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Lessons learned from building the kid's trial with an online children's and parents' research advisory group: a descriptive, qualitative study

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Abstract
Health research increasingly incorporates public and patient involvement (PPI) to enhance trial inclusivity and relevance, and it is often mandated by funding and regulatory bodies. PPI boosts public engagement with trials and aligns trial objectives more closely with the priorities of the groups they aim to benefit. The Kid's Trial, an online randomised trial co-created with children, aims to help them better understand what randomised trials are, why they matter, and improve their critical thinking skills. To ensure inclusivity and relevance, we established two PPI groups: the Children's Research Advisory Group (CRAG) and the Parents' Research Advisory Group (PRAG).

We recruited a representative sample of children and parents from diverse ethnic, geographic, and socioeconomic backgrounds to reflect the trial's target demographic. We engaged PPI group members through social media and email campaigns aimed at parents of children aged 7 to 12. PPI meetings were conducted online, followed set agendas, and included real-time trial updates, post-meeting feedback surveys, and polls. A PPI compensation plan was established in advance. Online interviews later captured their insights and experiences as PPI partners.

Seven family units, comprised of eight children and seven parents, were recruited over 15 weeks from six countries. PPI partners shaped the trial design by contributing to website animations, aesthetic changes, and language adaptations. Interviews were analysed using reflexive thematic analysis to explore the facilitators, challenges, and outcomes of participating in our online research advisory groups.

Reflections from researchers and PPI partners demonstrated that participation in the advisory groups enhanced children's learning and confidence. Many members, including children and adults, experienced unexpected positive outcomes, such as increased scientific literacy, science communication and confidence. Their involvement meaningfully shaped the trial's development and processes. This study also provides guidance for researchers engaging similar demographics in future PPI activities.

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Plain English summary

Health research now often includes input from the public and patients (Patient and Public Involvement or PPI) to make studies more inclusive and useful. Many funding and regulatory organisations require this. When the public is involved, research studies become more relevant to the people they aim to help.

The Kid's Trial is an online study designed with children to teach them how health research works and help them think critically about health information they encounter. To make sure The Kid's Trial was inclusive and meaningful, we created two PPI groups made up of children and their parents to help us design it.

We used social media and email to recruit a diverse group of children and parents from different backgrounds. These groups met online to discuss the trial, make improvements, and give feedback. They worked on the website, website animations, trial design, and the language we used. The PPI group members were compensated for their time.

Seven family units, consisting of eight children and seven parents from six countries, joined the PPI groups. We interviewed group members to understand what worked well, what was challenging, and what they gained from participating in the PPI groups.

Children felt that their confidence and learning had improved. Many PPI group members experienced unexpected benefits. Their input significantly influenced the design of The Kid's Trial. This study also offers valuable advice for researchers seeking to include children and parents as PPI partners in future studies.

Keywords Patient and public involvement, Qualitative study, Reflexive thematic analysis, Online advisory groups, Children's and parents' research advisory groups, CRAG

Introduction

Randomised controlled trials (RCTs), considered the gold standard for evaluating healthcare interventions, provide evidence for researchers to assess the effectiveness of an intervention [1]. However, conducting RCTs presents significant challenges, including difficulties in recruiting and retaining participants, high operating costs, and complex designs [2, 3]. Over the last few decades, the clinical trial community has focused on devising strategies to address these challenges, one of which is to invite patients and members of the public to work with research teams in the conception and conduct of trials [4], an approach often referred to as Patient and Public Involvement (PPI[1]). Working with PPI partners can increase trial relevance and inclusivity [5, 6], and reduce trial costs [7, 8]. Another strategy increasingly employed to improve trial access, participant recruitment, and lower trial costs is decentralisation, where trial data are collected at locations away from a central site using mobile clinics, digital technologies, or online platforms [9–11].

The Kid's Trial is an online randomised trial that invites children between 7 and 12 years of age worldwide to design, conduct, and report on a randomised trial in a safe and engaging way. The trial aims to help children understand randomised trials and why they matter, as well as improve their critical thinking around health claims. At the time of writing this manuscript, we are recruiting participants to the trial designed by children around the world. The question chosen by the kids to tackle within The Kids Trial investigates 'Does sleeping with a comfort item (for example, a toy or special blanket) make a difference to how well kids sleep compared to not sleeping with a comfort item?' In this trial, children are randomised (1:1) to either sleep with a comfort item or not sleep with a comfort item for seven nights.

In addition to conducting The Kid's Trial online, we aimed to further increase its relevance and inclusivity by establishing two PPI groups early in our planning: the Children's Research Advisory Group (CRAG) and the Parents' Research Advisory Group (PRAG). These two PPI groups met online as they comprised a geographically diverse group of children and their parents[2].

Combining decentralised trial methods with PPI, The Kid's Trial aims to be inclusive, relevant, and far-reaching. Although there are examples of successful recruitment for international PPI groups involving young people and children, they have recruited locally from established field sites through larger research networks [12, 13]. We did not have established field sites or networks from which to recruit. Additionally, while several frameworks provide excellent guidance on working with children and young people as PPI collaborators [14–16], in planning the formation and conduct of our PPI groups, we identified a gap in the knowledge base for doing this on a global scale and online. This absence of guidance serves as the driving force behind this paper. Its aim is to describe the development and facilitation of our online PPI groups, and to explore the experiences of PPI group

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[1] In this paper, when referring to patient and public involvement and engagement, we use the following terms interchangeably: PPI, advisory groups, and CRAG and PRAG.

[2] In this paper, we use the term 'parent' as a general term, acknowledging that often a child's guardian may have a different relationship to the child.

members and researchers in planning and designing The Kid's Trial. Specifically, we describe their roles and experiences, identify the methods that supported our collaboration, and propose recommendations to improve these methods in future work.

To collaborate with children in our PPI groups, we were guided by the *Lundy Model of Child Participation* [17] as a theoretical framework. This model is grounded in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) [18] and has been widely adopted by various organisations, including the Irish government's National Strategy on Children and Young People's Participation in Decision-making [19–22]. Established in 2007, the Lundy Model emphasises four interconnected elements: Space, Voice, Audience, and Influence, and was later expanded to incorporate the "four Fs" for meaningful engagement: Full, Friendly, Fast, and Followed-up feedback [17, 23]. Additionally, we referred to the *CIOMS 2016 International Ethical Guidelines for Health-related Research Involving Humans*, particularly Guideline 7 on Community Engagement [24]. For The Kid's Trial PPI groups, these theoretical frameworks laid the groundwork for creating a collaborative research environment that honoured the perspectives of all members, supported their engagement, and ensured opportunities for their meaningful contributions to shaping the trial's development.

