

Reflections from lived experience contributors and researchers on effective collaboration in the trial of a digital parenting intervention: exploring unexpected outcomes of patient involvement and engagement.

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Abstract

Background

Patient and public involvement and engagement (PPIE) has become an integral part of health and social care research. The limited existing evidence suggests that it can improve the quality and relevance of research and the experiences of study participants, PPIE contributors, and researchers. However, further research to better understand effective collaboration between researchers and PPIE contributors and its importance to research is needed.

Methods

This paper explores the experiences of PPIE contributors (n = 11) in the OPTIMA trial of a digital parenting intervention for families of children on a child mental health services waitlist, and the research team. The PPIE contributors were themselves parents who had sought psychological support for their children. Feedback was gathered from PPIE contributors at two timepoints via group discussion and emails, specifically focusing on the professional skills development and personal outcomes reported by both PPIE contributors and researchers, and on their experiences of working together.

Results

PPIE contributors highlighted developing valuable research skills, including qualitative analysis, editing and academic and non-academic writing. Beyond professional skill development, PPIE contributors described developing a strong sense of community and purpose and the opportunity to give back to other parents with shared experiences. Researchers reported an increased understanding of participant-sensitive communication and emphasised the substantial contribution of PPIE in informing key decisions of the study.

Conclusion

These findings contribute to a growing body of literature on meaningful PPIE in research, illustrating not only its value in improving research processes but also the personal and professional benefits generated through co-design and collaboration between researchers and those with lived experience.

Plain English Summary

This study explores the involvement of public contributors in a research project testing an online parenting support programme for families waiting for child mental health services. Contributors were parents who had previously sought mental health support for their own children and had lived experience of the study

topic. Researchers collected feedback from parent contributors and the research team about their experiences of working together.

Parents said they gained useful skills, such as helping analyse research data, editing documents, and writing for both academic and public audiences. They also felt a sense of community, purpose, and satisfaction from helping other families facing similar challenges.

The researchers said that working with the parents helped them better understand how to communicate sensitively with participants and make decisions that were more relevant to families' needs. They felt that the PPIEs' input had a significant influence on the study and contributed to keeping most parents involved in the study until the end.

Overall, the study suggests that involving people with lived experience in research can improve the quality and relevance of the research while at the same time providing personal and professional benefits for everyone involved. It highlights the value of researchers and public contributors working together as partners throughout the research process.

Patient and public involvement and engagement (PPIE) is an integral part of health and social care research. The Medical Research Council (MRC) strategy defines public partnerships as encompassing “a diverse range of communities and people of all ages and backgrounds, who bring different life experiences, knowledge and perspectives. This includes members of the public, patients and voluntary and community groups...” (1). Including a PPIE panel means research is done with or by people who have experience in the research topic, rather than to, about or for them (2). Involving people with lived experience ensures that the research remains relevant and concentrated on issues of importance to patients, thereby strengthening its quality (3) and reducing research waste through inefficiency (4)

Including PPIE in research is becoming increasingly standard practice for researchers and, for many funding bodies, a mandatory part of grant applications. One study that surveyed a clinical trials unit in the UK found that 71% of trials had included PPIE (5). However, while people with lived experiences are increasingly being included in research, less has been written on the quality of PPIE involvement and the learning outcomes for both PPIE contributors and researchers. Studies examining barriers to successful PPIE involvement have identified both practical and relational challenges. Practical barriers include the lack of adequate training and PPIE contributors feeling overburdened by tasks (5, 6). Relational barriers include contributors not feeling valued by research staff (5). With prior research exploring barriers and facilitators to incorporating PPIE into research, more focus is needed on the positive outcomes for both PPIE and research staff, leading to more effective research practices.

The MRC's Public Partnerships Strategy Action Plan(7) aims to embed meaningful public partnerships into UK research culture, so that health and biomedical research is accessible, inclusive and relevant to the public. Achieving this requires research partnerships in which researchers and PPIE contributors work collaboratively, with both groups contributing to and benefiting from the research process. Effective relationships between PPIE contributors and researchers are therefore central to meaningful PPIE. Consistent with this, methodological research on PPIE in clinical trials has identified the development of

“a strong and productive working relationship between researchers and PPIE contributors”(8) as a key priority for successful PPIE work.

