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Creating the conditions for meaningful and effective PPIE in community-based public health research: learning from a UK-wide lived experience panel

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Abstract

Background Research has been criticised for its extractive nature, often neglecting to reciprocate benefits to the communities involved. Addressing this, Patient and Public Involvement and Engagement (PPIE) has emerged as a crucial approach, engaging community members as research partners rather than subjects of research. However, it is important that PPIE is carried out in a meaningful way to avoid tokenism and extraction from communities. This paper reflects on the learning from the PPIE approach of the CommonHealth Assets (CHA) project, which partnered with 14 community-led organisations (CLOs) across the UK to evaluate their impact on health and wellbeing in their communities.

Main body The CHA Lived Experience Panel (LEP), comprised of around 13 individuals from the project-partnered CLOs, played a pivotal role in informing and influencing the research process to enhance the relevance and impact of the CHA project. Following community engagement resources, we aimed to create a supportive and inclusive environment for meaningful PPIE. Through the evaluation of the CHA LEP, this paper reports on its successes and limitations to offer recommendations on creating the conditions for meaningful and effective PPIE in community-based public health research.

From our evaluation, we found that adequately resourcing PPIE is crucial to its success. PPIE activities require a dedicated facilitator with expertise in working with diverse stakeholders to advocate for the sustained integration of PPIE into the research team, and to support contributors in their engagement. Being adaptive and responsive in your approach, utilising continuous evaluation and accountability in the process is also key. For contributors to have a meaningful impact, they must be engaged from the funding application stage and throughout the early stages of the project. Contributors must work closely with members of the research team at all levels, with researchers committing to facilitating authentic involvement of contributors, accessing training to work with diverse communication needs where required.

Conclusion Our findings demonstrate that meaningful and effective PPIE requires a strong, sustained commitment to valuing and integrating patient/public perspectives in research. We add to the knowledge base in this area by offering a practical example of implementing PPIE in community-based research settings.

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Plain English summary

This paper sets out ways to achieve meaningful Patient and Public Involvement and Engagement (PPIE) in community-based research.

PPIE is a way for communities to influence the design, delivery and outputs of research. PPIE improves research by making sure it is relevant and impactful. It is a way to ensure that research takes account of community expertise. To work well, PPIE must be a genuine collaboration that values lived experience alongside academic knowledge. Based on learning from the CommonHealth Assets (CHA) project, we make recommendations about the conditions needed for meaningful and effective participation. Building trust and balancing power dynamics between the research team and the PPIE panel are key. We recommend a dedicated, skilled PPIE facilitator to support the panel. In our project there were limited opportunities for PPIE at the funding application stages, which meant limited impact on the study design. More time for the senior team and researchers to work with the LEP would have strengthened our approach.

Background

Research is often criticised for its extractive origins of taking from communities, without giving back to them [1]. The subjects of research are viewed as those to be studied, rather than experts of their own circumstances and knowledge producers in their own right. This can lead to poorer quality, less impactful research due to the potential risk of overlooking critical aspects of the phenomenon in question and failing to align with the priorities, perspectives, and lived experiences of the community of interest [2, 3].

Patient and Public Involvement (PPIE), described by NIHR INVOLVE [4] as *"research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"*, is therefore vital in changing the historic extractive culture of research. Besides an ethical obligation, involving patients and members of the public in research has been shown to improve the quality, relevance and impact of research [5–8], as well as serving the broader democratic principles of citizenship, accountability and transparency [2, 3].

Effective PPIE benefits research by bringing alternative perspectives and experiential knowledge to the research design and conduct, as well as to the analysis and interpretation of findings. It provides important insights that can be missed from a reliance on evidence from literature reviews and commonly used data collection methods such as participant interviews and surveys. Evidence supports claims that PPIE aids researchers to gain an informed understanding of the context that the research is situated within, and the context of the data that is being collected, helping to produce findings that are more aligned with public interests and concerns [2, 3, 6, 7]. Patient/public contributors can also act as research champions or ambassadors, who can share and promote findings to audiences beyond academic, professional and clinical circles, and who can promote engagement and participation in research to the target community, as they are usually embedded within this [2, 3, 7].

Principles of effective PPIE

Despite growing recognition of the value of PPIE [8] the term encapsulates many approaches and varying levels of participation [2] ranging from advisory roles, where contributors provide feedback and guidance to the research team, to co-production roles, where contributors work with researchers to co-design and deliver the project from the outset [5]. The success of PPIE rests in part on the redistribution of power in research. The approach taken must support contributors to effectively engage and exert influence in the research process [2, 3, 7, 8]. For PPIE to act as a way of democratising research and valuing communities as experts in their own right, and to enable meaningful engagement, researchers, institutions and gatekeepers need to give up power. Furthermore, attempts to promote equality in knowledge production should not be diminished by relying on volunteers who are often under-remunerated for their efforts. Both the Scottish Government [9] and NIHR guidance recommends that non-academic contributors in research should be remunerated for their time and expertise appropriately, especially when working with marginalised communities [10].

To fully embed and value PPIE there is an additional responsibility of researchers to ensure that the community being researched, and the contributors involved, will benefit from the planned research [11]. PPIE activities should be meaningful to both groups, as well as to the wider research community [12]. Although the primary aim of PPIE is to bring benefits to the research (i.e., improve its quality, relevancy and impact), when PPIE is implemented well, there can also be direct benefits for contributors.

Wearn et al. [3] conducted a rapid systematic review of 19 research papers evaluating PPIE in health and social care research in the UK to assess the evidence-base around the contextual factors required, experiences within, and outcomes of PPIE. This review reported that people, participating in PPIE activities built skills and confidence, improved their knowledge on research and provided experiences beneficial to future employment and education. The papers were selected based on the quality of their evaluation of PPIE activities. Research conducted within clinical settings were excluded due to the specific barriers and facilitators to involvement in this area (e.g., ethical processes for controlled drug trials). The small number of studies included in this review highlights the lack of rigorous evaluation of the process and outcomes of PPIE in health and social care research, conducted in non-clinical settings, in the UK [3].

In clinical research settings, similar findings were reported by Ashcroft et al. [11], who explored the impact of involvement in research on patients and carers across eight diagnostic research specialties. Across these studies, a significant majority of respondents reported that PPIE had a positive impact on their lives. The benefits of PPIE included helping contributors to foster an improved relationship with their illness, and a new sense of purpose and outlook on their situation. However, negative impacts on contributors have also been reported, such as feelings of further marginalisation, when expectations on involvement are not met, when there is a lack of transparency in the PPIE process, and when research materials and activities are not communicated in an accessible way to contributors [3].

