areas of importance to those with lived experience.(4)

An initial systematic review of children's oral health literature between 2000-2005 found 87% to be conducted *on* children and young people, with only 0.1% of the included 3266 studies actively involving children in the research process.(5) In recent years, however, there has been a shift in the perception of involving children and young people in research and service development, acknowledging their unique perspective and lived experience as they navigate healthcare services.(6) This is in part due to the adoption of the UN Convention on the Rights of the Child and the subsequent move towards rights-based research, which considers children's perspectives and opinions, and their right to express them, as integral to research.(7) This was reflected in a repeat systematic review including literature between 2006-2014, where 17.4% of the included 2950 studies were conducted *with* children and young people.(8) However, only marginal improvement was seen in the proportion of studies actively involving children in the research process, reported as 0.3% of included studies.

Despite the multitude of benefits of involving children and young people in research, and the increase in active involvement in recent years, this involvement across the research process is often poorly reported. The following article details the involvement of children and young people in a qualitative research project, from the point of research design to co-creation of dissemination outputs. It explores the role of grant funding from the Royal College of Surgeons Faculty of Dental Surgery and the British Society of Paediatric Dentistry (FDS/BSPD Pump Priming Grant) and charitable matched funding from Candlelighters Children's Cancer Charity in supporting Patient and Public Involvement, to maximise research relevance and impact.

The research project

Up to eight in every ten children going through chemotherapy for curative cancer treatment, or prior to haematopoietic stem cell transplant, will develop oral mucositis.(9) When severe oral mucositis occurs, ulcerative lesions can be extremely painful.(10) This often prevents children from eating orally, and may necessitate inpatient hospitals stays for parental pain-relief and nutrition.(11) Oral mucositis has been found to significantly impact children's quality of life during their cancer treatment.(12)

Photobiomodulation is a red light or low-level laser treatment that can be used during chemotherapy, to reduce the risk of developing severe mucositis by approximately a half.(9,13) It is recommended in international paediatric oncology guidance for use during chemotherapy for children at high risk of developing oral mucositis, especially those receiving conditioning chemotherapy prior to haematopoietic stem cell transplant.(14,15) However, our previous research found photobiomodulation to be poorly implemented across children's cancer centres across the United Kingdom, with only two Principal Treatment Centres in Scotland delivering this treatment for children.(16) A concern raised by healthcare professionals in this earlier research, and within the paediatric guidance, related to the acceptability of photobiomodulation to children and young people.

The present study aimed to explore this acceptability with children and young people, their parents, and healthcare professionals involved in their care; this research was funded in the 2022 FDS BSPD Pump Priming Grant scheme.(17) Children and young people with experience of cancer, and their parents, were involved at each stage of the research process (Figure 1). Involvement of children and young people and their parents was included in the grant costing at each research stage. Families were remunerated with vouchers in line with NIHR guidance for their time and contribution.(18)

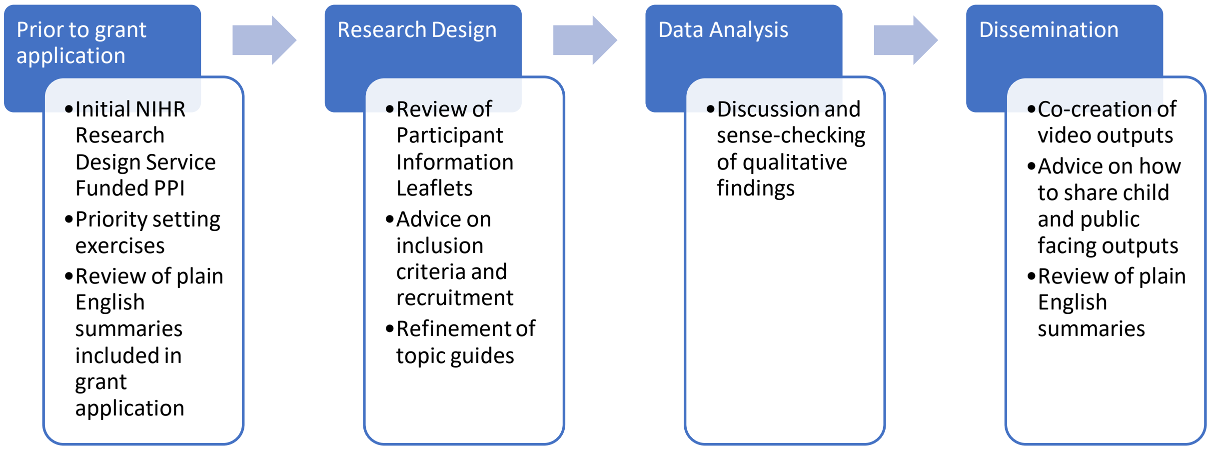

Figure 1. Involvement of children and young people with cancer, and their families, across the research process.