Methods

Research design

This descriptive paper outlines the activities and outputs of the two PPI groups, and qualitatively analyses semi-structured interviews conducted with members of both groups. It is guided by the GRIPP 2 reporting checklist [25], available in Supporting Materials S.1.1. We first explain how the PPI groups were established and detail their activities. Next, we describe our approach to conducting and analysing semi-structured interviews with their members.

PPI group establishment and logistics

Recruitment

The target demographic for The Kid's Trial is children between 7 and 12, and so we aimed to recruit child PPI collaborators within this range to ensure our CRAG reflected the target trial population. To include parental perspectives, we sought family units comprising at least one child and one parent. While no strict rules exist for advisory group size, clinical trial steering groups typically recommend around seven to eight members [26, 27], ensuring PPI contributors outnumber researchers [28]. We planned to meet with our PPI partners well before the trial was launched and therefore, aimed to recruit approximately eight family units to participate in meetings throughout the preparation and conduct of the trial (spanning approximately one year).

Our recruitment campaign for the PPI groups, launched in May 2023, utilised email and social media advertising specifically aimed at parents of children aged 7 to 12. The email campaign leveraged our professional and personal networks. One-third of the world population does not have internet access [29]. As a result, there was an unavoidable exclusion of potential PPI partners in families that either could not access our recruitment materials or lacked internet access for our online meetings. We endeavoured to promote inclusivity, where possible, by prioritising geographic diversity and collaborating with children's advocacy groups that support underrepresented populations, including minority and under-resourced communities. Email recruitment materials featured a letter of introduction and informational flyers, while social media recruitment materials included static and animated advertisements designed for each specific platform (Facebook, Instagram, X, LinkedIn).

As per the University of Galway Research Ethics Committee [30] and the Irish PPI Ignite Network [31] policies for working with PPI contributors, we did not require or seek ethical approval for the recruitment or conduct of the PPI groups. We did ask all members to complete Expression of Interest (EOI) forms. Participant information leaflets and EOI forms were emailed to interested parents for both children and adults. They had several weeks to review the materials, ask questions, and return the EOI forms. Upon joining the groups, PPI group members received access to a shared Google Doc outlining expectations and guidelines for all members. To ensure transparency, this document also outlined the expectations and guidelines for the research team. These documents are available in Supporting Materials S.2. All PPI partners could withdraw their participation in the groups at any time without consequence or explanation.

PPI group meetings and logistics

Once the PPI groups were established, the research team created a private, researcher-moderated online posting board (Google 'Jamboard') to build community beyond formal meetings and foster connections. This platform allowed members to share photos and discuss hobbies and cultural events in a safe, controlled environment that was accessible only to the group. Since the writing of this manuscript, Google has disabled 'Jamboards'.

We used online polls to find the best meeting times for the most members. When families couldn't attend a meeting, additional meeting times were offered. Meetings occurred via Zoom videoconferencing [32]. Agendas detailing key discussion points aligned with trial development were emailed to parents before meetings. After meetings, participants completed anonymous feedback surveys via QuestionPro Survey Software [33] or Google Polls to vote on action items. Survey results and meeting minutes were shared with all PPI members, ensuring transparency in decisions and outcomes.

Meeting children online raises concerns about internet access and privacy. Since the children were under the age of digital consent, we required parents to participate in our PPI groups to address data protection risks [34, 35]. Participants were advised to use nicknames in online meetings if they preferred and were not required to use webcams. The researcher took meeting minutes anonymously, and the meetings were never recorded. Participants were informed in writing and verbally that the outputs resulting from our PPI work would be used in The Kid's Trial and reported in an academic paper anonymously.

Remuneration of PPI partners

We considered compensating our PPI contributors essential to demonstrate our appreciation for their expertise and to establish an ethical precedent for compensating PPI collaboration in research. Compensating children further highlighted our dedication to a child-rights-based approach to co-production. We established a priori budgets for the compensation of both groups based on the UK's National Institute for Health and Care Research (NIHR) guidelines [36], research produced by Evidence Synthesis Ireland [37], and a systematic review investigating the compensation of PPI partners [38]. Our remuneration plan is available in Supporting Materials S.3.

Qualitative study design

This section outlines our qualitative data collection and analysis of semi-structured interviews with CRAG and PRAG members guided by the Standards for Reporting Qualitative Research (SRQR) (available in Supporting Materials S.1.2) [39]. Ethical approval for the semi-structured interviews was obtained from the University of Galway Ethics Review Committee (ref: 2024.03.008). Before being granted ethical approval, and in line with the requirements of the Research Ethics Committee of the University of Galway for conducting research with children, SL was vetted by the Irish police force (An Garda Siochána). The qualitative data consisted solely of these semi-structured interviews. Other forms of data collected during the activities of the PPI work, such as participant feedback surveys and Jamboard interactions, were excluded. In particular, Jamboard content often included private discussions about PPI members' personal lives and was therefore not suitable for inclusion in this analysis. The aims of this analysis were to:

- describe and examine their roles and experiences in designing The Kid's Trial,
- identify which participatory mechanisms they thought facilitated these activities,
- discover how these processes could improve.

Braun and Clarke's Reflexive Thematic Analysis (RTA) [40–42] aligned with our objectives and considered the insights of the project lead (SL) as the facilitator of the PPI groups' activities. RTA allowed us to explore PPI partners' perspectives while incorporating the project lead's interpretations and reflections [40–42]. Additionally, we drew on Byrne's recent work on RTA [43], which emphasises the 'researcher's interpretive analysis of the data conducted at the intersection of: (1) the dataset; (2) the theoretical assumptions of the analysis, and; (3) the analytical skills/resources of the researcher' [43].

Semi-structured interviews

After completing most of the PPI work, we invited members to participate in interviews by emailing participant information leaflets along with consent and assent forms. Group members could contact us if they were interested over the following weeks. Compensation for interviews was not provided; they lasted between 25 and 45 min and were conducted via Zoom [32]. Children were allowed to have parents present during the interviews or, with the parent's consent, could participate independently. Four parents (P1-P4) and three children (C1-C3) volunteered to be interviewed, with two children choosing to have a caregiver present and one parent including their child during their interview. The project lead (SL), who had established rapport with the participants, conducted all interviews. Sessions were recorded using Zoom's [32] automated transcription feature, which SL verified during data cleaning. Transcripts were imported into NVivo 14 [44] for analysis. Participant materials and the interview schedule are available in Supporting Materials S.4. Any participant who agreed to be interviewed was informed that they could withdraw from the qualitative study at any time without consequence and that their data could be deleted up until the time of data analysis.