This paper aims to explore how reciprocal collaboration between PPIE contributors and researchers was experienced within the Online Parent Training for the Initial Management of ADHD referrals (OPTIMA) randomised controlled trial (RCT) and how this collaboration impacted both the research processes and those involved. We specifically sought to answer three research questions:

- 1. How did PPIE contributors and researchers experience their collaboration during the trial?
- 2. What impacts did this collaboration have on PPIE contributors, researchers and the conduct of the trial?
- 3. What do these experiences suggest about the characteristics of meaningful, mutually beneficial PPIE?

This paper follows the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) short form (3) to guide the reporting of PPIE activities (see Table 1).

Table 1
GRIPP 2 Short Form

Section and topic	Item
Aim	Report the aim of PPIE in the study.
Methods	Provide a clear description of the methods used for PPIE in the study.
Outcomes	Report the results of PPIE in the study, including both positive and negative outcomes.
Discussion and conclusions	Comment on the extent to which PPIE influenced the study overall.
Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience.

Adapted from [2]

The research programme: Online Parent Training for the Initial Management of ADHD referrals (OPTIMA).

Recent data from NHS England show that at the end of September 2025, 63.6% of children aged 0–17 who were waiting for an ADHD assessment had been waiting over a year, with around 35% of this group waiting for more than two years (9). Long wait times may exacerbate ADHD symptoms and may negatively impact families (10, 11), lead to reduced engagement with services (12) and impact education (13). Many families report they receive little or no support from services during this waitlist period (14). The goal of the research programme, was to provide support for families for 3 months following their

primary-aged child being accepted onto a local clinical service waitlist for neurodevelopmental and/or mental health assessment.

The OPTIMA programme included a clinical randomised control trial of an unsupported digital parenting app – Structured E-parenting Support (STEPS) – designed to help parents manage their child’s behaviour. STEPS was inspired by the New Forest Parenting Programme (NFPP) (15), an existing evidence-based parenting programme for families of children with ADHD. More details on the OPTIMA trial and STEPS app can be accessed in previous publications (16, 17).

Methods

Recruitment and PPIE contributors

The PPIE panel was formed in 2021 at the time of planning the trial. The panel was recruited through an open call for parents with children aged 5–11 with experience of navigating mental health services for their child. An advert was disseminated through social media.

The PPIE panel comprised 11 parents living in England, which included nine mothers and two fathers. Two of the PPIE contributors were married to each other. Furthermore, several of them were educators or had decided to homeschool their children, giving depth to the understanding of neurodivergent children’s experiences with education. One PPIE contributor worked in academia. All of the panel had direct experience of the referral process for child mental health or behavioural support services.

Research team

The research team comprised both pre- and post-doctoral researchers and administrators working across the three trial centres. They each took on a range of tasks for the trial, including recruitment, data collection, promotion and administrative tasks such as payments, correspondence and similar. Some researchers took on additional roles in the trial, such as one researcher with a background in qualitative data leading the interviews and data analysis, and another researcher acting as PPIE lead, managing tasks, meetings and payments for PPIE. Working regularly across various tasks with PPIE contributors led to the research team forming a close professional relationship with them and considering them colleagues and active team members, rather than a separate advisory group.

Involvement procedure

The PPIE contributors met as a panel regularly, every two to three months, throughout the project. These meetings took place online and lasted between 60 and 90 minutes. Most time, these sessions started with the research team providing updates on the trial before moving to a discussion of the current panel activities. The PPIE contributors also attended three in-person meetings with the research team in London. Contributors worked either as the panel or in smaller working groups, as needed. Quite often

tasks were completed 'offline' with PPIE contributors completing the activities in the own time and submitting feedback or returning work via email. The panel was co-ordinated by a member of the research team and co-led by three contributors who acted as Co-Chairs. The Co-Chairs met monthly, attended the Trial Management and Co-Investigators' meetings and represented the panel in the steering committee meetings.

