

COMMENT

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Implementation of patient and public involvement and engagement (PPIE) for the therapies for long COVID in non-hospitalised individuals (TLC) project

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Abstract

Background Patients, their family members and caregivers have firsthand experiences of living with or supporting someone living with a disease or medical condition. This knowledge by experience cannot be replaced by the knowledge acquired by clinicians, researchers, or other professionals through study and/or work. The Therapies for Long COVID in non-hospitalised individuals (TLC) research project was funded in the UK by the National Institute for Health and Care Research (NIHR) and UK Research and Innovation to investigate the impact of long COVID on affected individuals. This article focuses on the implementation of PPIE for the TLC project. It provides details on the methodological approach that was adopted, the evaluation and reporting of the PPIE for the project and some previously unreported challenges we faced.

Main body A PPIE Lead was appointed to coordinate PPIE for the project and facilitate communication and relationship building with the patient partners. Our overarching approach was collaborative with patient partners actively involved in the various work packages of the project.. This was achieved by recruiting PPIE members from (1) direct contacts, (2) long COVID support groups (3) a local general practitioner (GP) surgery. Although we were unable to hold face-to-face meetings due to the social restrictions during the COVID-19 pandemic, we offered patients the choice of using virtual platforms like Zoom, telephone calls, and emails for communication. We adopted a 4-tiered model for the PPIE group with each tier providing different opportunities for contributing to the project. This model helped the PPIE Lead to effectively co-ordinate PPIE activities for the project as well as provide all patient partners the opportunity to contribute to the project whilst managing their condition. PPIE for the TLC project was co-evaluated with patient partners.

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Conclusions Despite the challenges we encountered with the pandemic, the TLC project provided a valuable opportunity for patients to shape the design, conduct and dissemination of the research findings. The information provided in this article may be useful to other researchers and patients when planning PPIE for future health research. The implementation of PPIE in healthcare research could help ensure that the outcomes of research are those valued by and relevant to the needs of patients and other end users.

Keywords Patient and public involvement and engagement, PPIE, Involvement, Engagement, Co-production, Patient partners, COVID-19, Long COVID

Plain English summary

Patients, their family members and caregivers have firsthand experiences of living with or supporting someone living with a disease or medical condition. This knowledge by experience cannot be replaced by the knowledge clinicians, researchers, or other professionals acquire through study and/or work. The involvement of patients, their family members and caregivers in decisions about how health research is carried out can ensure that the results of research meet patients' needs and leads to tangible benefit for them. The 'Therapies for Long COVID' (TLC) research project was funded in the UK to investigate the impact of long COVID on affected individuals. People with long COVID, who we consider our patient partners, contributed substantially to the project. The results of some of the studies conducted as part of the project have been published elsewhere. In this article, we focus on how we organised and managed PPIE for the TLC project. Despite some challenges, we were able to involve several patient partners in the project. This was achieved by recruiting PPIE members from (1) direct contacts, (2) long COVID support groups (3) a local general practice (GP). Although we were unable to hold face-to-face meetings due to the social restrictions during the COVID-19 pandemic, we offered patients the choice of using virtual platforms like Zoom, telephone calls, and emails for communication. PPIE for the TLC project was co-evaluated with patient partners and all TLC publications have been co-authored with patient partners. We hope that the information provided in this article will be useful to other researchers and patients when planning PPIE for future health research.

Background

Transformative advances in healthcare are typically underpinned by scientific investigation. It is crucial that patients, their family members/caregivers, and the public are given the opportunity to contribute to and inform decisions about research and healthcare policies that may affect their lives directly or indirectly [1–4]. Patients, their family members and caregivers can provide unique and valuable perspectives, based on their lived experiences of a disease or medical condition which cannot be substituted by expert knowledge from clinicians, researchers, or other professionals. The potential benefits of their contribution are being recognised by patients, caregivers, the public, healthcare professionals, researchers, industry, governmental organisations, and policy-makers [5]. There are several national and international initiatives to promote patient and public involvement and engagement (PPIE) in research and healthcare delivery [6]. Major funders of healthcare research increasingly request details of PPIE in the development of grant proposals as well as plans for PPIE within the proposed project [7, 8].