Charitable partnership

Candlelighters are a regional children's cancer charity working across Yorkshire and the Humber (Registered Charity Number 1045077). Candlelighters provides emotional, practical, and financial support for the families affected by childhood cancer across the region. This support is delivered at the Leeds Children's Hospital on the ward, at their family support centre, The Square, and in the community to provide support closer to home.(19) A key focus for the charity is investment in childhood cancer research; this commitment has resulted in the recent opening of the Candlelighters Supportive Care Research Centre at the University of York. The five-year £1m commitment from the charity for the centre will enable research addressing the side effects of cancer treatment and challenges of living with childhood cancer. (20)

Candlelighters' family support team provided initial public involvement in review of plain language summaries at the point of grant application. They provided support in kind, equivalent to £700, to aid the delivery of involvement activities in the project. Candlelighters' matched funding included use of The Square for involvement activities and staff support during activities. Additionally, advertisement for patient and public involvement was distributed through their family support network, increasing the reach of involvement beyond the children and families actively attending the children's cancer centre.

Format and Setting

Involvement activities included group workshops and individual involvement meetings led by two researchers (CH & BP). Involvement meetings were held at the family support centre of Candlelighters (The Square) or online by virtual conferencing based on the preference of each family. Children and families attend the Square throughout their cancer treatment for support groups, events, and as respite from the Leeds Children's Hospital as it is situated next door. The Square was chosen as families were already familiar with this non-clinical environment. All involvement meetings were conducted on weekends or weekday evening between 17:00-20:00 to limit the disruption to school and work schedules of families.

Utilisation of individual involvement meetings at the outset allowed us to explore the relative sensitivity of the research area with families on an individual basis, before embarking on group meetings. Additionally, it allowed use of virtual conferencing to increase flexibility for families and reduce travel burdens for families residing across the Yorkshire and Humber region; for some families, initial participation with an unknown research team may have also been more comfortable in their home environment. Group meetings with children and young people were then used to share qualitative findings and encourage discussions, to collaboratively design a storyboard for a co-created video, and to then gain feedback on the video.

Research design

Five family units took part in initial involvement activities: three child/parent dyads or triads, and two parents including one bereaved parent. Families advised us on content of topic guides for qualitative interviews, and how to explain photobiomodulation to families in interviews who had not yet experienced the treatment. They confirmed that inclusion of children who had not yet received photobiomodulation was important to answer the research question.

Families provided input on participant information leaflets, with children reviewing age-appropriate versions and providing feedback. Notably, in the context of children's cancer care where children and parents predominantly have experience of participation in clinical trials and observational studies, families advised us on how to explain qualitative interviews to other children and parents, which led to changes to study documents and information leaflets.

Understanding results and video co-creation

Following completion of qualitative interviews, a workshop was held with three children and young people aged eight to fifteen years-old (a fourth contributor was unable to attend due to cancer treatment side effects). These contributors provided feedback on our interpretation of qualitative findings and aided our understanding. Qualitative findings are reported elsewhere, however, families and healthcare professionals in interviews expressed desire for a resource that could explain mucositis and the photobiomodulation treatment in a way that was accessible to children and young people.

The experiences of the child contributors, combined with the findings of the qualitative interviews, were used to co-design a storyboard for such a video. The children involved in storyboard co-creation had clear ideas for the video content. This included: first-hand experiences of children describing mucositis and photobiomodulation treatment, inclusion of children going through active cancer treatment of different ages and genders, delivery of photobiomodulation both by children themselves and healthcare professionals, explanation of the treatment by knowledgeable healthcare professionals, and footage of children receiving photobiomodulation to show that it does not hurt. Different elicitation approaches were used, including use of picture and question prompts, facilitated group discussion, and opportunities for children to draw their own storyboards to discuss with the group. Through these approaches, a draft storyboard was constructed (Figure 2)

Figure 2. *Video co-creation group and storyboard for video resource*

Video Outputs

Funding to produce the video with Mosaic North had been included into the pump-priming research grant. Mosaic North Ltd are an established company with experience of filming with children and young people during their cancer treatment through their project JTV Cancer Support.(21) JTV Cancer Support works in partnership with the Teenage Cancer Trust to create and host thousands of educational videos about childhood cancer and its treatment. These videos are accessed worldwide by thousands of children and families.