All PPIE contributors were remunerated for their involvement in the trial in line with NIHR guidelines (18). The research team were always clear to outline in advance the level of remuneration for any activity, including covering travel and childcare costs when needed.

PPIE tasks and activities

Table 2 gives examples of the variety of activities that panel members participated in during the project. The PPIE contributors were always considered an integral part of the research team and, as such, their involvement in the trial developed over time. They regularly attended meetings and provided remote feedback on elements of trial delivery, both activities which remained constant throughout the trial. Additionally, they were occasionally invited to join smaller working groups to provide more focused input, such as thematic analysis contributing to the process evaluation work and contributing to the production of animations to aid recruitment. PPIE Contributors were also involved in a comprehensive review of the intervention.

PPIE paper team formation and production process

The idea for this paper emerged during the final year of the research project (year five), following team discussions reflecting on the successful collaboration between the research team and the PPIE panel. PPIE contributors were invited, through meetings and email, to contribute to the paper according to their interests; including writing, reviewing or editing.

All PPIE contributors were invited to give feedback and share reflections on their experiences of being part of a PPIE panel and working with the OPTIMA study team. These reflections, including quotes, were collected in February 2025 and formed the basis of this paper. Once the framework of the paper had been established, PPIE contributors who wished to be involved in drafting the manuscript wrote sections describing their own experiences (April-May 2026). The completed manuscript was circulated to all PPIE contributors for review and comments. Participation at each stage was voluntary, and involvement was remunerated according to NIHR guidelines.

Ethical Considerations

We carefully considered whether a formal ethical review process was necessary for this work and, based on the published guidance, deemed it not necessary (19). Instead, we adopted "an ethics of care approach" proposed by Mand and colleagues that reframes ethics not as a procedural task but as a

relational practice at the heart of PPEI work (20). This ensures ethical integrity where formal ethics may not be required. Indeed, as researchers, we aimed for an approach that improves inclusivity and forges positive relationships between researchers and PPIE contributors, taking into account their lived experiences (20). This is echoed by Suri et al., who suggest that rather than enforcing ethical approval on PPIE activity, it is anchored in a way that facilitates ethical practice (21). As the research team, we considered ethical integrity and practice throughout the work with the PPIE, ensuring contributors were supported at all times. Furthermore, all PPIE members who contributed to this commentary piece did so on a voluntary basis. All co-authors have seen and approved the manuscript, and the quoted material is included with their knowledge and consent, with quotes presented as contributors' perspectives rather than analysed as research data. Human Ethics and Consent to Participate declarations was therefore not applicable

The PPIE were advisors on the OPTIMA trial; ethical approval for the study was submitted to the North West - Liverpool Central Research Ethics Committee and received a favourable opinion on further information on 26 November 2021, (IRAS ID: 303121).

Table 2
Involvement of PPIE in the OPTIMA RCT

Activity	Detail
Research	
Qualitative Research	2 x working groups contributed to thematic analysis of interviews with participants.
	Review and feedback on interview schedules.
Intervention review	Conducting a comprehensive review of the OPTIMA to feed into any future re-development.
Participant information and activities.	Reviewing and advising on all communication with OPTIMA participants including study information materials, emails, newsletters, flyers, website content, OPTIMA app guide for parents and the OPTIMA portal which included think aloud sessions about portal layout and content. Child and parent etch a sketch task (ESO), trialling the game with their own children and providing feedback on feasibility.
Dissemination	
Media Outputs	Co-designing a programme of planned outputs focussing on PPIE activity including blogs and publications.
	Recording a podcast and a roundtable discussion to share their experiences and co-producing an animation to encourage trial participants' use of the OPTIMA including advising on animation storyboard.
Co-authoring papers	Co-authoring and editing academic papers for publications.
Programme Oversight	
PPIE meetings	Attendance at 45 + meetings occurring every two months.
Trial Management meetings	Presenting to the Trial Management Group and the Steering Committee on PPIE activities and progress.
Chair Meetings	Co-Chairs meeting monthly to discuss study progress and advise on forthcoming opportunities for PPIE contributors.