The COVID-19 pandemic has further highlighted the need for greater PPIE in clinical research and healthcare delivery. The term 'long COVID' was coined by individuals with long COVID bringing the condition

to the attention of the public and healthcare systems worldwide [9, 10]. Individuals who develop long COVID, a consequence of COVID-19, experience a variety of symptoms which affects their physical and mental wellbeing in ways that are still not fully understood [11, 12]. For this reason, it is crucial that individuals with long COVID and their family members/caregivers are actively involved in all aspects of research investigating the condition. The Therapies for Long COVID in non-hospitalised individuals (TLC) research project was funded in the UK by the National Institute for Health and Care Research (NIHR) and UK Research and Innovation to investigate the impact of long COVID on affected individuals [13]. Patient partners, who are individuals with long COVID, were an integral part of the research team and contributed substantially to the project. The outcomes and impacts of PPIE on the project and their specific contributions to individual work packages have been recently published [14, 15].

This article focuses on the implementation of PPIE for the TLC project. It provides details on the methodological approach that was adopted, the evaluation and reporting of the PPIE for the project and some previously unreported challenges. Information presented in this article may assist other researchers with the

implementation of PPIE for future healthcare research projects. Box 1 provides the definitions of key terms.

Methodological approach to PPIE

PPIE for the TLC project was conducted in accordance with the UK Standards for Public Involvement in Research [20]. A PPIE Lead was appointed to coordinate PPIE for the project and facilitate communication and relationship building with the patient partners. Our overarching approach was collaborative with patient partners actively involved in the various work packages of the project. The level of involvement across the project ranged from consultative to co-production as determined by the requirements of the individual work packages and the availability/interest of the patient partners (Fig. 1). There was more of a consultative approach during the initial stages specifically project set-up and the conduct of reviews for work packages 2 and 3 [21]. However, work package 4 which involved the co-production of a non-pharmacological intervention, and the feasibility study

required a substantially higher degree of collaboration [15]. In addition to contributing directly to the delivery of the project, a patient partner who was a member of the project management group provided strategic oversight and contributed to the decision-making process. Patient partners also co-authored all TLC publications.

Recruitment of patient partners

At the grant application stage, we approached individuals from acute care and outpatient and day services and through leaflets distributed across the National Health Service (NHS) trusts. Fourteen people with Long COVID and four caregivers provided feedback on the application. They confirmed the importance of the research questions and approved the research plans.

After receiving confirmation of application success, we commenced the recruitment of individuals with lived experience of long covid to establish a PPIE group.

Our goal was to recruit individuals from diverse backgrounds following the NIHR INVOLVE guidelines on

Box 1 Definition of key terms

- The **‘involvement’** component of Patient and Public Involvement and Engagement (PPIE) refers to activities and research carried out ‘with’ or ‘by’ members of the public or patients, rather than ‘to,’ ‘about’ or ‘for’ them. Patients and members of the public are actively involved in the development, running and management of research projects or activities [16, 17].
- The **‘engagement’** element of PPIE focuses on the dissemination of information and outcomes from research to patients and the public, so that they are informed of developments while providing them the opportunity to share their insights and input [16, 17].
- **Coproduction** is “an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.” Patients, members of the public and other stakeholders are equal partners in research with joint ownership of key decisions during the project [18].
- The World Health Organisation (WHO) defines **Long COVID** as a “Post COVID-19 condition that occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis.” [19]