Given that the lead research collected and predominantly analysed the data, it is important to describe her positionality here. SL is a white American female who has been living in Ireland for over a decade. At the time of preparing this manuscript, SL is in the final year of her doctoral studies. Before pursuing a doctoral degree, SL worked as a healthcare provider with experience in nursing and midwifery and has also taught healthcare education to adults. Additionally, SL has two young children and, as a result, frequently discusses scientific and health-related topics with kids of similar ages to those of the CRAG members in her personal life.

Reflexive thematic analysis

Each interview transcript was read multiple times, with notes taken prior to the initial coding pass using a semantic, open-coding approach [41]. While primarily inductive, this process incorporated deductive elements, as research questions guided how coding addressed the study's aims. The project lead (SL) focused on participants' meanings while integrating their interpretations during the coding process. Participants were not asked to validate themes. After the initial coding, a second iterative pass identified and refined potential themes. A second researcher (BW) reviewed the transcripts and the corresponding codes and themes with SL to enhance reflexivity and deepen the analysis. Although RTA does not require or recommend researcher consensus, this collaboration enriched the analysis within Braun and Clarke's framework, particularly during the theme-reviewing phase. BW's qualitative expertise provided mentorship, supporting SL's RTA process. Following a third coding pass and further theme exploration with BW, the iterative process continued until the interviews, codes, themes, and relationships were thoroughly examined. Table 1 presents the four themes and two subthemes generated during the analysis.

Integration of findings

The original aim of working with PPI collaborators was to make The Kid's Trial more inclusive, relevant, and accessible to both children and parents. However, as the work progressed, we recognised the value of reflecting on our collaborative efforts through member interviews. We believe this study could provide guidance for researchers engaging with similar demographics in future PPI activities. This section integrates findings from the PPI processes with themes from our qualitative data analysis. We first present the processes of the groups and how we implemented them, followed by insights from interviews with four adults and three children, as well as our reflections.

Recruitment and motivations for joining the PPI groups

This section examines what motivated children and parents to join the PPI groups, and how they viewed their roles and contributions. Over fifteen weeks, we received 36 inquiries from 14 different countries (Fig. 1). Ireland, where the study is based, generated the most interest ($n = 12$). Upon inquiry, families were provided with EOI forms; however, twenty-six families did not complete and return them. By July 2023, ten family units had committed to joining the groups; however, three families withdrew due to other commitments before the meetings started in August 2023. The finalised PPI groups included seven parents and eight children. The CRAG comprised four male and four female members, aged 7 to 11, while the PRAG consisted of three male and four female adults. Families were located in Estonia, Ireland, Kenya, Norway, Tanzania, and the United States. Recruitment concluded after 15 weeks to meet deadlines for starting work on The Kid's Trial. Most members (five family units) were recruited through professional and personal networks via social media or email. Two family units were recruited through a Kenyan children's advocacy group that connected us with parents in their communities.

This section examines members' motivations for participating in the PPI groups, their meaningful contributions, and how they perceived their roles through the first theme, 'We're doing something good'.

Parents' motivations focused on supporting their children's understanding of research and nurturing a desire for inquiry. They often emphasised that this was a unique opportunity to introduce research processes to their children interactively.

> *So, I guess it's research that I'm happy to support. I'm happy for [Child's Name] to have another experience and to support them. I think in terms of learning, the fact that this sort of thing is going on in the background, that things like this are happening, is important. (P1)*

> *Because I only learned about research in 3rd level,*

Table 1 Themes and their illustrative quotes

Theme & associated subthemes	Description of theme & subthemes	Illustrative quote
1) 'We're doing something good'	This theme describes the motivations for joining the CRAG or PRAG and that most participants expressed a desire to contribute in some way.	*I just liked helping out. (C2)*
2) 'A brave piece of research'	This theme describes the challenges that the research team and the CRAG & PRAG encountered from conceptual and logistical points of view.	*Trying to tackle it on a world basis, in hindsight, probably threw a lot of wrenches in it. (P1)*
3) What worked well • 3a) 'I always got a say' • 3b) 'You ran a good, tight ship'	This theme describes factors that made being a PPI member productive and enjoyable. The first subtheme (3a) explores what communication methods worked well for participants. The second subtheme (3b) explores what aspects of the group's activities facilitated our work together.	*I felt I was listened to. (P3)* *It was very clear to [them] what they were doing, and [they] were happy to do it. (P2)*
4) 'They got so much out of it'	This theme explores some of the expected and unexpected outcomes of participation described by the research advisory group members.	*It was something I was doing with them that wasn't school-related, they felt important. (P4)*

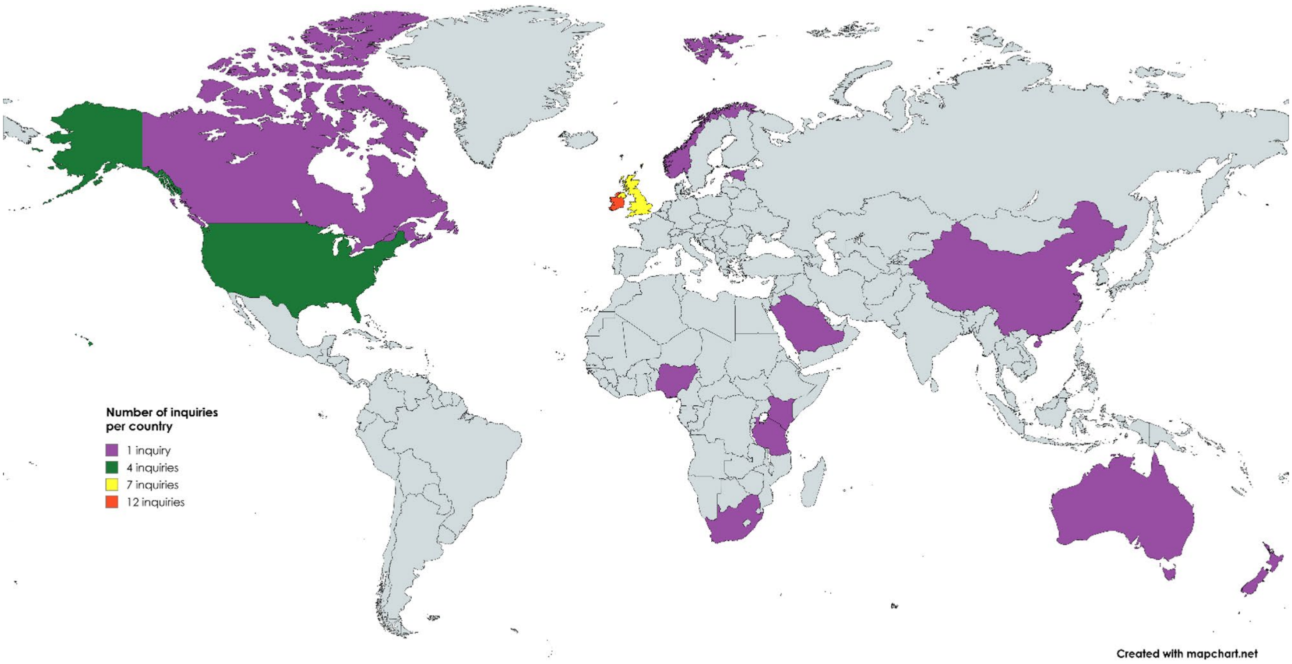

Fig. 1 Number of inquiries to join the PPI groups over 15 weeks. Two inquiries are unaccounted for, as the interested parties did not disclose their location

> *and probably realistically, towards the end of my degree. So the thoughts that my kids would know this at a young age was really appealing to me […] So, for kids to have these concepts presented to them in a fun, age-appropriate way with them being involved as opposed to it, just being spoken about in this abstract way, I thought, was absolutely brilliant. (P4)*

All four interviewed PRAG members are employed in healthcare or other research fields, and most wished for their children to gain a better understanding of their work.