Nine children aged between one and fifteen years-old were involved in filming of the video relating to mucositis and photobiomodulation. This included unscripted accounts of their experiences of having oral mucositis and receiving photobiomodulation during their cancer treatment. These accounts were filmed away from the clinical setting, at The Square, as advised by our co-creators. These accounts were combined with video footage of photobiomodulation delivery with a range of children and young people at Leeds Children's Hospital (Figure 3).

Figure 3. *Footage from the co-produced photobiomodulation video available at www.lchtv.com/photobiomodulation*

Through our work with children and young people during the project, it became clear that many children had not previously been involved in research and its development. An output of this project was to produce a film to explain this concept to other children in the future. A short film was made where contributors described their experiences and what they had gained from being involved with research. This was combined with footage from the video co-creation workshop to promote research involvement to other families.

Feedback and dissemination

The videos were initially shared with the children and young people involved in their co-creation, before being premiered at a patient and public involvement group with four families comprising of three children with experience of cancer, two siblings, and six parents. Positive feedback was received about the content and format of the videos, with families valuing the focus on the experiences of the children and young people involved.

During the storyboard involvement meeting, we asked children and young people where would be best to share the final videos. They advised us that they accessed videos from the Leeds Children's Hospital TV (LCHTV) website during their cancer treatment and so this platform would help us to reach our target audience. A webpage dedicated to this project has was subsequently made on the LCHTV (https://www.lchtv.com/photobiomodulation), with the video outputs freely available for children and young people, their parents, and healthcare professionals at other children's cancer centres (Figure 4).(22) The videos have proven popular, with the webpage being the most viewed on LCHTV for a number of months following release. Candlelighters have further supported dissemination of video outputs, and our wider research, through their family support networks; this has increased engagement with our ongoing research in this area and supports child involvement in subsequent involvement groups.

Figure 4. *QR code to access co-created video resources at Leeds Children's Hospital TV website www.lchtv.com/photobiomodulation*

Reflections

Shaping of the research

The contribution of children and their families from the outset helped to ensure that the research was of relevance to the group it sought to benefit. Initial involvement influenced the inclusion criteria for the study and identified areas for clarification in lay summaries. Contributors highlighted the challenges in describing qualitative research methods to this population which resulting in alteration of participant information sheets to support recruitment. Additionally, it highlighted the desire for information resources in this area and a preference for video formats, which were subsequently costed into the research grant.

During the research process, Candlelighters supported recruitment and contributors aided understanding of initial qualitative findings. Children and young people drew on these research findings, along with their own experience, to co-design a storyboard for an information resource on mucositis and photobiomodulation. This resource was inspired and driven by children and young people's experiences and information preferences, which supports dissemination and photobiomodulation treatment acceptability for children in the future.

Diversity in involvement

Children's cancer does not discriminate in the families it affects. Involvement of public contributors from diverse backgrounds is critical to reflect breadth of experience of families.(23) Collaboration with Candlelighters, an organisation with existing support networks for a small population across a wide geographical region, supported diversity in the involvement group.(24) Flexibility of contribution also supported diversity, with activities occurring outside of work and school hours, availability of remote options, and by hosting face-to-face activities within an inclusive and accessible setting.(25) Additionally, advertisement through the Candlelighters network increased equity of opportunity when compared to recruitment through clinical care by including children and young people outside of active cancer treatment and bereaved parents. Inclusion of travel reimbursement for families within grant costings supported involvement of families from geographically isolated areas, with some families completing round trips in excess of 120 miles to take part in involvement activities.

Committing to bidirectional relationships

Researchers should consider not only what their research can gain from the involvement of children and young people, but what they can offer in return to these groups. Involvement sessions should be structured so that contributors have opportunities to socialise with each other and ask their own questions of researchers, as well as contribute to the research activity itself. By nurturing child contributors, researchers can support them to build their confidence in research involvement and develop transferrable skills. Opportunities may arise for children and young people to be trained in specific skills, such as data analysis, academic writing, presenting research findings, and designing outputs.

Similarly, this bidirectional relationship should be considered when engaging with charitable partnerships. By establishing a collaboration, researchers in our group have contributed to wider events at Candlelighters. Engaging in such events can provides mutually beneficial opportunities. By running a science workshop at a Candlelighters activity day, researchers from our team were able to complete a priority setting exercise with children and young people (Figure 4). This serves a dual purpose of teaching young people what research is, and engaging them in its process, but also in gaining additional involvement to guide the future work of the Candlelighters Supportive Care Research Centre.