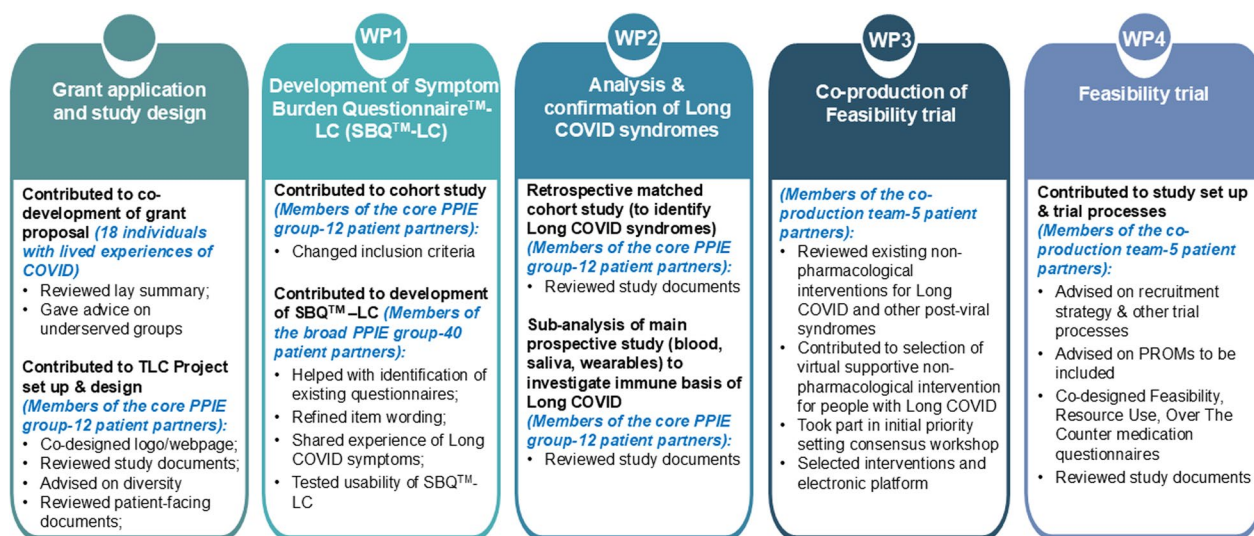


Fig. 1 TLC Workpackages

diversity and inclusion in public involvement [22]. This approach facilitates the acceptability, relevance, and quality of research [1, 23, 24].

We closely monitored the demographic characteristics of patient partners throughout the project to help us identify underrepresented groups early and tailor our recruitment strategies accordingly.

Recruitment channels

Early evidence during the pandemic suggested that Long COVID was more prevalent among women and individuals from ethnic minority groups [11]. Therefore, to ensure we had a representative group, we recruited PPIE members through the following channels:

- Individuals with Long COVID who reached out directly to the research team expressing an interest in joining the PPIE group. We established a database of the individuals that provided consent for us to keep their details (names and email addresses) for this purpose.
- Members of Facebook groups including Long Covid SOS, Long Covid Scotland and the Covid-19 Research Involvement Group on Facebook which is run by the charity Long Covid Support through their respective group coordinators, as well as other long COVID support groups.
- Individuals with Long COVID were also offered the opportunity to participate in the PPIE group by general practitioners (GPs) based locally in Birmingham. Contact details of individuals who expressed an interest were shared with the PPIE Lead.

Formation of PPIE group for the project

We adopted a 4-tiered model for the PPIE group with each tier providing different opportunities for contributing to the project. Membership of each tier was based on the amount of time patient partners were able to spend on the project and the requirements of the work packages in terms of patient input. This was explained to potential PPIE members at the point of recruitment. This model helped to effectively co-ordinate PPIE activities for the project as well as provide all patient partners the opportunity to contribute to the project whilst managing their condition. The symptoms they were experiencing such as fatigue and brain fog negatively affected their quality of life and limited their ability to carry out daily activities. It was therefore crucial we ensured that participation in the project did not place undue burden on patient partners. Whilst the meetings

were chaired by the PPIE Lead and other researchers with experience of facilitating PPIE, patient partners were encouraged to not only provide their perspectives on topics being discussed but also raise any issues or points they considered important for discussion. We noticed that as the project progressed and the PPIE members understood research processes better, they became more confident sharing their perspectives during the meetings and in email communications.