> *So, whenever they asked 'what do you do at the office?,' and I said 'research,' it's not, like, comprehensive for them, so they're in the trial now, they're kind of a participant of every step so that we could see what's happening, so that's what's most important for me… (P3).*

CRAG members primarily joined to contribute, learn something new, and satisfy their curiosity about research or their parents' work.

> *Well, just to find out more about kids' health and everything. I just liked helping out. (C2)*

> *So, my mum suggested it, and she asked if I would like to [join], and I thought it was really interesting since I've always wanted to know what she actually does. So, I thought, well, why not? And I joined. (C3)*

The children saw their role as contributing to project tasks and design, recognising the significance of their unique perspective and active participation.

> *I did a lot of surveys to help, and I helped create the website page and [helped with] the randomised control stuff. (C3)*

> *[The most important thing that the kids did was] probably, like, speak up. Yeah. So that people speak up, [and] ask questions. (C1)*

Parents viewed themselves as guides and facilitators for their children's involvement, emphasising the significance of prioritising children's voices.

> *I deferred to whatever you know [Child's Name] was doing, and like I say, mine [parent's role] was more of a sounding board to their ideas […] And so yeah, it was just to help them along. (P2)*

> *I think it was so important that it was the kids' voices heard much more than adults, and I don't think there was a huge amount for us to do in that part [project design] of it… So, it was really looking at their perspective as they were going through it, and what was important to them, and they really did have genuine opinions on things… (P4).*

Some parents questioned the extent of their impact, wondering whether they had been asked to do enough or had significantly influenced the project. This highlighted a tension between their desire to help and the tasks and activities we requested parents complete.

> *I guess I was sort of expecting a little bit more behind-the-scenes work than there was (P1).*

Despite some adults' concerns about their impact, both adults and children expressed a sense of meaningful contribution, recognising the importance of their input in advancing the project. One parent reflected, "***We're doing something good***"*(P3).*

During the interviews, the project lead (SL) recognised that although they viewed the PRAG as central to achieving the aims of working with PPI partners, they did not always communicate this clearly to the PRAG. Given the PRAG members' research backgrounds, SL assumed there was a shared understanding of this. Adult participants, in particular, may have benefited from clearer explanations of how their guidance and input contributed to the PPI groups' activities.

PPI groups' activities, their challenges and facilitators

Over approximately 1.5 years, PPI group members collaborated with the research team on various tasks and activities. However, most of their work occurred during the first five months following the formation of the groups. Together with the research team, PPI partners played a significant role in shaping the design of The Kid's Trial. Their involvement ranged from independently-led tasks, such as creating the logo and website icons, to more collaborative efforts that required deeper teamwork with the researchers, including refining the language used in consent and assent forms and developing transcripts for the website animations. This collaboration was realised through meetings, feedback surveys, and anonymous polling. Table 2 summarises their activities.

Over 17 months, eight topics were addressed across 19 meetings due to varying schedules and time zones. Consequently, a single meeting might include all PPI group members, while others featured only one family unit. Figure 2 illustrates the timeline of the meetings and the number of families present at each session, none of which exceeded 60 min. Between meetings, we sent email updates to maintain communication. Online meetings

Table 2 Tasks performed by the PPI groups and their descriptions

Research Advisory Group	Task	Process & Output	Reference
CRAG	Logo creation	Children created logos; two were combined for the final logo	The Kid's Trial
CRAG	Website icons creation	Children created icons to represent the different steps of The Kid's Trial.	'How it works' page of The Kid's Trial website
CRAG	Animation narration	Children recorded narrations for animated videos.	Website & YouTube channel.
CRAG	Kid's Information Flipbook review	Children provided feedback for readability within ethical constraints.	Website home page.
CRAG	Assent form review	Children reviewed and improved language for child-friendly communication within ethical constraints.	The assent form for each survey can be found in Supporting Materials S.5.1.
CRAG	Trial surveys review	Reviewed initial surveys, informing all subsequent survey layouts and language.	Supporting Materials S.5.2.
PRAG	Parents' Information Flipbook review	Adults improved readability within ethical constraints.	Website home page.
PRAG	Privacy Notice review	Adults reviewed for language accessibility of privacy and data notices.	Website privacy notice page.
PRAG	Consent form review	Adults reviewed and improved language for accessibility within ethical constraints.	Supporting Materials S.5.1.
CRAG & PRAG	Website aesthetics	Collaborative decision-making on colours, fonts, and design through voting and feedback.	www.thekidstrial.ie
CRAG & PRAG	Website animations	Provided feedback on animations, improved language accessibility, and requested an additional animation for further clarification for Randomised Controlled Trials.	Website & YouTube channel.
CRAG & PRAG	Question prioritisation	In collaboration with the research team, members evaluated and prioritised participant-submitted questions for trial feasibility.	Questions we couldn't answer are here.
CRAG & PRAG	Results sharing option prioritisation	Members reviewed and suggested options to be presented to The Kid's Trial participants to decide how and where the results of The Kid's Trial will be shared.	This step has not yet been completed at the time of writing.

