






Review article

The benefits of continuing patient and public involvement as part of a randomised controlled trial during the Covid-19 global pandemic

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Submission date: 19 February 2022; Acceptance date: 9 December 2022; Publication date: 20 March 2023

How to cite

Lewins, A., Hughes, T., Dalrymple, E., Shafran, R., Fonagy, P., Cross, H., Ford, T., Heyman, I., Stephenson, T. and Bennett, S.D. (2023) 'The benefits of continuing patient and public involvement as part of a randomised controlled trial during the Covid-19 global pandemic'. *Research for All*, 7 (1), 3. DOI: <https://doi.org/10.14324/RFA.07.1.03>.

Peer review

This article has been peer-reviewed through the journal's standard double-anonymous peer review, where both the reviewers and authors are anonymised during review.

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Abstract

Patient and public involvement (PPI) in clinical research strengthens the quality and relevance of research, and has been crucial to ensure that researchers continue to investigate relevant and important topics during the global Covid-19 pandemic. The MICE (Mental Health Intervention for Children with Epilepsy) randomised controlled trial relies upon PPI to steer the direction and delivery of the trial, and the PPI Research Advisory Group (RAG) adapted to remote online meetings during the pandemic. This article first describes how the PPI RAG supported the research trial during the course of the pandemic, particularly with key trial stages of recruitment, retention and follow-up. It considers how the PPI tasks were adapted to ensure that they remained meaningful throughout this period, particularly for children and young people. Second, the article explores the acceptability of PPI in

research using teleconferencing methods, via a co-produced survey of the PPI group members. Survey results indicated that, while participants valued face-to-face meetings, having remote PPI meetings was preferable to having nothing. There was some suggestion that teleconferencing platforms make it challenging for reserved members of the group, and for children, to contribute. Our findings emphasise the importance of continuing PPI even when circumstances are sub-optimal. We hope that our findings will contribute to the wider conversation about what makes PPI effective, particularly in a digital world.

Keywords patient and public involvement; Covid-19; remote delivery; teleconferencing; remote PPI

Key messages

- Remote PPI meetings are a valuable and acceptable option for research trials, particularly when circumstances dictate that face-to-face meetings are not possible, although there are some concerns that remote PPI meetings make it more challenging for more reserved group members.
- The first-hand experiences of families in similar situations to our research participants mean that they can provide unique insights into how to adapt the research to meet the needs of families in challenging circumstances over the pandemic, including recruitment, therapy/treatment and measure collection.
- Having the option for some face-to-face PPI meetings in research was considered important for parent/carer stakeholders, because group meetings are an opportunity for peer support for members.

Introduction

Patient and public involvement (PPI) within health and social care research aims to strengthen the quality and relevance of research by consulting the patients and public on which issues are relevant to them, and ensuring that these are addressed adequately in the research (Ennis and Wykes, 2013). Research has identified the importance of PPI for both clinical staff and researchers, as well as for service users themselves, finding that service users often gain personal benefits from their involvement, such as feeling listened to, empowered and valued (Brett et al., 2014; Paul and Holt, 2017). Actively involving patients and the public in research also corresponds with the ethical imperative 'nothing about us, without us' (McDonagh and Bateman, 2012). The National Institute for Health Research (NIHR) emphasises the importance of patient, carer and public input when designing, implementing and evaluating research (Chew-Graham, 2020), which is mandatory within NIHR grant applications. A recent systematic review indicates that PPI in research is gaining international recognition as a crucial element in improving health care and health services research (Biddle et al., 2021). Indeed, it has been argued that we are currently in a 'lived experience movement' by some (Byrne and Wykes, 2020).

Introduction to the Mental Health Intervention for Children with Epilepsy (MICE)

At least half of children with epilepsy also have mental health problems such as depression, anxiety or behavioural difficulties, which can have a significant impact on everyday functioning for the child and their family (Shafran et al., 2020; Subki et al., 2018; Puka et al., 2018). For children with epilepsy, the rates of mental health problems are often higher than for their peers without epilepsy (Jones et al., 2014; Davies et al., 2003; De Araujo Filho and Yacubian, 2013). Unfortunately, many children and young people do not receive adequate support for their mental health, partly due to epilepsy services being separate from mental health services (Hanssen-Bauer et al., 2007; Welch et al., 2018). This can often result in mental health difficulties in children with epilepsy going undiagnosed and untreated (Asato et al., 2014; Jackson and Turkington, 2005).