Consistent with Long COVID's origins in lived experiences of members of the public who identified it as a potential consequence of COVID-19 infection, the individuals recruited for the project self-identified as having Long COVID [25]. We did not require them to provide evidence of past COVID infection based on a positive polymerase chain reaction (PCR) or lateral flow as our PPIE group pointed out that testing was not available for all in the early days of the pandemic.

The four tiers were:

- (i) A broad PPIE group of 40 patient partners. This included all the individuals with Long COVID who contacted us directly expressing an interest in participating in the project, the individuals we recruited via a GP practice, and those referred to us by other individuals with Long COVID. Membership of this group required the least amount of time commitment.

Contributions: These individuals helped with aspects of the project including the cognitive and usability testing of the SBQTM-LC.

- (ii) A 'core' PPIE group which comprised of 12 patient partners from the broad PPIE group. These individuals worked closely with the researchers throughout the stages of the research and spent more time on the project than other members of the broad PPIE group.

Contributions: They attended meetings to discuss the research for each work package as required and regular 4-monthly meetings to discuss project progress. They also provided feedback on all study documents.

- (iii) A co-production team of five patient partners from the core group. Membership of this group required the highest amount of time commitment meeting with the researchers twice a week over 52 weeks.

Contributions: Members of this team co-produced the non-pharmacological intervention and the feasibility study with the researchers.

- (iv) A few individuals who preferred to work with the researchers on a one-to-one basis outside the formal group settings providing feedback on study documents.

Modes for obtaining input from the patient partners

Although the pandemic created challenges for PPIE [26], we were as flexible as possible in our modes of obtaining the input of patient partners to ensure that we were inclusive and obtained and incorporated diverse views. However, due to the social restrictions to curb the pandemic, we were only able to interact with patient partners for most of the project via videoconferencing, and online/email or telephone communication. Patient partners had the additional option of face-to-face meetings later in the pandemic (whilst complying with COVID-19 guidance).

In reality, our interactions with patient partners in the core PPIE group and co-production team were mainly via videoconferencing (Zoom meetings) and

emails. Members of the core PPIE group attended meetings that were scheduled to coincide with key project milestones where their input was needed such as the meeting to discuss the focus and search strategy for the systematic review on non-pharmacological interventions. Members of the co-production team attended regular meetings (twice a week) with the researchers as this was required for the delivery of the studies. Communication with the broad PPIE group was via email and regular newsletters throughout the project. A summary of feedback from patient partners that informed the research conducted in the TLC project can be found in Table 1.

Table 1 Sample of feedback from patient partners which informed aspects of the TLC Project

Feedback on project documentation and manuscripts	
Review of Patient Information Sheets (PIS) for cognitive testing of the Symptom Burden Questionnaire-Long COVID™ (SBQ-LC™)	i) The PIS contained the sentence: Download an app (Atom5™) onto your smart phone/tablet: You will be given a QR code to access the questionnaires Comment: <i>This [QR code] might need explaining for people who are not tech savvy, etc</i> ii) There was also a suggestion to consider splitting the hour-long cognitive test sessions into two half-hour sessions, especially for individuals suffering from extreme fatigue due to long covid
Review of the manuscript for the Clinical Practice Research Datalink (CPRD) data analysis	Original statement in Introduction section: "There is also a need to gain a better understanding of the risk factors that contribute towards the development of long covid." Comment: Mention that this was highlighted in the most recent iteration of the updated guidelines out November 2021 that mentioned this as one of the key priorities for research? Amendment in final article: "There is also a need to gain a better understanding of the risk factors that contribute towards the development of long covid which was highlighted as a research priority on the recently updated National Institute for Health and Care Excellence (NICE) guideline on managing the long-term effects of covid-19"[12]
Review of the manuscript for systematic review of non-pharmacological interventions in post viral syndromes	Result section: We discussed the randomised controlled trial by Neumann et al. which evaluated the effectiveness of a resistance exercise programme for patients experiencing prolonged musculoskeletal symptoms who have been exposed to the Chikungunya virus who attend a Rheumatology outpatient clinic Comment: Were these patients screened to remove any with PEM (Post-exertional malaise)?
Testing of the SBQ-LC™	
Cognitive testing of the SBQ-LC™	i) Patient partners felt that the question asking about 'tiredness' did not fully represent how they felt. They suggested changing 'tiredness' to 'Feeling of physical and mental exhaustion' ii) Some found the question on 'sense of self' difficult to understand. After it was explained, they agreed it was a very important question but suggested we change it to 'loss of identity'
Usability testing of the SBQ-LC™	i) Patient partners identified some programming issues such as hyperlinks that did not work, and male participants getting questions on female reproductive and sexual health ii) They suggested adding a message on the approximate time required to complete the questionnaire iii) There was also a suggestion to programme the App to allow respondents save partly completed questionnaires so they can return at a later date/time to complete and submit