Outcomes

In addition to the study outcomes which might reasonably be expected through a collaborative approach between researchers and PPIE contributors, several unexpected outcomes emerged as identified by PPIE contributors and researchers. In addressing our research questions, illustrative quotes are used to highlight individual experiences and perspectives. Rather than presenting contributors' and researchers' experiences separately, we integrated them throughout this section to reflect the collaborative nature of the project and emphasise the shared learning and reciprocal benefits that emerged from working together.

1. How did PPIE contributors and researchers experience their collaboration during the trial?

Teamwork and flexibility

Teamwork and flexibility were mutually demonstrated by both researchers and PPIE contributors. For researchers, the experience of engaging with alternative views and being able to integrate new ideas into an existing project was a valuable learning opportunity. Similarly, PPIE contributors reported that sharing their feedback with the team helped them to develop new confidence. The PPIE panel was not involved in the early stages of planning and production of the app, except for some informal input from parents outside of the OPTIMA panel in the early stage of the intervention development. Both researchers and PPIE contributors noted the absence of potentially valuable input at the concept and design stage of the intervention. Although some contributors expressed disappointment at not being involved from the early stages of the research programme and so missing the opportunity to input into the intervention development, the panel quickly spotted ways that the OPTIMA study could be made more relatable and acceptable to parents. For example, they suggested revisions to language, video content and reminder frequencies. Furthermore, all contributors reviewed the intervention and provided detailed feedback, which was recorded by the research team to inform any potential future developments.

"I feel strongly that we should always have an involvement from the earliest possibility in order to help shape and guide the ultimate aim of the research." (VF, panel member)

The research team were highly motivated to involve the PPIE panel throughout the trial and in a wide range of activities. However, they also recognised that a degree of flexibility was needed to include all contributors. No tasks were ever mandatory; for example, some contributors were unable to join the regular meetings due to work patterns, so meetings were recorded to be listened to at a time convenient to them. Alternative times were often given, for example, if the contributors preferred evenings and weekends. The research team understood that being a PPIE contributor was not their only responsibility, but this could sometimes be overlooked. For example, the Co-Chairs highlighted to researchers that insufficient time was sometimes given for task completion. Consequently, the research team responded immediately to plan for longer lead times for PPIE tasks.

The PPIE contributors were involved in most activities relating to reviewing communication with trial participants or participant-facing study materials, for example, information sheets, communication protocols and interview schedules. When their feedback could not be incorporated due to the need to comply with established ethical, academic or governance requirements, the researchers were transparent and clarified which suggestions could and could not be implemented and why.

"It was a real learning curve for me to get feedback from members who did not necessarily look at things through an academic lens. However, it was extremely useful to get different perspectives, especially in how best to present things to our participants. I am now a huge advocate of using PPIE in all studies." (EH, researcher)

A continuing sense of community and self-worth

All the knowledge and skills developed by the PPIE contributors demonstrate their engagement and commitment to the trial. Equally important, however, were the professional relationships that developed over the course of the project and the mutual support provided among the contributors, especially during some challenging times experienced by neurodivergent families. Many PPIE contributors reflected on personal growth over the five years of involvement in the project. Moreover, researchers described the added value of working closely with PPIE contributors, noting how their involvement provided important insight into the lives of trial participants. This, in turn, facilitated a more empathetic approach to the research. Researchers also acknowledged the importance of maintaining regular contact to foster a sense of inclusion. To achieve this connection, regular virtual meetings were held with the PPIE contributors, even when activity on the trial was reduced. As one PPIE contributor observed,

“I really believe it [feeling connected] helped the panel members to stay committed to the project, with most staying the full 5 years.” (CL, panel member)

1. What impacts did this collaboration have on PPIE contributors, researchers and the conduct of the trial?

The OPTIMA trial successfully recruited 352 parents with a high retention rate (at 12 months, 70% in the intervention group and 79% in the control group). The success of the trial retention can be attributed to research staff who worked to forge positive relations with participants and ensure they were supported through each part of the study. Furthermore, the continued input of PPIE contributors on best practice when approaching parents and identifying gaps where a different approach might be needed was vital in supporting the successful retention. Table 2 outlines the involvement and input by PPIE contributors that helped researchers be responsive to the needs of study participants and implement adaptations to the study where needed. In addition to this valuable impact on trial conduct, there were direct effects of collaboration experienced by both PPIE contributors and researchers.