This research reinforces the importance of the design and delivery of PPIE. To redistribute power, it is not enough to simply involve patient/public contributors in parts of the research process– PPIE must be carefully designed and managed to avoid producing harm and distrust between communities and institutions [7].

Implementing good practice guidelines

The evaluation and review of PPIE in the literature highlights that good engagement is reliant on interpersonal factors such as trust, respect and empowerment, which requires positive relationships to be fostered between public contributors and researchers [3, 7, 13–15]. The 'Valuing All Voices Framework' [16] offers considerations for intersectional and trauma-informed PPIE, identifying trust, self-awareness, empathy and relationship-building as key principles to engaging diverse and marginalised communities in health research. These principles were identified using a qualitative descriptive approach, by five engagement groups, identified as First Nation, Inuit and Metis populations, immigrant, refugee and "newcomer" populations and people with lived experience of a mental health condition, considered to be underrepresented voices in Canadian health research.

These principles are similar to recommendations in national guidelines for PPIE, such as the UK Standards for Public Involvement [17] and the Scottish National Standards for Community Engagement [18], which provide a framework for good practice in PPIE. However, despite access to such tools, it is not always clear how to implement the guidance in practice, especially under the constraints of academia and pressures of project delivery [1, 19, 20].

Although PPIE has become widely recognised as a valuable component of health and social care research and is increasingly a requirement of research funders, the extent to which research implementing PPIE reports on its methods, outcomes and impact remains limited [2, 3, 19, 21]. Furthermore, there is a gap in the literature on implementing PPIE in public health research in community settings, beyond co-production models such as community-based participatory-action research. Many examples of PPIE in health research are conducted with patient groups, aligned to a specific health condition or experience using a specific health service. This has differing contextual and practical implications compared to working with more 'public' groups [2, 3, 7], for example, making recruitment more challenging in public health settings, as the communities of interest may be more widely dispersed and diverse rather than being a tightly defined diagnostic 'patient' group [6]. To address the gap in the literature on PPIE undertaken in this context, this paper will explore the design and implementation of the CommonHealth Assets (CHA) Lived Experience Panel (LEP).

CHA is a research project, investigating the role of community-led organisations (CLOs) in improving health and wellbeing for communities in disadvantaged areas [22]. This paper draws on the experience and evaluation of the CHA LEP, comprised of participants from different community-led organisations partnered in the research based across England, Scotland and Northern Ireland. Although members of the LEP have the common experience of participating in, and benefiting from activities at community-led organisations, these organisations are different in structure, size, activities and location. Additionally, LEP members represent various experiences and identities outside of their participation in CLOs. These differing contextual factors require additional support to manage to ensure that contributors feel able to participate fully and comfortably with one another.

Reflecting on learning from the process evaluation of the CHA LEP, this paper highlights key considerations and recommendations for creating the conditions for meaningful and effective PPIE in a complex, multi-site, community-based research project, contributing to the gap in the literature in learning from PPIE in this context.

Establishing a PPIE approach

PPIE and community collaboration and engagement were key components of the NIHR funded CommonHealth Assets (CHA) project, which partnered with 14 CLOs from Bournemouth, East London, Glasgow and Lanarkshire, and Northern Ireland (Belfast, Derry and Fermanagh). In CHA, a realist economic evaluation approach has been taken, looking at what activities in CLOs work to improve individual health and wellbeing, for whom, under what circumstances, how and at what costs [23] - contributing to the evidence base on the impact of the work and activities of CLOs, which are regarded as highly complex forms of 'intervention' [24, 25]. CLOs have contributed directly to the project through staff and participant interviews, workshops and surveys and through a range of participatory methods, including participatory photography and Q-methodology, as described in Baker et al., 2022 [22].

Central to this collaborative approach is the CHA Lived Experience Panel. The Panel intended to provide a mechanism and platform for participants from the project partnered CLOs to have a direct link and involvement in the research. This included to shape, inform and influence the project design, methods and interpretation, and dissemination of research findings. This aimed to ensure that the research was grounded in the reality of how CLOs operate, and how they can support community health and wellbeing, and inform policy development.

CHA-partnered CLOs were approached to identify participants from their organisations who would be suitable and interested in taking part in the LEP. CLOs were asked to recruit contributors who would be comfortable sharing their thoughts in a group setting, who could listen to different ideas and opinions and who would be willing to travel across the UK for meetings. All 14 partnered CLOs were approached for recruitment in the aim of equality in geographical representation from the project sites. Interested individuals were provided with a participant information sheet and were put in contact with the LEP lead facilitator (MA) to discuss further. By June 2022 13 contributors were recruited, from 8 of the 14 partnered CLOs; Annexe Communities in Glasgow [26], Healthy Valleys in Lanarkshire [27], Colin Neighbourhood Partnership in Belfast [28], Bogside & Brandywell in Derry [29], The Oak Health Living Centre in Fermanagh [30], Vita Nova in Bournemouth [31], Poole Communities Trust in Poole [32], and Poplar HARCA [33] and Bromley by Bow [34] in London. Despite attempts, recruitment of Panel members was unsuccessful in 6 of the project partnered CLOs due to identified individuals being unable to join due to existing commitments. Other than location we did not target particular demographic characteristics in the Panel; but participation from underrepresented communities (i.e., racialised communities and disabled communities) and from individuals who had limited access to other opportunities within the CLOs was encouraged during recruitment conversations with CLO staff. This included recruitment of men who CLO staff reported would be less likely to volunteer for such activities than women. The demographic characteristics of the LEP are detailed in Table 1.

The recruitment approach recognises that CLOs' selection of possible LEP participants may have affected recruitment and the range of perspectives represented in the Panel. As partners in the CLOs might be more likely to approach participants they know well, and who they judge would be interested/able to participate effectively, others not as visible to CLO staff may have missed out on the opportunity. Despite this limiting the sample, it also brought benefits in ensuring that those recruited had knowledge and experience within their CLOs and were known to be reliable and willing to participate in such activities.