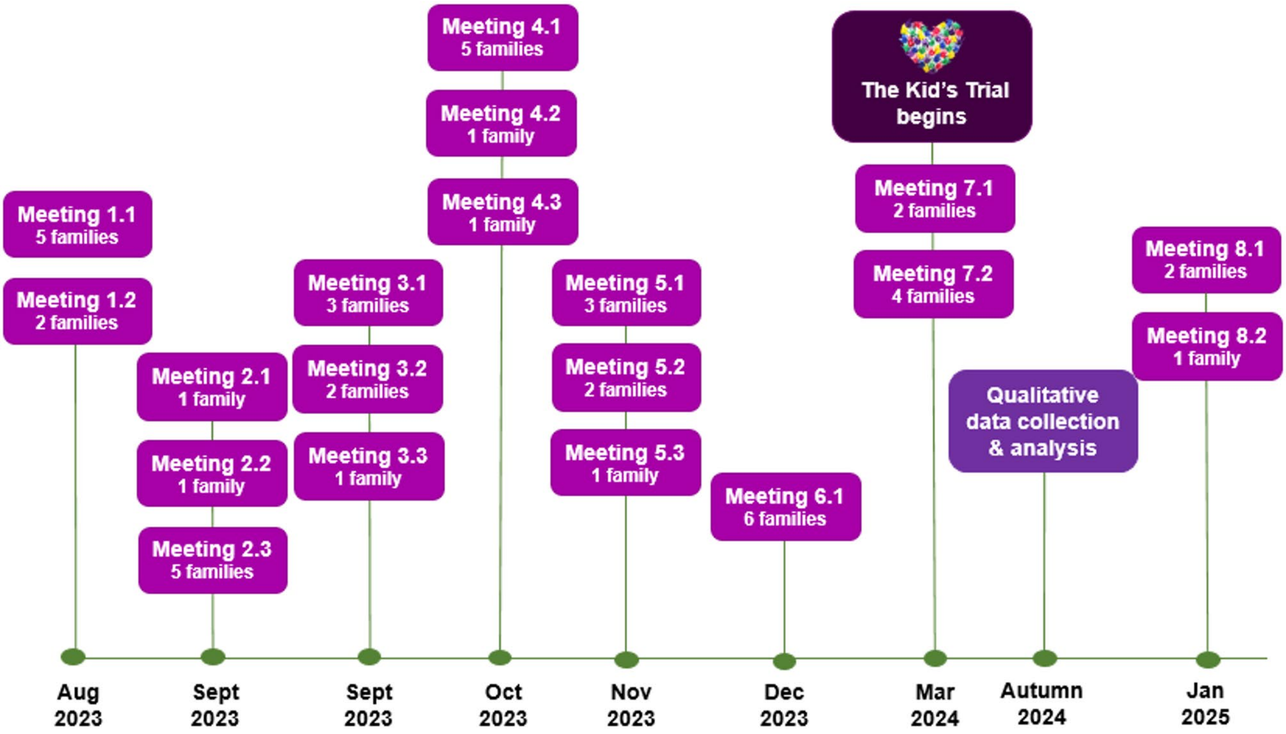

Fig. 2 Timeline of PPI meetings and the number of families that attended these meetings during the planning of The Kid's Trial

served as interactive open forums guided by the agendas members received before each meeting.

Challenges we encountered during the PPI groups' activities

The second theme, 'A brave piece of research,' explores challenges identified by PPI group members that impacted their engagement in the research process. The activities completed by the groups presented challenges, particularly in understanding the concepts surrounding RCTs and navigating participation in an online group. Some parents discussed the challenges for younger children to participate meaningfully in the PPI groups and understand the language surrounding trials.

> *I do wonder whether seven, eight-year-olds are actually ready for that, both in terms of the CRAG and in terms of actually participating in the research [...] I think in terms of the trial itself, just sort of shifting the age group a little bit up [might be better]. (P1)*

> *But actually, it was getting [Child's Name] to repeat it back where I was able to see where their gap was, and then they were really good at articulating themselves. What words they found difficult, what needs to be explained, more broken down, more for their age group. (P4)*

When asked about the most challenging aspects of being part of the CRAG, children discussed understanding randomisation and RCTs and the language we use around those concepts.

> *Probably understanding the language [was the most challenging part]. Like, at the first meetings, I didn't know what the randomised trial was. (C1)*

Members were asked how we could have improved communication. Upon reflection, one parent suggested that creating a centralised, online location where all the documents were stored would be useful so that they could access previous meeting outcomes and clear timelines of the work.

> *I was thinking, [...] rather than going back to emails and scrolling down, if I can have one link forever, until the trial finishes, and then if I can go through that link and track out where I am, or where the project is, or where my next steps are, that would be a bit easier. (P3)*

The global and online nature of the PPI work presented challenges for members and the project lead. One child also expressed a desire to interact more with other children during meetings. Two PRAG members suggested that in-person meetings could have improved collaboration and focus. One parent expressed that the sense of belonging to a team was lacking due to time zone differences and scheduling conflicts among families, making it difficult for all participants to meet simultaneously. This parent remarked,

> *The challenges are enormous. I mean, I can see that it's so hard. And I mean, every individual family has a different program. And when you're dealing with that around the world, it becomes next to impossible. I really was thinking that, you know, this is* ***a brave piece of research*** *and that's why it's research. (P1)*

Although manageable, coordinating meetings proved challenging. Throughout this process, SL frequently experienced a desire to accommodate each family's schedule and needs while also taking time 'off' from the project, as meetings took place on weekends. These reflections emphasize the need for flexibility on the researcher's part and the importance of balancing personal commitments with responsibilities toward PPI collaborators.

Efforts that facilitated the activities of the PPI groups

Despite the challenges we faced as a group, most PPI members had positive experiences. This section explores the theme 'What worked well', describing how the PPI members perceived the activities, meetings, and overall processes that improved the design of The Kid's Trial. We identified two subthemes: (1) 'I always got a say' illustrates how communication was effectively achieved among members and between the researcher and the members, and (2) 'You ran a good, tight ship' examines which aspects of the PPI groups' logistics and activities were successful for them.

I always got a say

The subtheme 'I always got a say' examines the facilitators that supported effective communication among PPI group members. To increase the group's comfort and familiarity with one another, the Google 'Jamboard' was created. The project lead, SL, set the example by posting pictures of themselves participating in their hobbies and writing about their family and interests. The children interviewed noted that the 'Jamboard' exercise was fun and allowed them to learn about the other group members.

> *Yeah, I liked it [the 'Jamboard']. Yeah, I liked that kids, like, told about themselves. (C1)*

> *Yeah, I thought it [the 'Jamboard'] was a good idea, and it helped me know people a lot more. (C2)*

Meetings began with all members sharing about their week, and the researcher often shared personal anecdotes involving their children or pets. Agenda topics were introduced by asking the children focused questions about what we had reviewed in the previous meeting or decisions made, which helped to open up a dialogue. The children initially reported feeling nervous about the meetings but gradually developed greater comfort in expressing themselves.

> *At first, I was really nervous. Like, is this [the online meetings] going to work or not? But then I started realising, oh, everyone else is going with the flow. I'm there, and they're really open. So, I thought maybe I should just relax as well. It was really fun. (C3)*

Both adults and children reported that they felt their voices were heard and could express themselves openly with the research team. During meetings, each agenda item was reviewed, and the researcher confirmed that all participants were comfortable before moving on to the next agenda item. After meetings, members received surveys to clarify discussion points, allowing them time to consider agenda items and respond anonymously. Members were also encouraged to email their thoughts or questions between meetings.