Skill development by PPIE contributors and researchers

This section describes the research-specific skills and knowledge both PPIE contributors and researchers felt they had developed by working together.

i. Developing transferable skills

PPIE contributors reported developing or strengthening both professional and personal skills. Panel members reported gaining new professional skills or refreshing existing skills that had not been used for some time, such as research skills, critical thinking, communication and collaborative working. These skills were particularly valued by contributors who had taken time away from paid employment to raise children, as they felt these would support their return to the workforce.

“Mostly, it has given me great examples of people skills and team working skills - as a full-time Mum/carer/teacher I have not necessarily had the opportunities for these things”. (TT, panel member)

Some specific tasks where PPIE contributors felt they both added value to the project and gained important skills included participation in dissemination activities such as recording podcasts and webinars. For example, two of the panel joined the programme lead and other researchers in recording a podcast for *Tooled Up Education!* (22). They shared both their experiences of involvement in the trial and personal reflections as parents of children who had experienced the clinical referral pathway. This activity fostered a strong sense of mutual respect and support between PPIE contributors and researchers. Contributors brought engagement, enthusiasm, time, and energy, while researchers valued their willingness to share experiences and perspectives, ask questions and offer constructive feedback in a public forum. This activity strengthened the collaboration and brought a sense of inspiration and empowerment to those involved.

"I never thought I would have the confidence to do a podcast but working alongside such supportive researchers and fellow panel members gave me the confidence to speak about my lived experience and it was empowering." (CL, panel member)

All PPIE contributors were encouraged to present at wider team meetings. The Co-Chairs reported that their augmented roles helped to strengthen their presentation skills; particularly valuing their experience of working with – and supporting – their fellow PPIE contributors and having their support to represent the panel at research team meetings.

"Chairing – leadership...this is quite a good opportunity for career/CV enhancement." (LP, panel member).

Contributors also spoke of gaining skills relating to their confidence in managing and completing tasks and improved self-worth in their ability to be part of a valued working collaborative.

"The whole team felt extremely inclusive and I felt valued. I became more confident in meetings." (TT, panel member)

ii. Analytical skills

As most contributors had little to no prior research experience, they were provided with an introduction to the key principles of research designs, including randomised controlled trials. Feedback from attendees was positive, reporting that they found this crucial to providing a framework for engagement in their role.

During the planning stage of the OPTIMA process evaluation, the PPIE panel were invited to apply for a role in supporting the analytical process. A presentation was given on qualitative work as well as a specification on the nature of the role, expected commitment and hourly remuneration rate. PPIE contributors who took part were then given further training in qualitative analytical work. At the end of the analysis stage, the qualitative lead met with PPIE members to discuss findings. This discussion yielded both a fresh perspective for researchers on emerging themes from the data but also unexpectedly resulted in identifying gaps in the overall study which were able to be addressed later. In this way, both the research project and the PPIE contributors benefitted by not only learning new skills (PPIE) but also helping to enhance the project overall.

"Training on coding was invaluable as I had never done this before." (CL, panel member)

Including PPIE in the analysis of transcripts was also perceived to be an unexpected benefit by the researchers by providing an alternative perspective on the deeper meaning behind parent interviews.

"For me, having the PPIE as part of the qualitative team gave a fresh perspective on some of the codes and themes. The PPIE's lived experience helped them take a more nuanced approach to what parents were saying. It helped us shape the codes and themes and made the research team consider aspects of parental feedback which we may otherwise have missed." (EH, researcher)

Improved confidence and self-worth

Being part of the PPIE panel also improved contributors' confidence and self-worth, both in learning new skills but also being able to contribute to something they deemed valuable and would help other people.