The CHA LEP approach was informed by the Scottish National Standards for Community Engagement [18], the UK Standards for Public Involvement [17] and the What Works Scotland Public Engagement Handbook [35] which highlight important considerations for meaningful engagement, including the creation of an inclusive and supportive environment and utilising co-facilitation and co-delivery methods to redistribute power in participation. Activities and initial session ideas were taken from the Scottish Community Development Centre (SCDC) Health Issues in the Community Course (HICC), a programme "*aimed at increasing community capacity, increasing community participation, and establishing/consolidating community development approaches to tackling inequalities in health*" [36].

In the development of the approach, an engagement plan was created following recommendations from the above resources. Staff at the CLOs were then consulted with and feedback was sought on the appropriateness of the plans for engagement.

A total of five LEP full day in-person meetings and three half-day online meetings, were held between July

Table 1 Demographic characteristics of CHA LEP members

	Categories	Number of Panel members
Gender	Female	6
	Male	7
Ethnicity	White British/Scottish/Irish	10
	Asian British	1
	Black African/Black British	2
Age	18–30	1
	30–45	5
	45–65	5
	65 +	2
Location of residence	Northern Ireland	2 Belfast 1 Derry 1 Fermanagh
	Scotland	2 Glasgow 1 South Lanarkshire
	England	3 East London 2 Bournemouth
Urban/Rural residence	Urban	9
	Rural	4
Disability status	Disabled	8
	No disability	5
	Unknown	3
Employment status	Unemployed	3
	Studying	2
	Retired/medically retired	4
	Employed	1
	Self-employed	1
	Unknown	2
Formal education level	Secondary school	4
	College/Further education	5
	University	2
	Postgraduate	1
	Unknown	3

2022 and October 2024 (Table 2) to ensure that community voice, expertise and perspective could inform and influence the development, establishment and implementation of the CHA project. In addition to formal LEP meetings (Table 2), regular catch-up and project update meetings, and learning and development opportunities were also held online throughout the duration of the project. For example, the Panel took part in workshops with arts and heritage charity Magic Torch Comics [37] to develop a comic to illustrate the CHA project Programme Theories, using their experiences within their local CLOs. This provided an accessible and engaging way to disseminate the project findings to community audiences.

Details of the attendance of CHA project researchers at each meeting are provided in Table 2 to provide insight on the involvement of the wider research team in LEP activities.

Evaluation of approach

The evaluation of the CHA LEP aimed to assess the impact of involvement in the Panel on its contributors, and the impact that the Panel's involvement had on the methods, interpretation of research findings and outputs of the CHA project. The CHA LEP evaluation plan has been published for further reading [38]. This paper will focus on the evaluation of the design and delivery of the CHA LEP, rather than its outcomes, to share insights on implementing PPIE in community-based public health research contexts.

Evaluations of the LEP were conducted and published online at key time points of the project—at baseline [39], at the project mid-point [40] and following the final LEP

Table 2 Overview of LEP meetings

Meeting date and location	Researcher attendance	Project-related activities	Group activities
July 2022, three online meetings	Researcher (Bournemouth) Researcher (Glasgow) PhD researcher (Bournemouth) Coinvestigator (Glasgow) Principal Investigator (Glasgow)	• Introducing the CHA project and its methods • Providing training and activities related to key concepts related to the research (e.g., social determinants of health, assets-based approaches and the different models of health) • Meeting the project team • Advising on the delivery of the CHA longitudinal survey	• Introductions and ice breaker activities • Creating a Working Together Agreement • Activity to share individual hopes and concerns for involvement • Post-meeting feedback form
November 2022, Glasgow	Researcher (Glasgow) Researcher (London) Researcher (Belfast)	• CHA project updates • Introducing programme theories and their role in CHA • Activity to identify 'programme mechanisms' from stakeholder interview transcripts and images from participatory photography – to inform the development of programme theories • Baseline evaluation	• Group dinner • Tour and introduction to Annexe Communities, Glasgow • Group visit to Kelvingrove Museum, Glasgow • Post-meeting feedback form
May 2023, London	Researcher (Glasgow) Coinvestigator (Belfast) Researcher (London) Researcher (Bournemouth) Researcher (Belfast)	• CHA project updates • Programme theories development – Two activities to interrogate how CLOs provide benefit to individuals under certain contexts, and the effect that different activities and conditions of CLOs have on individuals	• Group dinner • Tour Bromley by Bow Centre, London • Sharing of updates from Panel members respective CLOs • Post-meeting feedback form
October 2023, Belfast	Researcher (London) Researcher (Bournemouth) Researcher (Glasgow) Researcher (Belfast) Researcher (Belfast) Principal Investigator (Glasgow)	• CHA project updates • Programme theories development – activities to aid the researchers' understandings of programme and contextual mechanisms • Reviewing draft of the participant interview topic guide • Midway evaluation of LEP	• Free time to explore Belfast • Group dinner • Tour of Colin Neighbourhood Partnership, Cloona House, Belfast • Sharing of updates from Panel members respective CLOs • Mid-way evaluation feedback form
March 2024, Bournemouth	Researcher (Bournemouth) Principal Investigator (Glasgow)	• CHA project updates • Review of statements for the CHA Q study • Review of draft programme theories diagrams	• Group visit to Bournemouth pier and gardens • Group dinner • Sharing of updates from Panel members respective CLOs • Performance of 'The Nest' a play by Vita Nova • Post-meeting feedback form
October 2024, Glasgow	Researcher (Glasgow) Coinvestigator (Glasgow) Principal Investigator (Glasgow) Coinvestigator (Glasgow)	• Overview of CHA project and re-cap on aims and ambition of LEP • CHA progress and initial findings update • Activity to aid in the interpretation of data from questionnaire study • Activity to aid in the interpretation of initial findings from Q study • Final LEP evaluation	• Group dinner • Sharing of updates from Panel members respective CLOs • Guided tour of University of Glasgow and Mackintosh House • Group dinner • End of Panel evaluation form
June 2025, online	Full CHA research team	• Sharing of findings • Sharing of project output dissemination plans	

meeting—in addition to continuous evaluation undertaken throughout the duration of the Panel to assess the effectiveness of engagement methods, facilitation and communication. Continuous evaluation ensured that ongoing learning and improvement was fostered in line with the Scottish National Standards for Community Engagement [18] which guided our PPIE approach (Table 3).