The Mental Health Intervention for Children with Epilepsy (MICE) study aims to conduct a full-scale randomised controlled trial of a telephone-delivered psychological intervention for mental health problems (the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma or Conduct Problems – MATCH-ADTC; Chorpita and Weisz, 2009), assessing its clinical and cost-effectiveness. In the first work package of the study, MATCH-ADTC was modified for children and young people with epilepsy (Chorpita and Weisz, 2009; Shafran et al., 2020). In the second work package, National Health Service (NHS) staff, including epilepsy nurses and assistant psychologists, were trained to deliver the intervention. An open trial evaluated the feasibility of the remotely delivered MATCH treatment in 34 participants (Bennett et al., 2021). The randomised controlled trial forms the third work package and is currently ongoing. Treatment effectiveness is assessed by comparing clinical outcomes of those receiving the treatment to those receiving usual care.

PPI in MICE

PPI plays a substantial role in the MICE study, and has done for over three years. Coordinators set up and facilitated an active PPI group to help advise the trial from its inception, in accordance with guidelines set out in the King's Fund paper *Making Shared Decision-Making a Reality* (Coulter and Collins, 2011). The group consists of parents and children and young people with epilepsy (with an age range of 6–15 years), all of whom have been involved from the start. Initially, PPI groups were conducted face-to-face at the UCL Institute of Child Health (University College London, UK) on a quarterly basis, and groups were facilitated by members of the research team and an appointed PPI lead. The group was separated into parents, and children and young people, to allow for open, honest conversations in a safe space. All PPI members have advised on several aspects of the research study, from creating appropriate epilepsy-specific materials to be used in the therapy manual (including a set of 'frequently asked questions' for families about the relationship between epilepsy and mental health), to informing on the types of questions parents should be asked during qualitative interviews.

Impact of Covid-19

The impact of Covid-19 on epilepsy care management has further reinforced the importance of integrating the physical and mental health needs of young people with epilepsy. The mental health of those with pre-existing health conditions has been reported to remain significantly worse than those without pre-existing health conditions (Pan et al., 2021), emphasising the importance of continued care. Reilly et al. (2021) conducted an online survey in June 2020 to gather young people's and carers' perceptions of the impact of Covid-19 on their epilepsy. Findings indicate that young people reported an increase in seizure frequency, and a deterioration in mood and sleep; moreover, caregivers reported an increase in stress and anxiety.

Research into the impact of Covid-19 has also highlighted the importance of continued PPI. O'Conner et al. (2020) lay out the research priorities for those in psychological science, as informed by an expert panel at the British Psychological Society. Researchers emphasise the importance of engaging with stakeholders and those with lived experience during this time of national crisis (O'Conner et al., 2020). PPI is needed to ensure that researchers are investigating topics that are relevant, current and important to the patient groups themselves, during a time of global crisis (Holmes et al., 2020).

Findings from a large systematic review indicate that the voices of those with lived experience have continued to be overlooked during the Covid-19 pandemic (Ocloo et al., 2021). In particular, there has been little focus on the effectiveness of PPI facilitated remotely during this time. Prior to the pandemic, there have been some promising findings into the feasibility, acceptability and functionality of PPI via an online forum for carers of people in palliative care (Brighton et al., 2018). Qualitative findings indicated that participants found the online PPI platform supportive and helpful, but equally felt that it was too researcher-led (Brighton et al., 2018). Their findings suggest that technology should not be considered

a barrier, but that members should instead be supported to overcome any technological difficulties. Findings also suggested that being involved in online PPI provided a sense of control and empowerment in what is otherwise an unpredictable life due to caring responsibilities or disease progression. Both Brighton et al.'s (2018) and Daveson et al.'s (2015) research emphasised the importance of utilising a flexible approach to PPI implementation and facilitation, ensuring to meet the needs of its PPI members, and that a combination of face-to-face and remote methods provide more accessibility for its members. Communication between PPI members and researchers in online settings is critical to empowerment and facilitation of collaborative relationships.

The Covid-19 pandemic has inspired discussions about the many benefits of keeping services online after restrictions are lifted, for example, increased accessibility and decreased costs and travel. In this article, we aim to consider: (1) how the PPI Research Advisory Group (RAG) supported the research, during the course of the pandemic, using a 'you said, we did' approach; and (2) the benefits and disadvantages of remotely delivered PPI, through a survey of the MICE PPI RAG members regarding their views.