"There are hidden benefits to all of this which includes boosting the self-esteem of parents who have been navigating a difficult system for their child(ren) and might feel disheartened and let down. Being a part of the PPIE group has been rewarding because everyone understands the problems that exist when navigating the SEN system. For some parents all they have ever known about this process is negativity, and working with the researchers and other panel members and professionals is very reassuring and helps people to feel optimistic instead of powerless." (NG, panel member)

Many contributors had not been involved in research or PPIE before and shared feeling apprehensive in the early project stages. However, their active contribution to the research allowed them to acknowledge the value of their own experiences and voices.

"I think parents may be put off research by thinking they do not have the qualifications, training or educational knowledge to be of use on a panel when actually their lived experience is probably the most essential ingredient needed in Research & Development." (VF, panel member)

Finding support on their own journey

All parents had some experience of seeking mental health support for their child. While many parents had spent years advocating for their child, bringing a wealth of experience to the group, they also reflected on the added benefit of feeling better equipped to support their child and gaining confidence in advocating for their needs.

"I truly believe being part of the PPIE group helped enable me to push forward my views and needs of my child to the LA in a strong and confident manner, battle the EHCP system with new confidence knowing my views were valid which resulted in gaining my child an EHCP and a place at a specialist secondary school where he is now thriving in an environment that fits his needs." (CL, panel member)

For researchers, understanding the importance of lived experience was an invaluable takeaway. For some research team members, this was the first experience of working with PPIE contributors. Their positive experience reinforced the importance of incorporating lived experience into future research.

"After I started working with the PPIE panel on OPTIMA it really reinforced what an asset they were to the project. I started to learn more about PPIE and attended a conference on PPIE inclusion as I can see how valuable this will be for me for future projects." (EH, researcher)

Some researchers commented how working with the PPIE gave them a greater understanding of the parents' and children's experiences, which encouraged a deeper motivation for working on the trial.

"I have gained a real appreciation for just how isolating this whole referral/assessment process can be for parents." (CB, researcher)

1. What do these experiences suggest about the characteristics of meaningful, mutually beneficial PPIE?

Being respected by the research team and seen as an equal.

A large part of the success of OPTIMA was the way in which the team worked. We worked as a cross-functional team focusing on the diverse skills that each team member could contribute, whether those were academic or lived experience. Whilst this may have been an intended outcome of the research staff, it was unexpected by PPIE contributors.

"From day one of joining OPTIMA PPIE I felt very valued by the whole team. Having opportunities to meet in person really helped with this, we really were made to feel like part of the team, we were treated as though we were the same as everybody else in the room. We were given the chance to ask questions and equally we were asked for our views on things. As a panel we were included in a variety of decisions that had to be made and I think this really helped our understanding of the project too." (TT, panel member)

PPIE contributors also highlighted the training which reduced barriers to understanding the fundamentals of the project and tasks at hand, as well as feeling supported to ask questions without fear of judgement. As one PPIE contributor described her experience of being able to put forward her ideas in meetings:

"I gained confidence to put forward contrary views in a safe space. I am not the most confident of people and certainly not the most confident verbal communicator, often speaking with a pounding heart and having to abruptly stop due to losing my train of thought. I found that as time went on, I became more confident." (TT, panel member)

The research team was recognised for their efforts to foster group cohesion and to ensure PPIE contributors felt included and had access to other opportunities outside of the current research project. This took a variety of forms such as forwarding other research opportunities to the PPIE panel, updating the panel on relevant conferences and training courses and funding these, and providing annual certificates to enable panel members to provide evidence of their contribution and experience for other jobs.

"The research leads have considered ways to recognise and show appreciation e.g. recent issuing of certificates of participation achievement, visibility e.g. in the podcast, and hopefully visible roles in

publications and dissemination and implementation.” (LD, panel member)

Feeling part of a community

Teamwork contributed to PPIE members feeling part of a wider community. Many contributors reflected on the loneliness of parenting a neurodivergent child and that being part of the PPIE panel made them feel part of a supportive and understanding community. For many contributors, giving back to other parents who were only just beginning to seek mental health support for their child was a strong motivation to be part of the PPIE. As one contributor described it:

“Often being a parent of a neurodiverse child can be a lonely and exhausting experience. Being part of a PPIE group with other parents of neurodiverse children is a really wonderful experience. It enables you to feel connected to a small group of people who are going through similar struggles, lows and highs with like minded people who just get it.” (CL, panel member).