Table 3 Evaluation of the CHA LEP against the Scottish National Standards for Community Engagement

National Standard	Aim	How data was collected for evaluation
Inclusion	Identify and involve the people and organisations that are affected by the focus of the engagement, including identifying and involving marginalised groups and those with opposing views	Notes on recruitment and selection criteria were recorded. Demographic information was collected about Panel members throughout the project. The range of perspectives represented were recorded in facilitator diaries and meeting notes.
Support	Identify and overcome any barriers to participation	Potential barriers to participation were recorded along with steps taken to overcome them. Individual support needs of each Panel member were assessed and recorded, along with actions taken to accommodate these. Questions relating to the support provided to the Panel were included in the mid-way and end of Panel evaluations.
Planning	Ensure a clear purpose for the engagement, based on a shared understanding of community needs and ambitions	Feedback, from staff at CLOs, on the engagement plan for the LEP was collected and recorded. The hopes and concerns of Panel members, for their involvement in the CHA project, were recorded at the outset of engagement and revisited following the first Panel meeting, and at the mid-way and end points of the project. Panel members contributions to the design of LEP meetings and activities, were recorded on the PPIE Impact Record Form.
Methods	Ensure methods of engagement are fit for purpose	Feedback was collected from Panel members relating to the engagement methods used, and activities delivered in each meeting. Challenges within engagement, and engagement levels amongst Panel members were noted in facilitator diaries following each meeting. The engagement methods used and the Panel's responses to these were recorded in meeting notes.
Communication	Ensure clear and regular communication with the people, organisations and communities affected by the engagement	Feedback was collected from the Panel on communication methods and information access, using feedback forms at each meeting and mid-way/end of project evaluation forms. Feedback from the LEP and actions taken as a result, with rationale, were recorded on You Said, We Did logs and communicated to LEP members.
Working Together	Ensure the research team and LEP can work effectively together to achieve the aims of the engagement	Decision making processes were recorded and communicated through the design of the CHA 'feedback loop'. LEP input into the CHA project was tracked using an Impact Record Form and meeting notes. Feedback on the communication, support and information sharing between the research team and Panel members was recorded within feedback forms at each meeting and within the end of Panel evaluation forms for researchers and LEP members. Feedback on the perceived impact of the LEP on the CHA project was collected through evaluation and feedback forms.
Impact	Assess the impact of the LEP and use our learning to improve future community engagement	Feedback from Panel members following each LEP meeting was used to inform the engagement approach throughout. Learning on the design and delivery of the LEP was recorded and shared publicly throughout, via blogs, videos and reports, and presentations at CHA research team meetings on the progress of the LEP. Overall impact of the LEP on the CHA project, and the impact of involvement on LEP members, was assessed using feedback forms and evaluation forms. Impact of the LEP on the delivery and outputs of CHA was also recorded within meeting notes and on the Impact Record Form.

Evaluation was informed by feedback provided by the Panel on the delivery of the LEP, through feedback forms administered at the end of each Panel meeting [see Additional file 1] and through evaluation forms administered at key points of the project, as described. At the final Panel meeting (October 2024), evaluation forms were completed by both Panel members [see Additional file 2] and project researchers [see Additional file 3] to gain additional insights.

Responses from feedback and evaluation forms were collected anonymously and analysed thematically by reviewing responses and grouping them according to recurring themes, without formal coding to allow for flexibility and ease in analysis. This approach allowed for an intuitive identification of key patterns within the data while maintaining the qualitative depth of individual perspectives. The themes identified in analysis are listed as subheadings under ' Successes in our approach' and ' Limitations of our approach'.

A 'You Said, We Did' log was updated after each meeting to respond to the Panel's input into aspects of the CHA project [see Additional file 4]. This was a key method of communication between the LEP and wider research team, implemented as part of the CHA feedback loop (Fig. 1).

To monitor and evaluate the impact that the Panel had on components of the CHA project, responses from the 'You Said, We Did' log were collated on an Impact Record Form [see Additional file 5] [41]. This form, in addition to the collated feedback from the Panel and project researchers, aided the assessment of the impact of the CHA LEP, informing the end of project LEP evaluation, which was completed in accordance with the Guidance for Reporting Involvement of Patients and Public (GRIPP2) Short Form [see Additional file 6] [42].

This paper will draw from the evaluation methods used within the CHA LEP to describe and reflect on our implementation approach, highlighting considerations for creating the conditions for meaningful, effective PPIE in complex, multi-site, public health research undertaken in community settings.

Successes in our approach

From the thematic analysis of feedback and evaluation form responses, key themes related to the successes of our PPIE approach were identified. These are described under the subheadings below—trust and relationship building, managing power dynamics, high level of resource allocation and mutually beneficial engagement.

Trust and relationship building

The evaluation of the CHA LEP highlighted that the relationships built between Panel members, and between the Panel and facilitators, was crucial to creating an environment where members felt able to contribute effectively.

> *"I made new friends that made me feel part of a family." [LEP member 007]*

Building relationships and trust was a priority from the outset of the LEP as contributors were recruited from different areas across the UK and together represented various backgrounds and experiences. It was recognised that to mitigate any potential tensions and to promote good participation within this group dynamic that strong foundations of trust and respect would be required to enable contributors to effectively engage in research activities in a group setting.

The first Panel meeting was held online, due to risks related to the COVID-19 virus at the time, and was split into three shorter meetings to allow a gentle introduction to the project and group, and to avoid 'Zoom fatigue' [43]. With an awareness of barriers of digital access and poor digital literacy skills, we worked with CLO staff to put support in place for LEP members who required it. As a result, some LEP members joined the meeting from their CLOs, which helped to make this early experience less daunting.

Furthermore, to make the group feel comfortable in a virtual space when meeting for the first time, we sent out a welcome pack to each Panel member which contained a welcome letter, information sheet about the project, a notebook, pen and tea bags and biscuits, in an attempt to create a relaxed, welcoming environment and emulate the feel of an in-person meeting. Time was also dedicated to social elements, creating space for members to get to know one another and the communities each person was situated within, using ice breakers and group activities. One activity was focused around finding commonalities in the CLOs that each individual participated in, which helped the Panel relate to one another and identify shared experiences. Other activities included, co-creating a 'Working Together Agreement' [see Additional file 7] to give the group the opportunity to share what they needed in the space to feel comfortable and to set expectations with one another, and a discussion around the hopes and concerns each member had for their involvement. These activities also helped to convey genuine care about the Panel's needs in taking part in the CHA project.

Feedback from the first meetings showed success in creating a relaxed environment where Panel members felt comfortable to participate. This was crucial in setting the tone for subsequent in-person meetings.