Materials and methods

Design

Group set-up

Our pre-existing PPI group advise the MICE randomised controlled trial running at Great Ormond Street Hospital for Children in London and the UCL Institute of Child Health. Originally, the PPI groups were conducted face-to-face, as well as over a group WhatsApp, with communication between group members through email and messaging, as the researchers strived for meaningful group collaboration. Consultation workshops run with patients in other research indicate that face-to-face meetings combined with between-group contact via social media platforms and online forums are the optimal way to avoid contributions feeling tokenistic (Daveson et al., 2015). The MICE study researchers wanted to learn from PPI members, and therefore every effort was made to reduce hierarchal structures and traditional decision-making power imbalances. There was sufficient feedback to ensure that members understood the value of their contributions as a result of implementation, which are key aspects for successful PPI (NIHR, 2017; NICE, 2013).

The PPI meetings continued throughout the Covid-19 restrictions, on a quarterly basis. Groups were conducted via the online platform Zoom, and were facilitated by two researchers, as well as our MICE PPI lead, with the group mostly consisting of parents. Having given consent, all contributions from PPI members were audio-recorded and transcribed, from which actions were derived and addressed by the researchers before the following PPI group. We utilised a 'You Said, We Did' approach, a methodology commonly used by NHS clinical commissioning groups when engaging with the public and patients, to ensure that the recommendations given to us by the PPI members were documented and acted upon.

Ethical approval

Ethical approval for the MICE study was obtained from South Central – Oxford A Research Ethics Committee (reference: 18/SC/0250). This involvement project fulfils one of the four aims of the MICE trial's PPI, as quoted in the Integrated Research Application System (IRAS) form to create a 'meaningful experience for the members of the RAG'. The present article reports on engagement activities related to the MICE study.

Survey development and procedure

To address the second aim, we surveyed the MICE PPI RAG members regarding their views on remotely delivered PPI to make sure that future meetings met their needs, and that everyone felt able to contribute fully. The survey used both closed and open-ended questions to give the members adequate

space to have their opinions heard. The survey was hosted on Qualtrics Q Lite, an online platform, and was anonymously completed. Electronic results were anonymised by replacing participant names and other identifiable information with assigned numbers. The survey included demographic questions, nine of which focused on the issue of research. Participants responded using the following five-point Likert scale: *strongly agree*, *agree*, *neutral*, *disagree* and *strongly disagree*. All nine questions had a free-text option for qualitative analysis. Survey questions were designed to explore respondents' opinions and attitudes towards remote public engagement, and were created in collaboration with one of the PPI group members. Items on the survey encompassed a range of factors that may constrain or facilitate remote participation, inspired by previous literature highlighting the common benefits and challenges of remotely facilitated therapy (Batchelor et al., 2020). Items were balanced, with some of the questions on the survey being statements in favour of remote PPI (for example, 'The group running remotely was helpful in other ways, e.g. peer support') and others highlighting the challenges (for example, 'I find it harder to express my views in the remote PPI group, compared with in person').

Participants were approached in December 2020 during the PPI group, around the time of the second wave of Covid-19 in the United Kingdom and during the second national lockdown, when many social restrictions were implemented across the country, such as closing restaurants, religious public spaces and museums (GOV.UK, 2020). Medical appointments that could be conducted over the phone or online were encouraged to be carried out in this way, for example, appointments with a GP. All the PPI members attending the PPI group were invited to participate, and all completed the survey ($n = 9$, including three couples). Eight of the participants were female and one participant was male. Participants ranged from 25 years and under to 65 years and over; the modal age category of the group was 35–44 years old. Eight participants identified their ethnicity as 'White', and one participant identified as 'Other' ethnicity.

Descriptive statistical methods in SPSS were used to analyse the quantitative data. The free-text answers were reviewed qualitatively, and authors identified key topics and ideas in the quantitative results. Results were discussed with the PPI RAG facilitator.

Results

Aim 1: To consider how the PPI RAG supported us to consider the necessary adaptations required for research during the pandemic

Although the MICE trial was designed to run remotely, and so in many ways was in a better position than most studies to continue throughout the pandemic, the lockdowns created significant challenges for both the research and the PPI, as discussed below.