> *I think it [the communication] was really good [...] even if I didn't get my choice, I'd feel fine. But that never happened. I always got what I needed or wanted and* ***I always got a say in it. (C3)***

> *There was always an opportunity if I would like to talk, so yeah, I felt comfortable...So it's just communication was nice, and I felt that I was listened to [...] So, I'm part of it. You know, my say is there, my voice is there. (P3)*

The multimodal communication approach, which included online meetings, anonymous feedback surveys, and reports of meeting minutes and survey outcomes, worked well for participants. It accommodated different comfort levels and ensured comprehensive input from all group members.

> *I think you did take advice, probably advice outside the meeting when I thought about something, and I would just let you know what I thought was probably more useful than what actually happened within the meeting. (P1)*

> *I also like the surveys because then I got to say what I wanted, and you didn't have to tell everyone else what I felt like. They don't know who did it. But [...] that someone said it. (C3)*

Many participants highlighted the online, global aspect, valuing engagement with different people and perspectives.

> *I think the most important part was that you gathered like everyone together so that we could all learn together[…] I like it because then I get to interact with people that are from other countries and I don't know them […] we have fun and we learn together as a group. (C3)*

> *I think throughout the whole process [the most important thing the kids gained] was listening to other kids. Taking on board other people's opinions, seeing things from a different perspective was really good for them […] they'd actually listen to other kids, and that would change their mind a little bit. (P4)*

Throughout our work with the PPI groups, we consistently reflected on how to align our feedback with the Lundy Model of Child Participation's four Fs: Full, Friendly, Fast, and Followed-up [17, 23]. To ensure feedback was both comprehensive and timely, we promptly mapped out our decisions based on surveys, polls, and meeting minutes, sharing updates via email as soon as they became available. Maintaining a friendly environment was supported through the interactive 'Jamboard' and informal conversations about the members' lives. Follow-up with the groups continued until January 2025, when final meetings were completed. However, all members have been encouraged to contact the lead researcher, SL, with any questions or inquiries about our work together in the future.

You ran a good, tight ship

The subtheme 'You ran a good, tight ship' explores what processes facilitated the groups' activities and what members felt worked. By approaching meetings as a co-creative space, using open communication strategies, and clearly setting tasks for members, PPI partners clearly understood what we were asking of them and how we made decisions about the trial's design and planning.

> *'**You ran a good, tight ship** there, so [Child's Name] knew what they were asked and what they needed to do.' (P2).*

> *I think there was a good natural flow to it […] they certainly had a good grasp of what the expectation was, where it was going. What was next, you know. (P4)*

The children focused primarily on what they enjoyed about the project and the creative aspects of their contributions.

> *I think my logos were really good. Because I did spend a lot of time on them, and it was really fun to do it […] It was really fun to be creative and stuff. (C3)*

> *I mostly enjoyed just helping on the website just how it all looked and everything. (C2)*

Having the parents present, at least in the first few meetings, improved the children's comfort and confidence and helped the adults better support their children in understanding the groups' tasks.

> *I would say in the first meetings, like, the first three meetings, maybe [parents should be present]. Because, like, I wasn't very confident, and I didn't really know what to say, some words I didn't really know. (C1)*

The children discussed collaborating with others during meetings. They felt that the moments when the researcher shared their screen for live design changes were when they were truly working together as a team, despite the online nature of the PPI work.

> *Interviewer: Did you ever feel like you got to be able to work as a team? Child: Uh, well, almost every meeting, there was at least some [kids who] came before me, and we, like, talked a bit. (C1)*

> *There were a lot of agreements when working on the website. Yeah. So, I'd say, so, yeah, [we worked as a team]. (C2)*

During the first meeting, PPI group members were informed they would be compensated for their time. They were asked to track the time they spent outside of meetings on trial tasks using the provided timesheets. All members appreciated the gesture but emphasised that it was not a motivating factor for their participation.

> *They took great delight in that. I think, learned about, you know, value of time and the fact that efforts have a value, and I think that was a great thing to do […] It wasn't in any way a motivation, but it was an interesting learning experience for them, of which they were very proud. (P1)*

> *Yeah. I mean, it's good for me. Since I can, like, save*

> *up for more opportunities. Like, for example, university. (C1)*

> *I wasn't too bothered on it. I really just wanted to just do the program like, just do CRAG work [...] Yeah, it didn't really matter to me that much. (C2)*

Reflecting on the meetings, our communication, and how the tasks for the PPI groups were set, more live collaborative tasks in meetings would have benefited all members. The anonymous feedback mechanisms and 'Jamboard' were both very successful, giving the researcher an opportunity to gain insights into members' opinions and feelings in a safe and protected space.

They got so much out of it- lessons learned

The final theme, 'They got so much out of it', explores the expected and unexpected learnings from participating in the PPI groups. One of the biggest challenges was teaching the children about randomisation and RCTs, an essential 'training' aspect of our work with them, equipping them with the tools to advise on the project. Over time, an iterative process emerged through discussions, working on the animation transcripts, and gathering feedback, which enabled the research team to simplify trial language. By continuously breaking down complex concepts into accessible terms, we learned together how to best translate the language of trials for the group.

In our interviews, both children and adults highlighted this. Parents noticed their children becoming more engaged in discussions at home about research and randomisation. Some children even challenged their older siblings' understanding of RCTs, demonstrating how much they had learned.

> *Because [Older Sibling 1 and Older Sibling 2] were trying to help to come up with things [we could test in The Kid's Trial]. But they [CRAG member] were able to reject what their older siblings wanted to do, because they're like, actually, "that couldn't be a randomised, controlled trial" [...] that for me was a real 'yes, you got it', you know. (P4)*

These older siblings, while not members of the CRAG, also learned about RCTs. Their parent commented,

> *[Older Sibling 1 and Older Sibling 2] for different science classes, had to do a CBA [classroom-based assessment], and they both decided to do RCTs [...] They had heard about it so much, you know? For me, that's the true importance. I think research should be spoken about at a young age. You know, the ethics involved in research, trusting the evidence now in particular, this is so important, [understanding] misinformation and disinformation. (P4)*

Another child decided to present their work with the CRAG to their school class, which their parent noted was an unexpected positive outcome of participation.

> *We put together a little presentation that [Child's Name] gave to their class. So, I think that was useful for them. The teacher said they did a great job [...] So, I think that was probably the first time they'd sort of stood up and promoted something themselves or talked about something they're doing, which I appreciated. (P1)*

Parents also discussed how the experience enhanced their ability to convey complex concepts to diverse audiences, increased their understanding of collaborating with PPI partners in their research, and provided deeper insights into their children.