One parent reflected that involvement in the PPIE panel had provided personal benefits by encouraging greater reflection on her own needs as the parent of a neurodivergent child.

“As a parent I have taken my children to support groups and as a consequence I have also become part of a community where I could speak to other parents of neurodivergent children. However, I would never have sought to find a support group for myself. I feel that being part of OPTIMA PPIE has given me that. I felt part of a community with other parents; it has been extremely therapeutic to be part of such a project.” (TT, panel member).

The research team had not expected the level of cohesiveness and support that developed within the group over the five years of OPTIMA. As the project ended, it was a difficult time for both researchers and PPIE contributors to navigate. For researchers, the sense of responsibility they felt towards giving continued support and purpose to the panel was unexpected and something that they felt should have been considered earlier in the process.

“In hindsight we should have incorporated ideas on how to support PPIE contributors beyond the trial and prepare them for the end of the research programme. Although we had hoped for more funding to continue working together, when this fell through the disappointment for everyone was tangible. Going forward on future projects, I will consider from the outset how to navigate the end for PPIE contributors so that it is not so abrupt and ensure everyone feels supported.” (CB, researcher)

Discussion

We aimed to report reflections of both PPIE contributors’ and researchers’ on their respective experiences of working together over five years on the OPTIMA trial. Firstly, we reported on the positive impact that working collaboratively had on both the PPIE contributors and researchers. Through the team’s own voices, we found a clear sense of cohesiveness and mutual respect between members. Secondly, for PPIE contributors, the trial brought the unexpected outcome of giving them support and validation in their own journey to advocate for their child, as well as increased confidence and valuable professional skills that

could be applied in future work. For researchers, the experience highlighted the importance of valuing lived experiences alongside academic expertise and encouraging a wider and more inclusive approach to research processes. In OPTIMA, inclusion of the PPIE contributors' views was recognised as one of the key factors underpinning the successful trial delivery, including a high retention rate and positive feedback from trial participants. Thirdly, we believe this paper has highlighted some of the characteristics of successful researchers-lived experience contributors collaboration, such as viewing the work as a genuine partnership, shared decision-making, mutual respect and open communication where all voices are valued. Together, these experiences demonstrate that meaningful PPIE extends beyond ensuring the inclusion of lived experience within research, creating reciprocal learning opportunities that enhance both the quality of the research and the experiences of those involved.

Kearney et al. found that PPIE's contribution to co-designing information for patients, such as participant information sheets and intervention guidance, was considered within the top three most important topics pertaining to PPIE's involvement in clinical trials(8). In OPTIMA, the PPIE panel guided the use of appropriate language and terminology in participant communications, while also giving insight into how parents, who may already be overwhelmed by information from multiple organisations, are likely to receive and interpret study-related information. For researchers, this provided an excellent example of best practice when communicating with potentially vulnerable parents, many of whom were struggling with their own mental health, neurodivergence, or facing other barriers. Our study also supports Butler et al.'s findings in that PPIE contributors valued being able to use their own experience and expertise to support and "pay it forward" to study participants (23).

One issue that has been raised in literature concerning PPIE engagement is inconsistency across studies in terms of recruitment methods, training and even payment structure (5) The OPTIMA trial ensured that all PPIE contributors were given adequate training in each task they were set, for example, training in research methods and transcript analysis for the qualitative work task. Moreover, we followed NIHR involvement compensation guidelines (24). This contributed to, as one panel member put it, "an exceptionally well facilitated and supported PPIE panel". We believe that following existing frameworks, providing training and following guidelines set out by the NIHR, facilitated the relationship between researchers and PPIE contributors ensuring a cohesive and professional work approach.

Wicks and colleagues identified a lack of knowledge and skills by researchers as a barrier to successful co-production (25). In the OPTIMA study, a designated PPIE lead co-ordinated all PPIE activities from the start, ensuring that the panel had a stable and strong facilitator who specialised in working with the PPIE and ensured the link between research and lived experience was at the forefront of the study rather than an afterthought.