Participant recruitment

The researchers' usual approach of attending epilepsy clinics and meeting families in the waiting room came to a halt due to the national lockdown resulting in cancellations of all face-to-face clinics. Consequently, the team received fewer referrals than the proposed recruitment figures agreed upon with the NIHR. PPI members provided valuable advice on recruitment of families pre-pandemic, and the researchers hoped that they could provide additional insight into how best to recruit families. PPI members explained that they regularly receive letters in the post from epilepsy specialists (for example, epilepsy nurses) containing information about clinics or appointments. Our families stated that they would trust fliers advertising research opportunities sent enclosed with these letters, as they would expect advertisements sent via this method to be reputable research opportunities. In contrast, they explained that they would be unlikely to consent to take part in research advertised on social media, due to a lack of trust. Following the advice of our PPI group members, the MICE research team created a self-referral recruitment poster to distribute widely across the NHS sites involved in the trial. This yielded nine self-referrals and six recruited families in the early phase of the pandemic.

Therapy

One PPI member described the PPI group as being 'canaries in the mine' – they could give early warning of the daily challenges of families with children with epilepsy during the pandemic. All PPI members considered it vitally important that the research continued, not least because they felt abandoned by many other services, which were reducing appointment frequencies and postponing operations. However, they also reported that finding a weekly hour-long uninterrupted slot for therapy when home-schooling and working from home could be difficult, if not impossible, for many families in the research. We therefore allowed for greater flexibility in the research protocol than had previously been the case, including more leeway with session timings, having sessions over the phone or email rather than Zoom, if required, and having shorter sessions and/or a longer interval between sessions. We recorded such differences in delivery as deviations from the protocol to ensure that the effect of this could be examined at the end of the study. A positive result was that only one participant withdrew from the research during the course of the pandemic.

Follow-up

The research team contacted parents of the children and young people participating in the study, at 6 months and 12 months after randomisation to complete standardised questionnaires (some on the telephone and some online) to assess the efficacy of the MATCH-ADTC intervention. Scores to questionnaires were then reported in a letter which was sent to all professionals involved in the child's care (for example, GP, neurologist, paediatrician). PPI group members provided advice on how best to contact families regarding their follow-up assessment, including how to describe this phase of the study from the outset, with a strong emphasis on the importance of their contributions, through to their 6- and 12-month time points. The researchers also sought advice regarding how to make the follow-up letters meaningful for families, with a particular focus on the scores to questionnaires. PPI members provided valuable advice, including providing families with a glossary of terms at the beginning of the study, as well as brief summaries of each questionnaire that parents completed.

Maintaining meaningful PPI involvement

PPI contributions were necessary to ensure that the research continued to meet the needs of the families it was designed to support. However, running PPI groups remotely came with its own challenges. First, the difficulties with recruiting led to a one-year extension of the study time frame. We were therefore in a different study phase than originally planned, with a recruitment period longer by a year. We wanted to ensure that PPI contributions remained meaningful and not tokenistic during this extended recruitment period. The group chose to make audio recordings that could be used for teaching, training and dissemination, specifically on the following topics: Why is PPI important?; Why is researching mental health interventions for children and young people with epilepsy important?; and What makes meaningful PPI? These recordings will be used in presentations going forward through the study, and will therefore enable dissemination throughout the study period and not only at the end, in line with NIHR guidance (Hayes et al., 2012). Meaningful involvement of children and young people was particularly challenging; many of the children and young people in our PPI RAG had intellectual and/or neurodevelopmental disabilities, and they had previously been seated in a separate room from their parents in RAG meetings to ensure confidentiality. Finding a space separate from their parents at home caused logistical difficulties. In addition, it was more difficult for some of the younger RAG members to concentrate for extended periods of time on a screen. As such, it seemed inappropriate to include the younger members of the RAG group in the survey about online involvement groups. Instead, it was decided that audio recordings for the videos be completed in the PPI members' own homes, in their own time, alleviating the pressures during the session. This was particularly beneficial for our younger RAG members, who were then able to participate and contribute to the videos.