> *And yeah, I suppose trying to broach stuff with kids, and the language like, I'm very used to dealing with people and talking in layperson's terms and explaining that to people at a whatever age group. But still, it's funny the way you, no matter how much you think you know, [kids] surprise you with their take on certain things. (P2)*

> *Because I used to work with grown-ups as my research participants, so this is my first time I'm doing like under 18 kids research trials, and I directly saw how you guys were engaging end-users in the research…I would love to implement [this] in my research as well in future. (P3)*

> *I've probably learned more about [Child's Name] and how they react to situations, which is always a good thing. (P1)*

A PRAG member who works with children sometimes enrolled in RCTs commented,

> *I've always been able to explain it to the parents [...] So being able to explain it to them [children enrolled in RCTs] in much more child, appropriate language, yeah, I've definitely learned that. (P4)*

For the children, their learning extended beyond merely understanding RCTs. They gained confidence and experienced a sense of accomplishment and pride in their work. Narrating animations for the website was open to all CRAG members, and five children chose to participate despite the challenges of the task. One parent, who had two children in CRAG, said,

> ***They got so much more out of it*** *than I thought they would, and one of the most important things for both of them was narrating the videos [...] they felt even more part of it then, because it's their voices. And I think you can tell by the kids narrating it that they actually really understand the concepts involved. You know, it's not stilted. It's not rote reading. They get it. (P4)*

The research team was surprised by some of these findings. In particular, we did not anticipate the learning related to the language of RCTs and PPI work for the adults. The sense of involvement, enhanced understanding of research, and application of new knowledge for the children, although not entirely unexpected, confirmed that children's participation was valuable for them.

Discussion

To enhance inclusivity, accessibility, and relevance to The Kid's Trial, we established two online research advisory groups who acted as our PPI groups: the CRAG, which included children aged 7 to 11, and the PRAG, comprised of their parents. As we collaborated with these groups, it became clear that capturing their experiences and insights would be invaluable for our future work and for others undertaking similar initiatives. This paper outlines the methodology behind forming and facilitating these groups, alongside key findings from semi-structured interviews with their members. Here, we examine the ethical considerations, effects of global participation, and the facilitators and challenges of working with children and their parents as PPI partners in an online format.

While PPI collaboration ideally starts at the funding application stage of an RCT, this was not feasible for The Kid's Trial, as is often the case, nor is it desirable for every project. The practical implications of involving children as PPI partners at a pre-funding stage are difficult [13, 45]. Although ethical approval is not typically required to engage with PPI members serving in advisory or collaborative roles, ethical and logistical considerations remain. Funders work within fixed timelines and goals to establish trial feasibility, whereas engaging children as PPI partners requires significant time and has different priorities. Depending on their age group, certain aspects of this process may not engage children's interest [45]. Each trial presents distinct opportunities for meaningful involvement. Researchers must evaluate the willingness of the children (and their parents, if involved), the developmental stages of participating children, and at which stages of the trial all parties would gain the most from PPI collaboration.

We expected that the global recruitment of PPI members would be a barrier, but our objective to be inclusive and draw from as diverse a group of people as possible outweighed these challenges for us. Despite recruiting over multiple platforms and targeted email campaigns, recruitment to the PPI groups took longer than anticipated. The most effective methods involved targeted emails and social media outreach through our professional networks, alongside engagement with children's advocacy groups that served as gatekeepers. This led to a rich cultural and geographic diversity within the PPI groups.

Global online participation presented logistical challenges, for example, coordinating across time zones, and some parents observed that in-person meetings might have fostered a better team dynamic. While all interviewed children enjoyed interacting with other CRAG members, more interactive tasks would have increased their engagement. Nevertheless, PPI group members valued the exposure to individuals from diverse backgrounds and locations.

One of the main objectives of engaging with our PPI partners was to help make the language surrounding RCTs more accessible and child-friendly. Therefore, it should be no surprise that many of the children in the CRAG initially struggled with these concepts. Members discussed the complex ideas related to RCTs, and questions arose about engaging children as young as seven. Upon reflection, raising the minimum inclusion age to eight years old may have been beneficial. However, while we recognise that some younger children required additional parental support to understand these concepts, their involvement underscored for the research team the importance of tailoring communication for different age groups and resulted in the creation of resources that can be used in future trials with children. Combining meetings, feedback surveys, and decision mapping through meeting minutes and survey outcomes established a comprehensive communication approach. Notably, the surveys proved to be an especially effective tool, with children particularly valuing their interactive and anonymous features, especially for those who were reluctant to express their opinions in a group setting. This multimodal approach to communication illustrates a powerful strategy for fostering meaningful participation in paediatric PPI groups.

PPI group members' involvement had an impact beyond the trial. The older siblings of some CRAG members, influenced by discussions at home, decided to conduct their own RCTs for school science projects. One child presented their work at school, and members of the CRAG who narrated videos for the project website expressed pride in tackling this daunting task. Without

PPI input, The Kid's Trial would have been significantly less inclusive, comprehensive, and engaging.

Study strengths and limitations

This study has several strengths. The PPI groups included participants from both the global north and south, demonstrating the feasibility of global online engagement. Our work was grounded in strong ethical foundations, with careful attention to online safety, privacy, clear communication, and equitable remuneration. Our child-centred approach is rooted in the *Lundy Model of Participation* [17, 23], which guided our engagement with CRAG members. We created SPACE through age-appropriate methods that balanced independence with parental support, amplified children's VOICE through prioritising their input in meetings and feedback, provided an AUDIENCE through active listening, and enabled INFLUENCE by involving them equally in decision-making. We also aligned our approach with the CIOMS 2016 *International Ethical Guidelines for Health-related Research Involving Humans*, on 'Community Engagement' [24]. This included early involvement of PPI partners in the planning stages of *The Kid's Trial*, building trust through transparent communication and consistent feedback, carefully balancing the time and effort required of participants with project needs, and clearly defining roles and expectations to support mutual understanding.

Notwithstanding the strengths identified, our study has several limitations. Despite our aim of recruiting PPI group members from diverse geographical and socioeconomic backgrounds, we adcknowledge that a digital divide exits [29], and the nature of online advisory groups inherently excludes families that do not have access to digital devices or the internet due to geographic, resource, or digital knowledge inequalities. The online format also presented challenges in building a team atmosphere and managing scheduling issues across time zones. Twenty-six families did not return our EOI forms for PPI group membership, and we don't have their reasons for this. This may have offered valuable insights into barriers to participation. Eliciting reasons for non-participation can be difficult, but future research should consider methods to do so.