Reimbursement

We believe patient partners should be reimbursed for their time, skills and expertise they contribute to the research work and out-of-pocket expenses such as parking fees and transportation costs directly related to their participation in the project. Patient partners were reimbursed for their time and expenses in accordance with the NIHR payment guidance at the time regardless of their tier group [27]. In addition, for face to face meetings where carer support was required we also reimbursed carer fees.

Co-evaluation of PPIE

Rationale

It is vital that the impact of PPIE on research is critically evaluated and transparently reported to generate and make available valuable insights and evidence that may inform future practice [28–30]. It is also essential that patient partners and other public contributors to a project are involved in the evaluation process [31, 32]. Capturing their perspectives alongside those of researchers may provide a more rounded and potentially less biased assessment. Patient partners for the TLC project working with the PPIE lead, reflected on and co-evaluated their contributions to the project.

Approach to the evaluation of PPIE

We considered PPIE in research as a methodological activity to improve research quality and utilised research methods including group discussions, interviews and survey for its evaluation [33].

Evaluation process

- Drawing on the recommendations of the Public Involvement Impact Assessment Framework (PiiAF) Guidance [34], an initial meeting was held with members of the core PPIE group to determine how to evaluate the project's PPIE.
- Working with the core PPIE group, the PPIE Lead for the project utilised the PiiAF Guidance to develop and finalise the assessment plan.
- The patient partners and the PPIE Lead agreed on the types of evaluative questions to ask members of the wider PPIE group and the researchers who interacted directly with patient partners. These included four questions namely:
 - o In your opinion, what were the benefits of PPIE on the TLC project?

- o What were the challenges/barriers from your perspective?
 - o What facilitated your participation in the TLC project? (*patient partners only*)
 - o What could have been done differently?
- Patient partners suggested conducting focus group discussions, one-to-one interviews, and the administration of a survey to capture the perspectives of patients and researchers involved in the project.
 - The suggestions were taken on board. An initial group discussion was conducted with patient partners, and six structured interviews were conducted with researchers. The PPIE Lead made notes during these meetings and the insights were used to develop a survey of key considerations for PPIE which subsequently informed the design of two checklists [14].
 - The feedback from the patient partners is reported in Table 2.

Reporting of PPIE

We reported PPIE for the project using the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist [35]. As it is often challenging to determine whether a particular PPIE activity has led to an impact, we chose to report together the outcomes and impacts of PPIE for the project. We used the stages of the research cycle as described in the NIHR Handbook for Researchers as a framework for reporting the outcomes and impacts of PPIE for the project [36].

Challenges

We encountered some of the challenges with PPIE recently reported by the NIHR [37]. These included:

- (i) *Representativeness of patient partners*: Due to the lockdown restrictions to combat the COVID-19 pandemic, we were unable to approach potential patient partners in person within the local Birmingham community. In person community recruitment drives might have facilitated the recruitment of more men and individuals from ethnic minority groups.
- (ii) *Impact of medical condition on patient partners' ability to be involved*: Long COVID is a debilitating condition associated with several symptoms including fatigue and breathlessness. For some patient partners their symptoms fluctuated substantially making it challenging for them to join meetings sometimes. To address this, we kept PPIE meetings to a maximum of one hour duration and introduced breaks during meetings.