Aim 2: To consider the benefits and disadvantages of remote PPI through a survey

Remote PPI group meetings are preferable to no PPI group meetings

As shown in Table 1, all respondents liked the fact that the PPI group continued to run remotely. There was general acknowledgement that, while participants valued face-to-face meetings, having remote PPI meetings was preferable to having none at all:

Although I miss face-to-face groups, I feel relieved that the group carried on during lockdown. (P7)

Continuing the group remotely was important for the continuity of [the] project. (P8)

As demonstrated in Table 1, most participants would recommend remote PPI groups for other clinical trials. Participants suggested that remotely delivered PPI is a good compromise within the context of a global pandemic, with some participants suggesting that a mixed approach (of some remote and some face-to-face meetings) be taken after the pandemic:

Given that it will be a while before we return to 'normal' it's a good option. Or, maybe use a mixture of both when we can. (P6)

Yes, but only in the context of Covid-19. (P7)

This would depend on the group make-up. Certainly a mixture of face-to-face with online could have further benefits than solely one or other. (P9)

Table 1. Overall findings for each question asked in the survey (Source: Authors, 2023)

Question	Strongly disagree Number (%)	Disagree Number (%)	Neutral Number (%)	Agree Number (%)	Strongly agree Number (%)
Q1 = I liked that the PPI group continued to run remotely	0 (0%)	0 (0%)	0 (0%)	1 (11.11%)	8 (8.88%)
Q2 = The PPI group running remotely was helpful in other ways, e.g. peer support	0 (0%)	0 (0%)	1 (11.11%)	1 (11.11%)	7 (77.78%)
Q3 = Attending the PPI group remotely was more convenient for me than face-to-face	0 (0%)	0 (0%)	5 (55.56%)	2 (22.22%)	2 (22.22%)
Q4 = The PPI group running remotely made other things more difficult to balance	4 (44.44%)	2 (22.22%)	1 (11.11%)	2 (22.22%)	0 (0%)
Q5 = I felt that my views were listened to during the remote PPI group	0 (0%)	0 (0%)	1 (11.11%)	4 (44.44%)	4 (44.44%)
Q6 = I found it harder to express my views in the remote PPI group, compared with in person	1 (11.11%)	1 (11.11%)	4 (44.44%)	2 (22.22%)	1 (11.11%)
Q7 = I experienced technical difficulties with remote PPI	2 (22.22%)	6 (66.67%)	1 (11.11%)	0 (0%)	0 (0%)
Q8 = I would recommend PPI groups for other trials to run remotely	0 (0%)	0 (0%)	3 (33.33%)	4 (44.44%)	2 (22.22%)
Q9 = I prefer groups face-to-face to remote	1 (11.11%)	0 (0%)	2 (22.22%)	3 (33.33%)	3 (33.33%)

Overall preference for face-to-face PPI groups

Overall, despite agreeing that remote groups are preferable to not having PPI group meetings at all, most respondents preferred face-to-face groups to remote ones (Table 1). There was a general feeling in participants' answers that remotely facilitated PPI lacked a 'dimension' that face-to-face PPI groups had:

I would still rather meet in person as even well-facilitated online meetings lack warmth and feel a little two-dimensional. (P2)

It's always nice to see people! (P8)

What participants liked about remote PPI

All participants except one felt that the group running remotely was helpful in other ways, such as for peer support. There was general acknowledgement in the free-text answers that the PPI members have always valued being part of the group for the opportunities to receive support from other families who have had similar experiences:

... the group has always provided this but for participants who have been shielding or who have little to no familial support, it has become even more important. (P2)

... it's always great to catch up with those who have understanding of how you feel. (P8)

Almost half of the PPI members found attending the PPI group remotely more convenient than attending face-to-face meetings, with five participants reportedly feeling 'neutral' about this (Table 1). A few respondents elaborated on this in the survey, by explaining that they found not needing to travel to Great Ormond Street Hospital convenient. Participants mostly disagreed that the PPI group running remotely made other things more difficult to balance, although a small group of PPI members did agree with this statement (Table 1). Technical difficulties were not felt to be a barrier to remote PPI by most participants.

What PPI members found challenging about remote PPI groups, compared with face-to-face group involvement

As seen in Table 1, the majority of participants felt that their views were listened to during the remote PPI groups. Group members thought that an online teleconferencing platform may make it more challenging for more reserved members of the group to make contributions:

I worry for other participants, as face-to-face I can read non-verbal cues if someone is dominating or someone wants to contribute but can't find a gap. (P2)

... meeting over Zoom tends to discourage the less forthcoming therefore stronger characters could dominate discussions. (P9)

Conversely, one member reported that:

... all participants are respectful and interested in others views and comments. (P8)