Our PPI activities were time-consuming from a researcher perspective, requiring extensive coordination across time zones and multiple meetings on single topics outside traditional working hours. Given the small number of members in the PPI groups, our sample size for the semi-structured interviews faced significant limitations. The four adults interviewed had healthcare or research backgrounds, which introduced a potential selection bias towards participants who were likely more interested in research, making the findings not generalisable across most families. This shared interest in evidence-based research among the lead researcher and PRAG members may have contributed to her being viewed as an 'insider' by both group members and the interviewer. Additionally, the lead researcher conducted the interviews, which likely reduced critical feedback. To mitigate this, we informed PPI members who were interviewed that their honesty, including critical feedback, was essential for enhancing our methods and processes in the future. With only seven PPI group members interviewed, we have captured a narrow slice of experiences. Future research should address these methodological concerns through more diverse recruitment and independent interviewers. Budgetary planning should consider this early in the planning process.

Recommendations for future work

To successfully engage with children and their parents in online formats, we recommend the following guidance (Table 3), which was developed from interviews with PPI group members and the research team's reflections.

Conclusions

Our objective in writing this paper has been twofold: (1) to outline our methodology for recruiting and conducting online global PPI groups of children and their parents, and (2) to explore their experiences in contributing to the design of The Kid's Trial. We described their roles, identified participatory mechanisms that supported their involvement, and highlighted areas for improvement.

Our methodology and recommendations offer a potential roadmap for research teams aiming to engage similar PPI groups. While recruitment took longer than expected, collaboration with professional networks and children's advocacy groups proved most effective. Despite logistical challenges, the online format enhanced accessibility and enabled participation from a diverse, global cohort. A key focus was making the language around RCTs more accessible to children, emphasising the need for age-appropriate communication. Surveys emerged as a particularly effective engagement tool, especially for children hesitant to express their opinions in group settings.

Insights from semi-structured interviews revealed how children and parents perceived their PPI roles as meaningful and impactful. Their contributions shaped the development of The Kid's Trial and informed our recommendations (Table 3) for enhancing global, online PPI processes. Beyond the immediate scope of the project, participation in the PPI groups encouraged children and families to engage further with research in creative and educational ways.

Finally, participation in PPI work had a clear impact on children's learning. Through active involvement, children deepened their understanding of the research process

Table 3 Recommendations for facilitating online PPI groups with children and their parents

Recommendation	Example
Create tailored, age-appropriate educational materials to simplify complex concepts.	Create or use videos, games, and real-life examples to explain complex concepts. Store these in a centralised location where members can access them at any time. For example, our members received animated explainer animations and access to Google documents that further explained the language and concepts around RCTs.
Create a safe, monitored, private digital space for members to interact with each other to promote group cohesiveness.	Create or use private, moderated spaces to help members interact more easily with each other in an informal way. For example, we used Google Jamboard. This has since been discontinued, but Google Classroom or similar may be useful.
Feedback to participants frequently and consistently with concrete outcomes. Centralise resources for participants to track the project's progress.	Develop a standardised feedback system. For example, our feedback was emailed to members after each meeting, detailing the minutes of the meeting, the results of surveys or polls they had completed after each meeting, and our decisions based on that. If our decisions were not clearly in line with meeting discussions or survey results, we outlined the justification for that. However, keeping all the documents in a central drive members could access at any time would be our recommendation.
Use multimodal communication to meet the needs of different participants.	Consider multiple ways that members may want to communicate. When in doubt, ask the PPI partners! For example, after three meetings, we polled all our group members if they were happy with our communication methods and if they would like us to add or take away any of the methods we were using.
Consider the needs of families and the research team in logistical decisions, and remain flexible to meet these needs.	Online advisory group meetings will likely require time from the research team outside of 'standard' working hours. If the groups are in different time zones, consider this in the planning process and identify how this can be achieved.
Create as many interactive tasks to be done live with the groups as possible.	Live, interactive tasks are appreciated by both children and adults and create a sense of group cohesion. Live, design changes made to our website worked well, but online notebooks or breakout rooms should also be considered.

and developed key skills in communication, critical thinking, and collaboration. Parents observed growth in their children's confidence and ability to contribute effectively. As researchers, we gained a deeper understanding of how children and parents can shape research meaningfully. The active involvement of PPI partners was central to ensuring The Kid's Trial was more inclusive, relevant, and aligned with the needs of its intended population. These insights will inform our future work and that of the broader research community.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40900-025-00749-5.

Supplementary Material 1
Supplementary Material 2
Supplementary Material 3
Supplementary Material 4
Supplementary Material 5
Supplementary Material 6
Supplementary Material 7
Supplementary Material 8
Supplementary Material 9
Supplementary Material 10
Supplementary Material 11

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Author contributions

This work contributes to one of the authors' (SL) doctoral projects. Conceptualisation: DD, LF, SL. Data Curation: SL. Formal Analysis: DD, BW, SL. Funding Acquisition: DD. Investigation: SL. Methodology: DD, LF, BW, SL. Project Administration: DD, LF, BW, SL. Resources: DD, LF, BW, SL. Software: N/A. Supervision: DD, LF, NT, BW. Validation: DD, BW, SL. Visualisation: SL, BW. Writing– Original Draft Preparation: DD, BW, LF, NT, SL. Writing– Review & Editing: DD, BW, LF, NT, SL.

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Data availability

The transcripts generated and analysed during the current study are not publicly available to protect participant privacy. Although all interviews have been pseudonymised, some interview transcripts contain identifying information as part of the transcript. The supporting materials for this article are available in the Open Science Framework (OSF) repository, Building The Kid's Trial, https://doi.org/10.17605/OSF.IO/F7VM4 [46]. All materials are available under the terms of the Creative Commons Zero "No rights reserved" data waiver, CC0 1.0 Public domain dedication. The project contains the following underlying data: Supporting Materials S.1.1: GRIPP 2 Checklist. Supporting Materials S.1.2: SRQR Checklist. Supporting Materials S.2.1: BTKT CRAG EOI Form. Supporting Materials S.2.2: BTKT PRAG EOI Form. Supporting Materials S.2.3: BTKT Expectations and Guidelines for Members of the CRAG & PRAG. Supporting Materials S.3.1: BTKT CRAG_PRAG Remuneration Plan. Supporting Materials S.4.1: BTKT Assent_Consent Forms. Supporting Materials S.4.2: BTKT Interview Schedules. Supporting Materials S.5.1: REST Trial Assent_Consent_Demographics Form. Supporting Materials S.5.2: The Kid's Trial Survey 1.

Declarations

Ethics approval and consent to participate

This study was approved by the University of Galway Research Ethics Committee (ref: 2024.03.008). All participants gave informed consent to be interviewed for this study. In the case of children, guardian consent was obtained in addition to the child's assent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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The findings and conclusions in this document are those of the authors and not necessarily those of NICE or other authors' employing organisations.

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