Table 2 Patient partners’ assessment of PPIE for the TLC project

Category	Quotes from patient partners
Early involvement	<p>"I mean, we can add in certain things that you all might miss out because we know certain things that you might miss out so, I think that an early time is better to get involved in it by giving a little bit of suggestion where you don't have to revisit it later on"</p> <p>"...involve PPI from the very beginning, don't bring us in halfway, it's a little difficult to grasp what's going on so, bring us in at the very beginning while you are writing your plans you know, for the projects."</p>
Tangible outcomes and impacts	<p>"...I can see how I have changed a particular design study because I can see comments that have been integrated..."</p>
Assistance with recruitment	<p>"...I remember the recruiting part, recruiting participants so, that is when you ask us, but you could ask us from the beginning as well because we have long, as patient partners, we have most of us, would have long Covid and we are in a support group..."</p>
Practical initiatives	<p>"We realise as well having Zoom, it takes a lot out of you so, we introduce a five-minute break [yeah] during an hour of the Zoom."</p>
Training	<p>"I think I have learnt a lot and I think yeah, it's kind of forming it as you go along, but having that kind of at the front thinking, what is this going to be?"</p> <p>"maybe when you set the objectives out according to your research you would probably be able to mentor, put a mentor with new PPI's so, that everyone is singing from the same hymn sheet, basically [okay]. You know so, if we had like for example, said she's yeah, like a buddy system or if you don't want to team us up then, if there is someone we can go to if something is bothering us, we could say well, there is a point of contact for that"</p>

(iii) *Maintaining continuity over time:* As time passed, some patient partners recovered enough to return to work and so were unable to participate regularly. We gave such individuals the option to contribute via emails and recruited new patient partners over time.

Other challenges worth mentioning include:

- (i) *Current legislation on the reimbursement of PPIE:* Whilst participation in PPIE activities is not classified as employment, there was a concern that for patient partners receiving welfare benefits, reimbursement for PPIE may affect their benefit claims. Especially for those in the core group and the co-production team who contributed frequently on a regular basis. Therefore, there is a need for researchers to check and follow the latest guidance from the NIHR and His Majesty's Revenue and Customs (HMRC) and for patient partners to clarify their position with the Jobcentre Plus before accepting reimbursement.
- (ii) *Reliance on video platforms due to the COVID-19 social restrictions:* Some patient partners used online video conferencing platforms for the first time when they joined the PPIE group and initially struggled with the technology. One-to-one support from the researchers and continued use helped to address these issues. There were also difficulties with patient partners downloading and inserting their feedback and comments directly into Word documents. To address this, patient partners were provided with support and reminded of the options to give their feedback either in the body of an email reply or verbally if they preferred.

Discussion

The implementation of PPIE for the TLC project provided a valuable opportunity for patients to shape the design, conduct and dissemination of the research findings. The contributions of our patient partners clearly had substantial impacts on the project outputs.

Other studies have reported the importance of patient input in the research cycle. For instance, Leggett et al. [38] highlighted the need for patient input in the design of participant information sheets. It is important that these patient-facing documents are written in plain language to optimise study recruitment and participation. The study confirmed our findings on the initial difficulties and discomfort patient partners had with the use of virtual platforms for meetings instead of face-to-face meetings. It also highlighted the need for research teams to build trust through effective communication with patient partners, study participants, and the general public. For the TLC project, maintaining a continuous flow of communication with the public was particularly challenging during the early stages due to time and resource constraints.

Despite the challenges we encountered with conducting PPIE virtually, we were able to obtain valuable insights from our patient partners. Feedback from patient partners was that they preferred the virtual interactions once they got used to the format as their debilitating symptoms would have made travelling for in-person meetings difficult. They also felt they had a high risk of re-infection with COVID-19 and so limited their movements even when social restrictions were lifted. Jones et al. [39] provided some recommendations to enhance remote working with PPIE members that complement the ones provided in our previous article. These include

considering the individual needs of public contributors when planning meetings and covering small expenses such as phone, electricity or WiFi charges in addition to reimbursement for their time [39].