> *"The meeting was comfortable and enjoyable. It was good to see many shared values and that peo-*

> *ple came with open minds." [LEP member, following the first LEP meeting]*
> *"Really appreciated the diversity and genuine concern for meaningful participation as well as group bonding." [CHA researcher, following the first LEP meeting]*

These relationships were maintained in the LEP by hosting a group dinner on the evening before in-person meetings to allow the opportunity for Panel members to socialise in an informal setting, further strengthening relationships between members. The Panel were keen to maintain contact with one another between formal meetings, therefore a WhatsApp group was created for informal communication and information sharing between Panel members. Online catch-up meetings were held every 4–6 weeks, where brief progress updates on the project were shared, and where Panel members could share personal and CLO-related updates.

The facilitation style and personality of the LEP facilitator was also described as important to the Panel in aiding their participation and enjoyment, in particular giving time for people to think and respond at their own pace.

> *"...the first meeting on Zoom I remember I was nervous, I was just sitting listening. I was happy that [the Panel facilitator] didn't push anyone to answer, [she] let people talk about their experiences at their own pace." [LEP member 004]*
> *"[The facilitator] is amazing and very supportive and understanding about people 10/10." [LEP member 004]*
> *"... [the facilitator's] calming personality makes me slow down my thinking to participate more thoughtfully." [LEP member 007]*

The facilitator made a deliberate effort to be aware of dynamics in the group and to encourage participation from those who appeared less confident to speak. It was explicitly communicated and reiterated that there were 'no wrong answers' and that all opinions were valued throughout. Communication was also adapted to suit individual's needs, which were identified during one-to-one meetings with each Panel member upon recruitment. For example, one Panel member struggled to communicate via email, so the facilitator communicated important information to this member via regular telephone calls and text messages.

Our emphasis on providing tailored support and fostering strong relationships within the Panel helped to build trust and create positive working relationships between Panel members, and between the Panel and project researchers.

Managing power dynamics

Power dynamics within the CHA LEP and wider research team were managed through fostering ongoing evaluation, accountability and transparency in our approach to ensure that the Panel felt valued and understood how their involvement was contributing to the CHA project.

Accountability and transparency were embedded by implementing a feedback loop (Fig. 1) which detailed how input from the Panel would be recorded, used and responded to by the research team. The Panel's feedback and input into different components of the research was recorded on a 'You Said, We Did' log after each meeting [Additional file 4], which detailed how project researchers utilised LEP feedback and the resulting actions. If no action was taken, researchers were required to provide justification. Panel members fed back that this approach was useful in ensuring transparency in the LEP.

> *"I think the researchers have been quite diligent in their feedback of how they have incorporated our suggestions. The you said we did summaries have been quite useful." [LEP member 003]*
> *"I feel that everyone's opinions have been taken on board and relayed back to us all in clear formats for us to see." [LEP member 009]*

The impact recorded was then entered into an Impact Record Form [Additional file 5] which allowed the involvement of the Panel in CHA to be monitored and assessed over time. This enabled signs of tokenistic involvement to be identified so that more meaningful engagement could be advocated for by the Panel facilitator.

Furthermore, in addition to the facilitators of the LEP, the CHA project's Principal Investigator and project researchers attended and contributed to each Panel meeting, including the group dinners (Table 2). This helped to further balance power dynamics as having the opportunity to have informal conversations, and for the research team to directly interact with the Panel, helped to mitigate an 'us vs them' divide which can be present between 'professionals' and PPIE contributors [44].

> *"...[I] had several side conversations with the project PI where she seemed genuinely interested in my input." [LEP member 003]*

The relationships fostered between CHA researchers and Panel members also promoted greater engagement and involvement from research participants at each project site. The role of Panel members as gatekeepers of knowledge and contacts within their communities, also helped to shift power in this setting.

Panel members, in rotation, represented community voice and perspective on the CHA Study Steering

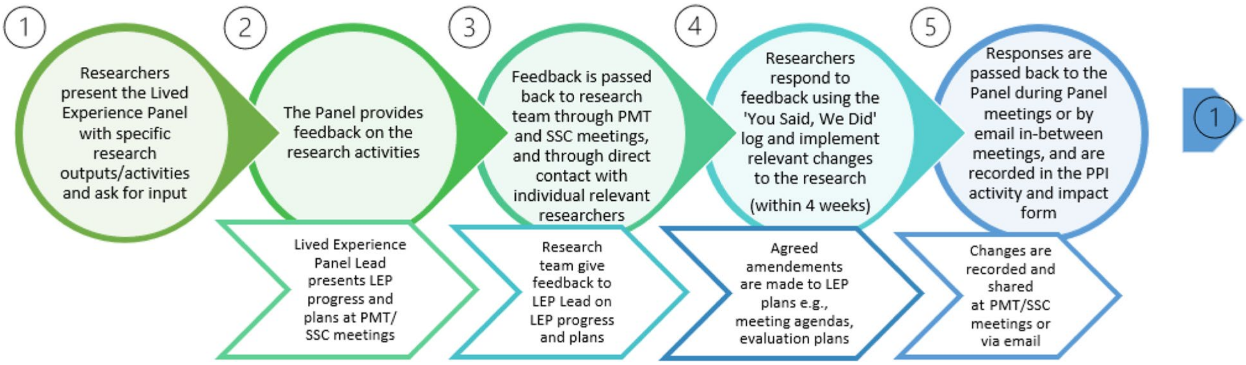

Fig. 1 The CHA LEP Feedback loop

Committee, supported by the LEP facilitator, and were also invited to Full Research Team meetings, where they could meet members of the CHA wider research team. This space for ongoing interaction and engagement with extended members of CHA teams ensured that the Panel felt, and were regarded as, an integral and valued part of the project.

> *"As a member of the Panel we all connected well with the researchers we came in contact with. Having representation on the steering group also allowed for more connection." [LEP member 005]*
> *"I feel like being part of a team working towards common goals." [LEP member 007]*

In addition, Panel members had the opportunity to shape and inform the content, delivery and design of Panel meetings through their feedback. We were flexible in our approach to respond to the needs and requests of the Panel, which further demonstrated the value of their involvement.

> *"Yes I think [facilitator] integrated our suggestions really well and was very responsive and dynamic in this respect." [LEP member 003]*
> *"My needs are met and what I said matters and was taken on board throughout." [LEP member 007]*

A payment of £150 per day for attendance and participation at each full-day meeting was provided to Panel members in line with NIHR guidance [10]. This was an important aspect of redistributing power in the PPIE process, demonstrating appreciation and recognition of the Panel's expertise and experience as a valuable and valid form of research knowledge and insight. Panel members reported that they felt adequately, or more than adequately, compensated for their time and expertise.