Strengths and Limitations

We acknowledge OPTIMA benefited from an extremely engaged PPIE panel of contributors who genuinely believed in the wide-reaching value of the redacted app. Their commitment to the research spanned five years, with most contributors remaining involved through the whole project. This paper not only

represents multiple perspectives from both researchers and PPIE contributors but also aims to be transparent on the collaborative process acknowledging what worked but also what could be improved,

The literature on assessment of PPIE in health and social care research often speaks to the lack of diversity in panels (26). Hatch and colleagues found that a diverse sample of the public would be interested in getting involved in PPIE work but that more effort was needed to ensure these opportunities were made available to different groups to ensure a broader representation (27). In our study, we faced real challenges in recruiting and retaining contributors from minority ethnic groups. With a trial population of 23.6% non-white and an all-white PPIE panel, in this respect our panel was not representative. This should be addressed in any future studies, with more thought being given to addressing barriers to participation.

Reflections

OPTIMA PPIE is an exemplar of successful PPIE work that is grounded in building trust, relationships and shared understanding. Providing the opportunity for shared experiences can motivate participation, strengthen involvement and create safe, validating spaces. There is also a reported altruistic element to PPIE work, with patients and the public feeling a reward from helping those living with the same issues as them; which was reported by our panel members. All of this contributed to improved research practice and a better-informed study, but so much more on a personal and professional level.

Evidence from our PPIE contributors' feedback found that they valued gaining knowledge and skills from the various tasks, and this inadvertently led to an increase in confidence. Very little research has focused on this important aspect of collaborating with PPIE in research. Some PPIE contributors involved in health research may have faced barriers to employment due to their own health needs or caring for others. For PPIE contributors to have gained skills that may aid them in future employment is an important takeaway that needs to be explored further. Ensuring PPIE can gain experience in different areas of delivering research, as well as asking them if there are any specific skills they would like to learn and giving them autonomy on assisting in different areas of research, could prove hugely beneficial to contributors. Importantly, including a PPIE panel should also consider contributors' roles beyond the end of the study. We believe PPIE contributors should be viewed as part of the research team and as such should be offered the same support to move on to other roles in the same way that researchers are. Preparing team members for the end of the study and reflecting on skills gained and how these can be transferred to other projects is vital and should be considered from the outset.

Guidelines such as the Gripp-2 (3) and guidelines from the Health Research Authority and NIHR among others, offer best practice guidance and frameworks to enhance the inclusion of PPIE in research. We hope that by exploring some of the more unexpected outcomes of the collaborative work undertaken on the OPTIMA project we can add to the growing body of literature on successful PPIE inclusion in health research, to continue to improve this important but often overlooked aspect of health research.

Declarations

Ethics approval and consent to participate

We carefully considered whether a formal ethical review process was necessary for this work and, based on the published guidance, deemed it not necessary. Therefore Human Ethics and Consent to Participate declarations was not applicable.

Ethical approval

for the trial in which the PPIE panel worked was obtained from:

Informed consent

was obtained from all participants prior to their participation in the study.

Consent for publication

All contributors to this manuscript are named authors on this paper and have read and consented to this paper being submitted for publication.

Declarations

Competing Interests

ESB has received speaker fees, consultancy or research funding from Takeda, Neurotech Solutions, QBtech, Medice, The Lego Foundation He has received royalties from the New Forest Parenting Programme. He is a founder and shareholder in Neuly.ai

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Author Contribution

CB and EH drafted this manuscript. CC, LD, VF, DG, NG, CG, CL, LP, DR, TT and RW all contributed through providing quotes or writing sections of text for this manuscript. KKA and ESB reviewed and edited the first

draft. All named authors on this paper are responsible for conception, reading, editing and approving this manuscript. ESB is the overall chief investigator of the trial for which the PPIE took part.

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Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Competing interests

ESB has received speaker fees, consultancy or research funding from Takeda, Neurotech Solutions, QBtech, Medice, The Lego Foundation He has received royalties from the New Forest Parenting Programme. He is a founder and shareholder in Neuly.ai.

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