Opinions were mixed about whether participants found it harder to express their views remotely, compared with face-to-face. PPI members indicated that it may be more difficult to express opinions during remote PPI, because of the inability to use social cues and body language to indicate when you or someone else would like to speak:

It's easier to find a gap to talk when face-to-face. Remote is harder because you lose the ability to see the room of people and pick up on subtle body language and facial expressions. (P7)

I personally don't but it can be difficult moving people along and trying to ensure an equal 'floor space' to those who may be more introverted members. ... In face-to-face meetings, I can spot someone with their hand up or taking a breath to speak ... this is almost impossible to do online. (P2)

Discussion

This study had two aims. First, to consider how the PPI RAG supported us to consider the necessary adaptations required for research with children and young people with epilepsy and their families during the course of the pandemic, while accounting for individual differences. Second, to consider the benefits and disadvantages of remote PPI specifically, through a survey of our PPI RAG.

Regarding our first aim, the PPI members provided insight into all stages of the research process that the research team would not otherwise have been able to access. As a direct result of PPI discussion and feedback, the research team created a recruitment poster that aided recruitment during the pandemic, provided more flexibility in therapy delivery, and supported the researchers on how best to communicate participants' contributions to the research during 6-month and 12-month follow-up stages, ensuring the successful continuation of the study throughout the pandemic. They also created videos using PPI members' own voices to demonstrate the importance of PPI involvement in research. This supports previous literature which found that one of the key benefits of doing PPI in research is the ability to access crucial insights from people who live with a physical health condition (Staly et al., 2021). As researchers, we recognise that the MICE trial would not have been able to continue during the Covid-19 pandemic without the PPI group's invaluable advice on how to recruit, retain and follow up families in the study.

However, moving online also highlighted the barriers to involving children and young people in PPI, and learning from their input. This was particularly challenging in our PPI group, due to the high rates of additional needs of the children and young people. Future clinical trials running during uncertain times should take this into consideration, and should consult parents of children with additional needs to gather ideas about how to meaningfully include their children using remote methods from inception to dissemination. Future researchers would benefit from planning ahead and considering creative ways of engaging children and young people in remote PPI. Researchers might consider suggestions made in recent literature on the subject (Kleine et al., 2016), including drawing, storyboarding and visual technology.

Regarding our second aim, on the whole, our PPI members were glad that PPI groups continued to run remotely; however, they preferred face-to-face meetings, despite the practical barriers of conducting meetings face-to-face, such as travel, cost and time, and they agreed that remote meetings were a 'compromise' during a global pandemic. Our results indicate that our PPI members valued face-to-face meetings and believe that face-to-face meetings should be resumed after the pandemic. In particular, our qualitative results indicated that the elements of PPI discussions, such as communication through body language, facial expressions and tone of voice, were lost during remote groups, and concerns were raised regarding other people's ability to contribute. However, no one reported this to be their own experience, meaning that the extent to which this impacted participants is unclear. Findings from studies of group-based tele therapy support the present findings, however, by demonstrating that factors such as 'therapeutic alliance', 'group cohesion' and 'connectedness' were significantly lower in video therapy compared to traditional face-to-face therapy (Greene et al., 2010; Lopez et al., 2020).

Our findings also indicate that face-to-face groups were preferable because they enable a 'social' space in which people can support each other, as well as the core task of discussions about research. Our findings indicate that the 'support group' element of the group was lost when the meetings moved online, and that this was an important element for our members' involvement with the PPI research. This finding is particularly relevant for parents and carers, as research indicates that carers lack peer support groups and face difficulties accessing services for the person they care for, as well as for themselves (Rand and Malley, 2014). Malm et al. (2019) explore carers' views and experiences of involvement in research,

finding that their involvement provided a 'sense of community', and that spending time with other carers with similar experiences provided a sense of relief and a therapeutic element.

Our results show that most participants disagreed that remote meetings made other things more difficult to balance, compared with face-to-face meetings. Moreover, there were no comments about practical issues, such as childcare, getting in the way of effective remote PPI meetings. This finding was unexpected to the research team, given that, prior to the pandemic, children in the PPI group were engaged in separate group activities with researchers while the adult members engaged in discussions. It was thought that this set-up gave the parents/carers time and space to express their views. Our findings on this topic are in line with previous research, which found that videoconferencing interventions for parents of children with autism were preferable to face-to-face sessions because they reduced the burden of having to coordinate childcare (Lodder et al., 2020). It is possible that the practical advantages of remote PPI, including the ability to 'mute' or turn the camera off momentarily to attend to children's needs, may have been helpful components of online facilitation.