> *"The vouchers were a great help and beyond what I initially expected." [LEP member 003]*

The accumulation of these activities helped to place value on the contribution of the LEP which helped to create a positive environment for mutual respect and collaboration.

High-level of resource allocation

A high level of financial and human resource was allocated to the CHA LEP to reduce barriers to participation and to promote mutually beneficial engagement, recognising PPIE as a core component of the project. Financial barriers to participation were mitigated by providing payment in vouchers for attendance and covering costs of childcare, caring responsibilities and any other expenses needed to attend meetings. In addition, all travel, hospitality and accommodation costs incurred during LEP meetings were met by CHA.

The high level of resource available enabled a dedicated LEP facilitator, employed and hosted by an external partner organisation, to be appointed. The facilitator was responsible for organising and delivering LEP activities and for communication with, and between, the Panel and research team. The LEP facilitator attended regular meetings with CHA researchers and Project Management Team and Full Team Meetings to gain knowledge on the progression of each component of the project and to feed in lived experience insights. They worked closely with project researchers at each site to ensure that the input of the LEP was timely to the research process, and that the information brought to the LEP was in an appropriate, accessible and engaging format.

With a professional background in public health and community engagement and development, the LEP facilitator was able to successfully relate to both the LEP members and to the wider research team, acting as a bridge between them and as an advocate for the LEP's perspective in team meetings.

Having a dedicated PPIE facilitator, whose sole responsibility was the management of the LEP, also meant that there was a strong infrastructure for engagement, as a substantial amount of time could be committed to supporting and maintaining relationships with individual Panel members and ensuring that the delivery of the Panel was well considered.

> *"Connecting with [the LEP facilitator] as a key contact has made making enquiries easier and she responded as soon as possible." [LEP member 007]*
> *"[The LEP facilitator] never gave up on me. I lost my phone went through personal issues but she persisted. Emails are hard for me but [the facilitator] text and called me." [LEP member 004]*
> *"The input benefited from ongoing engagement and leadership by [the LEP facilitator and her manager]. Previously I've seen researchers try to do this as well as the research tasks and pressures, and struggled with time and skills." [CHA researcher 004]*
> *"I appreciate that the LEP benefitted from having a dedicated staff member to provide professional support, knowledge and guidance. I think this is essential to ensure its effectiveness and unique value." [CHA researcher 002]*

The resources allocated to the CHA LEP were integral to creating the conditions for effective engagement over time, as we were able to provide sustained, tailored support to the Panel, reimburse them for their involvement and mitigate barriers to participation. Without such dedicated resource, it would have been difficult to engage such a diverse group and to maintain such a strong connection to the Panel throughout the duration of the project.

Mutually beneficial engagement

The intention was for the LEP to be a mutually beneficial experience for Panel members and the research team. Collecting hopes and concerns, and feedback on what the Panel wanted from meetings ensured that ways to integrate beneficial activities for the Panel could be identified, aside from providing payment for their participation.

Panel members had a strong sense of pride and investment in their CLOs due to the impact that the CLOs had had on their lives. A strong motivation for becoming a member of the CHA LEP was to be able to identify additional ways to support their CLOs in their volunteer roles, and to learn from other organisations across the UK.

This ambition was supported by hosting Panel meetings at the project partnered CLO venues, and organising tours and opportunities for each CLO to showcase their work to the Panel. Time was also incorporated at the beginning of each in-person meeting, and at catch-up meetings, for Panel members to share updates about their CLOs, including information about new projects and issues they were facing. This provided a space for peer support, encouragement and advice, and provided the research team with a greater understanding of the work of the CLOs partnered in the project. From these peer-led conversations, obtaining funding emerged as a common issue shared amongst the CLOs, and an area that the Panel lacked expertise in. The Panel wished to learn more about how they could support their CLOs to apply for funding and obtain donations. In response, an external organisation was commissioned to deliver a bespoke fundraising workshop for the Panel.

The opportunity to visit other CLOs and to access peer support was reported as a highlight for the Panel in their involvement in the CHA project.

> *"I really enjoyed meeting everyone face to face. It was really helpful to hear about projects in other areas." [LEP member 001]*
> *"I have learned more about funding and how to get restricted funding. I have also learned about new ideas that are missing in our own community e.g., social café, social hub facility." [LEP member 005]*
> *"Experiencing the different communities and contexts the different CLOs work in was very interesting and having the opportunity to have a break away was appreciated and therapeutic." [LEP member 003]*

In some cases, there were Panel members who were based in the same geographical area but represented different CLOs. For these individuals, taking part in the CHA project brought an awareness of other local projects and services in the area. Connecting with others and travelling for LEP meetings also built confidence in Panel members and provided new experiences, such as taking a flight for the first time and travelling to new areas across the UK.

> *"It has made me more confident in travelling independently and I made new friends and learned a lot about myself." [LEP member 004]*
> *"Travelling to new places has been great, I would never have considered going to some of the sites, such as Bournemouth, had it not been for this project." [LEP member 005]*
> *"It has been hugely influential on my own confidence and wellbeing I've met new people been to new places and travelled both physically and mentally outside of my post-covid bubble." [LEP member 003]*

The success of our approach is also captured by the retention rate of our Panel, which saw 10 of the original 13 Panel members retained throughout the 3-year life span of the project. It was anticipated that personal circumstances might impact on commitment and interest over time, which was the reason given for the drop-out of three members early in the process.

By asking the Panel what they wanted from the LEP, and by providing relevant opportunities, we were able to create an enjoyable process for the Panel which helped to place value on their contribution to the CHA project and provided motivation for continued involvement throughout the project duration.

Limitations of our approach

Thematic analysis of feedback and evaluation form responses also revealed key themes related to the limitations of our PPIE approach. These were identified as; limited impact of the LEP, challenges of balancing time and priorities, and gaps in researcher support, as discussed below.

Limited impact of the LEP

Despite the Panel's input in multiple areas of the CHA project (as detailed in Additional file 5), feedback from CHA project researchers was mixed in terms of the impact that the Panel had on the CHA project.