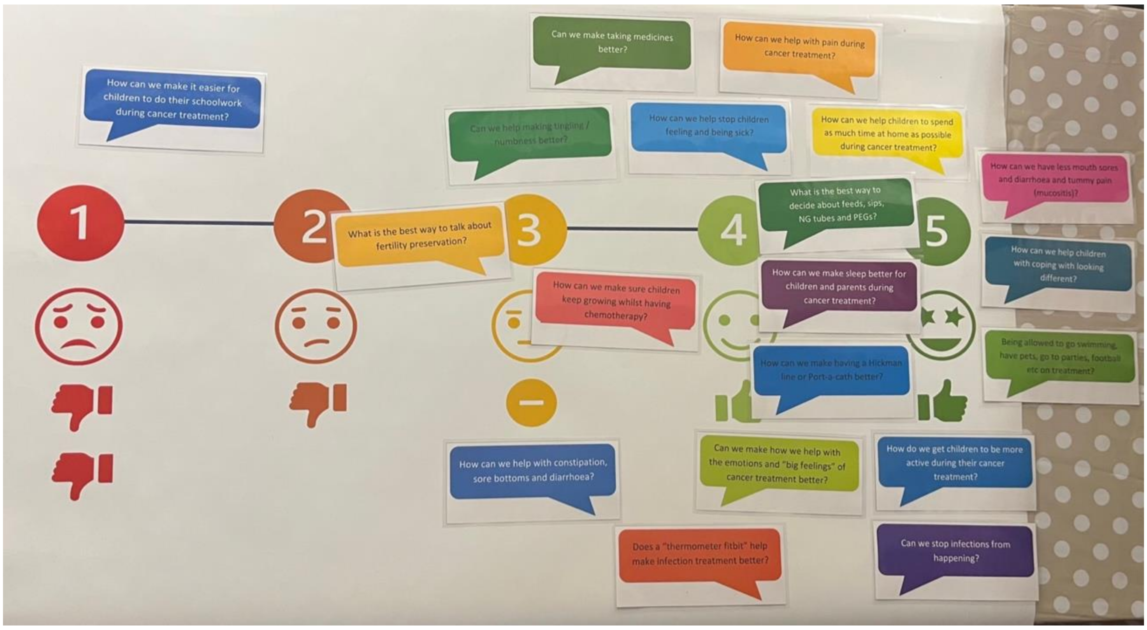

Figure 5. *Example of a wider involvement completed through a priority setting exercise at a charity activity day.*

Challenges in involving children and families during cancer treatment

A child's life is subject to a lot of change during cancer treatment and children and young people may not feel able, or want to be involved, at all stages in the research process. By adopting a flexible approach to involvement, children and young people can engage in different projects and different points in the research process of most interest to them and at a time to suit them.

Additionally, research in supportive cancer care may result in challenging topics of conversation arising at involvement groups. Consideration should be made to the composition of involvement groups, the setting in which these conversations occur, and whether appropriate support is available. Collaboration with Candlelighters provided additional support for families within a safe setting, with availability to signpost to further support groups as needed.

Establishing a fixed involvement group

Following the success of our collaborative approach with Candlelighters in creating this patient and parent involvement group, associates of the Candlelighters Supportive Care Research Centre have worked to establish an ongoing patient and parent involvement group. The co-created video output from the present research project explaining involvement in research was played at the launch of this group to explain its purpose.

This group builds on the relationships formed through this research project to engage and involve children and their families in a wider range of research projects relating to supportive cancer care. Through this group we aim to foster a culture of conducting supportive care research alongside children, in an accessible setting, to ensure that their voice is heard. It is hoped that children and young people will develop confidence and research skills through their ongoing contribution and that, supported by relevant training, they will progress to act as researchers and co-lead in future projects.

Conclusion

Involvement of children and young people in research is essential in ensuring that research is designed, delivered, and shared in a way that is accessible to the patients it aims to benefit. Researchers should build bidirectional relationships with children and families involved in their research founded on mutual respect.

Children with cancer and their families have been actively involved throughout this project to ensure maintenance of the child voice and delivery of accessible research outputs. This has been achieved in part through grant funding to reimburse families for their time, expenses, and contribution, and through charitable matched funding. Collaboration with relevant charities can support involvement groups through provision of inclusive and accessible spaces, access to wider networks to improve diversity, and access to support groups for child contributors and their families.

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