Our experience with the implementation of PPIE for the TLC project highlights the need for and the potential challenges with achieving diversity among PPIE members. Diversity among patient and public contributors is an important step in addressing the existing inequalities and underrepresentation of minoritised groups in healthcare research. It is therefore essential that the demographic characteristics of patient and public contributors and their contributions are proactively monitored during the research cycle and necessary steps taken to address issues related to diversity and representation [40]. The evaluation of PPIE practice should be conducted with patient and public partners through an inequalities lens to provide a deeper reflection on the impacts of PPIE initiatives on diversity in healthcare research [41]. Whilst we utilised a combination of recruitment channels to enhance diversity for the TLC project, our patient partners were mostly White women [40]. The social restrictions in place when the project began prevented us from doing community outreach which might have assisted with the recruitment of more individuals from ethnic minority groups.

Whilst the use of implementation frameworks such as the Consolidated Framework for Implementation Research (CFIR) might have some benefits for the evaluation of our work, we did not utilise any of these due to several reasons. First, most of the commonly used frameworks were not designed for the evaluation of PPIE and therefore had several elements that are not relevant. For instance, the CFIR often used within healthcare settings for the evaluation of interventions has several domains that are not relevant to PPIE work including Innovation domain, Outer Setting domain, Roles subdomain, and the Outcomes Addendum. Second, we needed to use methods that our patient partners would understand which would not be burdensome for them especially given their issues with fatigue and brain fog. Third, there were time constraints to complete the project as scheduled. We used the Public Involvement Impact Assessment Framework (PiiAF) Guidance which was purposely designed for the assessment of PPIE work [42], less burdensome for our patient partners, and widely used by other researchers [42–45].

Conclusions

The implementation of PPIE led to substantial impacts for the TLC project. However, we faced some challenges some commonly experienced by healthcare researchers and some directly linked to the social restrictions

due to COVID-19. Other researchers may draw on our experiences of implementing PPIE for future healthcare research.

Abbreviations

CPRD	Clinical Practice research datalink
GP	General practitioner
GRIPP	Guidance for reporting involvement of patients and the public
HMRC	His Majesty's revenue and customs
NHS	National health service
NIHR	National institute for health and care research
PCR	Polymerase chain reaction
PiiAF	Public involvement impact assessment framework
PIS	Patient information sheet
PPIE	Patient and public involvement and engagement
SBQ-LC	Symptom burden questionnaire-long COVID
TLC	Therapies for long COVID in non-hospitalised individuals

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Author contributions

OLA, MJC conceptualised the reporting of PPIE for the TLC project. OLA drafted the manuscript. All authors read, provided feedback, and approved the final manuscript. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care or UKRI.

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Availability of data and materials

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This project was approved by the HRA and the West Midlands Solihull-Research Ethics Committee (IRAS project ID:296374; REC reference: 21/WM/0203).

Consent for publication

Not applicable.

Competing interests

OLA receives funding from the NIHR Birmingham Biomedical Research Centre (BRC), NIHR Applied Research Collaboration (ARC), West Midlands, NIHR Blood and Transplant Research Unit (BTRU) in Precision Transplant and Cellular Therapeutics at the University of Birmingham and University Hospitals Birmingham NHS Foundation, LifeArc, Innovate UK (part of UK Research and Innovation), The Health Foundation, Gilead Sciences Ltd, Merck, Anthony Nolan, GSK, and Sarcoma UK. He declares personal fees from Gilead Sciences, Merck, Innovate UK, and GSK outside the submitted work. SEH receives funding from the NIHR Applied Research Collaboration (ARC), West Midlands, NIHR Blood and Transplant Research Unit (BTRU) in Precision Transplant and Cellular Therapeutics at the University of Birmingham, and Anthony Nolan. SEH declares personal fees from Cochlear Ltd and Aparito Ltd outside the submitted work. CM receives

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