> *"This is the best experience I've had of PPIE and I appreciated the input from the panel throughout" [CHA researcher 004]*
> *"At all stages it seemed to me that the ideas generated by the LEP were an important part of the team's deliberations." [CHA researcher 007]*
> *"At times I felt that not all of the research team were engaged with the LEP, or that they were at the forefront of people's minds during discussions. I'm not sure what could help this, but I think when the bid went in it could have been more to the fore in each work package, and more explicit on how the LEP would contribute or not to each bit." [CHA researcher 005]*
> *"Sometimes it felt more like a tick box that had already been decided by those running the project. No fault of LEP leads or Panel." [CHA researcher 007]*

Only one negative comment was received by the Panel however, about the level of involvement that the Panel had in CHA. This was received at the mid-way point of the project (May 2023).

> *"It might be better to have more opportunity to understand and comment on the work of the research group, sometimes [engagement] feels somewhat superficial" [LEP member 003]*

At that stage, LEP input had been limited to the initial development of the project Programme Theories, due to the period of primary data collection. This comment was fed back to the wider research team from the LEP facilitator, with the ask of more opportunities for involvement to be created. This resulted in the Panel's attendance at a Full Researcher Team meeting in November 2023 and an additional online meeting to review a participant interview topic guide in September 2023. No further feedback of this nature was provided by Panel members following these activities.

Initially it was a challenge to identify areas for meaningful input for the Panel. Contributors were recruited following the award of funding, and six months into the project duration, and so were not involved in key decisions related to the design of CHA project, and the research questions chosen and data collection methodologies used. Due to this lack of early engagement, it took time to identify appropriate opportunities for the LEP to have a meaningful impact on the project, and for lived experience voice to be heard.

Furthermore, although the project's Principal Investigator (PI) and project researchers at each site had direct engagement with the Panel at Panel meeting and through the LEP facilitator, engagement from those in project management and data analysis roles with the Panel was limited.

> *"Getting more engagement from senior members would provide some more legitimacy to the Panel for the rest of the team. At times it felt like the Researchers dealt with the Panel and fed back the discussions. Though [the project PI] got involved when she could." [CHA researcher 005]*

The lack of engagement opportunities at the early stages of the project meant that the LEP played more of an advisory role, rather than a role in co-producing the research. Furthermore, despite strong relationships between project researchers and Panel members, the Panel lacked key relationships with more senior team members, contributing to the limited impact they had on the project.

Challenges of balancing time and priorities

Balancing time and priorities of Panel meetings was another issue that arose. As there were often long travel times and high costs associated with attending LEP meetings across the UK, in the initial delivery of the LEP it was difficult to find a balance between ensuring trips were worthwhile and enjoyable whilst not overstretching capacity of LEP members. Panel members fed back that early meetings felt *"rushed"* and contained *"a lot for a single day"*. However, facilitating continuous feedback helped us to adapt our approach over time. In response to this feedback, the content of subsequent meetings was split across two days to allow more time, with Panel members arriving at the meeting location earlier. Feedback from later meetings was more positive, as more time and space for reflection and socialisation was provided.

Gaps in researcher support

Feedback provided by one of the CHA project researchers revealed a gap in support in enabling researchers to engage effectively with the LEP, as a group of individuals with diverse communication and learning needs.

> *"[The] wide range of literacy and comprehension was challenging to prepare for and engage with at times when moving from one panel member to the next. Better training in this would be helpful to anyone only used to interacting with groups who have a narrow and homogenous abilities spectrum."*
> *"Training in how to work with an engage panels would be helpful for those of us who don't routinely interact with participant stakeholders." [CHA researcher 009]*

In the planning and development of the Panel, the knowledge and skills of the LEP facilitator in working with contributors with diverse needs and backgrounds was crucial however, this was overlooked in terms of the experiences of the wider research team. The LEP facilitator offered assistance in designing project-related activities for the Panel and supported the Panel's engagement with activities at meetings, however, more support could have been provided to researchers in this area to enable them to engage with the Panel more confidently.

Discussion

This paper highlights key methodological considerations for fostering meaningful and effective PPIE in complex, multi-site, community-based public health research settings. Drawing on learning from the delivery of the CHA Lived Experience Panel, the results of our evaluation contribute to the knowledge base around implementing PPIE in this context, which as previously discussed currently remains limited. The additional files, available as supplementary material, and the CHA LEP evaluation plan [38] and CHA LEP baseline evaluation report [39], provide further resources and detail which can be adapted for use in future PPIE activities and evaluation.

Our evaluation emphasises the importance of trust and relationship building, reciprocal engagement, reducing power imbalances and adequate resourcing as imperative to effective PPIE, which echoes findings from other authors and the available literature in this field.

Having a well-resourced, dedicated PPIE delivery budget, proved to be pivotal to the effectiveness of the CHA LEP as it allowed for costs relating to access barriers, training and support, and payment for expertise to be provided. The evidence base states that for PPIE to be successful, a high level of resource must be committed to the process [12, 13, 44, 45], which this paper further supports. A dedicated delivery budget demonstrated the commitment of CHA to PPIE and its role and value within the project, and ensured an inclusive approach. There is, therefore, a need for PPIE to be adequately costed in the funding application stage to ensure that it is regarded as central to the research and not an 'add on' that is facilitated with unused, or no budget. Such allocation of resource also allows for a skilled and dedicated PPIE lead to be employed, which, as illustrated, played a critical role in the successes of the CHA LEP, and which is cited in the literature as key to improving engagement and involvement outcomes, and the experience for PPIE contributors [3, 6, 12, 45]. This resource also enables an adaptive and responsive approach to be taken to PPIE, providing the necessary capacity to prioritise building relationships and fostering an inclusive environment.

A key element of this relationship building involves building trust, which the literature highlights is facilitated through shared experiences, open communication, and the creation of 'safe spaces' where contributors feel valued and respected [7, 14, 16]. Our findings discuss the practical ways in which the CHA LEP achieved this by incorporating social elements into meetings, creating a relaxed atmosphere, setting expectations and using a responsive and friendly facilitation style. Setting a culture of transparency and openness within the LEP, through implementing processes such as the 'You Said, We Did' logs and regular feedback forms also helped to build trust between the LEP and research team by demonstrating that we cared about their experience.

These transparency processes also enhanced accountability and reinforced the value of contributors' input which aided in reducing power imbalances, and in aligning and supporting bidirectional dialogue and shared decision-making as mechanisms for promoting equitable partnerships in PPIE [12, 46]. Such practices also allowed for greater depth in the evaluation of the impact of PPIE in CHA, providing a simple tool for outcome evaluation which has been cited as lacking in the literature [7].