It should be noted that our findings may not be representative, and that opinions on this topic may differ for other families who do not have the privilege of space at home. Questions have been raised about whether the increased focus on online methods for PPI reduce or increase existing social inequalities, for example, access to the internet and confidential space (Clark et al., 2021). The impact of children and young people overhearing discussions on sensitive topics (such as their mental health difficulties) should also be considered in PPI where parents and caregivers are being consulted.

Overall, our findings support existing research regarding the best ingredients of effective PPI. Brett et al. (2014) report how PPI members feel empowered and valued, and are able to gain confidence and life skills through participation in PPI groups. NIHR INVOLVE (Hayes et al., 2012) report on key aspects of PPI that are difficult to implement remotely, such as buddy systems, refreshments and finding a 'neutral' meeting place; therefore, this needs to be considered in PPI implementation.

Limitations

There are several limitations to the present study that should be acknowledged. The sample size surveyed is small, meaning that results from the study cannot be generalised and should be viewed only as the beginning of a broader conversation on this topic. Moreover, the present study only surveyed parents and carers, and failed to survey children and young people with epilepsy, due to practical issues. Future research into the effectiveness and acceptability of remotely facilitated PPI should be conducted with a greater sample size, and with participants from a variety of backgrounds. The present study selected a relatively homogeneous sample of PPI members, with most participants being parents/carers and the predominant ethnicity being White. There is evidence for a lack of diversity within PPI (INVOLVE, 2012), and a recent systematic review (Dawson et al., 2018) reported that people from ethnic minorities (excluding White minorities) continue to be unrepresented in international PPI, particularly PPI in later phases of research (for example, data analysis and interpretation). Formal qualitative interviews with our PPI group members may have enabled us to gather richer data on their experiences. Future research could utilise the overarching themes reported in this study to help develop an interview structure which would provide more detailed feedback on remote facilitated PPI. It is also noteworthy that our PPI group was facilitated face-to-face for many years prior to the pandemic, and therefore findings could plausibly differ if the group had originally been set up as an online entity.

Research and clinical implications

Our findings add to the existing evidence base emphasising the importance of continuing PPI whenever possible, even when circumstances are challenging. They also support the development of remotely facilitated PPI involvement, considering both the opportunities and challenges associated

with it. Despite the challenges faced with online facilitation, remote PPI was found to be preferable to no PPI at all.

Conclusions

This article has reported on the importance of continuing PPI associated with a research trial over the course of the pandemic, and the advantages and disadvantages of remotely facilitated PPI. Overall, the PPI RAG provided extremely important insights into life for families of children with epilepsy, which ensured that the research protocol remained acceptable for participants during this time. Future research should consider the difficulties in engaging young people with additional needs in PPI remotely. Regarding the acceptability of the remote PPI, face-to-face PPI was found to be preferable, although remote PPI was suggested to be a 'good compromise' during the pandemic. Some members felt relieved that the group continued, as it provided them with a sense of peer support, and they felt it was important for the continuity of the project. Based on our findings and our experiences of facilitating the groups, we suggest that a 'blended' approach to facilitating PPI groups would be a positive alternative as we continue to experience the effects of the pandemic. A blended approach to PPI may increase inclusivity of its members, for example, those from remote geographical areas, with long-term health conditions, financial constraints or caring responsibilities would be enabled to participate (Shaghaghi et al., 2011). We hope our findings will be the beginning of a wider conversation about what makes PPI effective in a digital world.

Acknowledgements

We would like to thank the members of our PPI group in particular for continuing to volunteer their time during a period full of uncertainty. All research at Great Ormond Street Hospital NHS Foundation Trust and UCL Great Ormond Street Institute of Child Health is made possible by the NIHR Great Ormond Street Hospital Biomedical Research Centre.

Funding

This work was supported by the NIHR Programme Grant for Applied Research (Grant Reference Number RP-PG-0616-20007). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Declarations and conflicts of interest

Research ethics statement

The authors declare that research ethics approval for this article was provided by South Central – Oxford A Research Ethics Committee (reference: 18/SC/0250).

Consent for publication statement

The authors declare that research participants' informed consent to publication of findings – including photos, videos and any personal or identifiable information – was secured prior to publication.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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