Furthermore, gathering feedback on an ongoing basis enabled us to identify areas for reciprocity, where we could implement support and learning opportunities that would be beneficial to the Panel. Again, through the successes of our approach we demonstrate how in addition to PPIE strengthening the research as a whole, it can also achieve positive outcomes for PPIE contributors such as increased confidence, peer-support, and increased interest and knowledge of research, as reported in the literature [3, 12].

Table 4 Lived Experience Commentary from BL

Lived Experience Commentary
As a member of the public or service user it is all too easy to feel alienated and dissociated from research being done on your community, regardless of your background or prior association with the research process. My time with the CHA LEP has done much to bridge this gap for myself and for the organisation that I represented, enabling me to genuinely feel acknowledged and empowered by the process. Initially it was easy to be sceptical about how seriously the researchers were taking the Panel, however I was impressed by the level of effort that was taken to ensure we felt integrated into the research process, from the "You Said, We Did" feedback, to regular opportunities to engage with senior research staff either in person or through Panel representation at research meetings and steering groups. As this paper describes, it was at times difficult for researchers to pitch research-related activities during meetings due to the varied needs and educational levels of Panel members. As a participant this was also something I felt at times throughout the meetings. However, potential tensions or interpersonal issues were easily relieved by jokes and banter due to the investment in ensuring we had ample time to get to know one another and develop trust and meaningful relationships outside of the formal meetings, to the extent that I have developed genuine friendships that I will take beyond the Panel. A highlight for me was contributing to the dissemination of the project programme theories, through the development of a comic, where our experiences within CLOs were used to illustrate the theories. The comics have already generated a buzz around our community centre as people read and discuss our stories. This demonstrates the value of involving community members in the preparation and dissemination of research findings, ensuring that findings are relevant to the communities being studied and can have an impact beyond academia.

Studies reporting on the limitations, challenges and negative consequences of implementing PPIE in research remain limited in the evidence base [3, 7, 19, 21]. Although a small number of negative comments on the LEP were received during delivery and in evaluation feedback, these were addressed through ongoing learning, reflection and adaptation, and in sharing the limitations of our approach to support future PPIE approaches. The constraints of our approach, as described, of engaging project management members and senior researchers, and our ability to integrate lived experience into the pre-funded phases of the project confirm the need for capacity-building amongst funders and research teams to establish PPIE as a key stage in project development and to improve researchers' ability to work effectively with contributors in community-based settings. The latter point is illustrated by Tremblay [47] who, by comparing trends in community research partnerships, reported that over 60% of contributors had rarely, or never, been involved in the grant applications for the collaborative research projects that they were involved in. This was partly due to the challenges of funding mechanisms in facilitating engagement pre-grant award. To ensure meaningful and authentic engagement with patients/public in researcher, institutions and funders must recognise and find ways to support researchers to share power to embed the voices and experiences of community members throughout the research process, from early development to completion, to strengthen the real-world relevance, quality and impact of their research.

Capacity within research teams to engage patient/public contributors can also be reinforced by the strong leadership of PPIE activities. Facilitation of PPIE requires expertise in community engagement and experience working with groups that the research seeks to involve. A skilled, dedicated PPIE facilitator enables appropriate and authentic support to be given to PPIE contributors but can also enable support to be given to the research team who may lack the experience and skills to work with diverse public groups. Providing further reflection on the CHA PPIE approach, Table 4 provides a 'Lived Experience Commentary [48]' sharing the perspective of a member of the CHA LEP (BL) in response to our findings. (Table 4).

Conclusion

The findings from this paper underscore the need for intentional and sustained efforts to ensure that PPIE is not only impactful for research but also beneficial and empowering for contributors. Meaningful and reciprocal PPIE requires more than adherence to guidelines; it demands a genuine commitment to fostering trust, ensuring mutual benefit, and addressing power imbalances. Our findings also demonstrate that meaningful and effective PPIE requires a strong, sustained commitment to valuing and integrating patient/public perspectives in research. By embedding these principles into the CHA project, the LEP provided valuable insights that enhanced the research while offering contributors a rewarding and empowering experience. This paper and our findings contribute to the growing evidence base on how to implement PPIE effectively in public health research, particularly in complex, multi-site community settings by providing a real-world example of conducting and evaluating PPIE which presents not only the successes of the approach taken but also areas of challenge and the limitations of the approach.

Future research should place a focus on capturing a greater level of transparency on the influence that PPIE contributors have had on research, and on monitoring the longer-term impacts and benefits of PPIE on contributors following completion of the project. Future work should also consider how opportunities for sustained involvement beyond the project end date can be fostered. To support the development of the literature on PPIE, further evidence is required to advocate for PPIE which is embedded and resourced in the project development and funding application stages.

Abbreviations

PPIE	Patient and Public Involvement and Engagement
CHA	CommonHealth Assets
CLO	Community-Led Organisation
LEP	Lived Experience Panel
NIHR	National Institute for Health and Care Research
SCDC	Scottish Community Development Centre
GRIPP2	Guidance for Reporting Involvement of Patients and Public
PI	Principal Investigator

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40900-025-00727-x.

Additional file 1: Example Lived Experience Panel Meeting Feedback form

Additional file 2: Copy of the Final Lived Experience Panel meeting evaluation form

Additional file 3: Copy of the end of Panel evaluation form for CommonHealth Assets researchers

Additional file 4: An example of the You Said, We Did log used to communicate feedback to the Lived Experience Panel on their input in research activities

Additional file 5: Impact Record Form detailing the input that the Lived Experience Panel had on the CommonHealth Assets project

Additional file 6: Completed GRIPP2 Short Form

Additional file 7: A Working Together Agreement co-created by members of the Lived Experience Panel

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Authors' contributions

CHA LEP design, delivery, management – J.M and M.A. Data collection and evaluation – M.A. Writing, review and editing- M.A and J.M. Conception of proposal and ideas, contribution to reviewing and editing – R.B, C.D and M.J.R. Writing of lived experience commentary – B.L. All authors read and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

The CommonHealth Assets project has ethical approval from Glasgow Caledonian University School of Health and Life Sciences Ethics Committee ref HLS/NCH/20/034. Panel members consented to participation upon recruitment and consented to the use of their feedback within reports and evaluation. They were informed that although findings would be published, all data would be anonymised and not linked to individuals.

Consent for publication

Consent for the publication of participant data (demographic information and evaluation data) was obtained from Lived Experience Panel members upon data collection.

Competing interests

The authors declare no competing interests.

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