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Negotiating pace, focus and identities: Patient/public involvement/engagement in a palliative care study

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Abstract

Patient and public involvement and engagement (PPIE) is an increasingly important component of research conduct to enhance processes and potential for impact, yet is rarely critically interrogated. This paper draws on Foucauldian analysis to highlight the disciplinary powers and tensions arising in PPIE. The paper draws on a nested evaluation interview study with three PPIE members and eight academics, who had been involved in an implementation science study focused on palliative care. PPIE members were involved in the whole study and are co-authors of this article. Through shared values and commitments to the study, a team culture of equality was developed. Yet while power was dispersed and taken-up by all team members, in so doing a self-governance approach within the team was developed. The pace and focus of discussions was at times more subjugating than co-production. Identities and positions were porous; the simplistic division of 'academic' and 'PPIE' did not stand up to scrutiny, with an

increasing blurring of boundaries as people's experiences and insights changed over time. Continual, subtle, negotiations of roles, inputs and identities were manifest throughout the project. PPIE in research involves subtle, complex and ongoing disciplinary practices enacted by all members of the team.

KEYWORDS
co-production, negotiation, palliative care, patient/public involvement and engagement, power

BACKGROUND

Patient and public involvement and engagement (PPIE) and its relationship with power is central to the sociology of health and illness (Haarmans et al., 2022; Maguire & Britten, 2018). Medical sociology has played a key role in rendering visible power relations in health-care spaces (McLaughlin et al., 2023), including whether involvement promotes compliance rather than autonomy in clinical encounters (Henwood et al., 2003) and how power inequalities operate to silence particular voices (Hodge, 2005).

The shift towards greater user engagement is rooted in both consumerism focused on service improvement, and activist movements seeking greater empowerment and more democratic transformative knowledge production (Beresford, 2020; Faulkner & Thompson, 2023). There is variation in the meaningfulness and authenticity of participation, with mechanisms ranging from more tokenistic forms of collaboration through to co-production, which requires more egalitarian power relations (Rose & Kalathil, 2019). The disability movement and mental health research have played a pivotal role in highlighting oppression grounded in hegemonic medicalised discourses and providing alternative understanding and new knowledge about people's interactions with the health and care system (Barnes, 2019; Beresford & Rose, 2009, 2016).

Alongside user engagement in services, lived-experience has become central to health and social care research (Daly Lynn et al., 2021) and has led to a proliferation of collaborative research approaches (Bennett & Brunner, 2022). Citizen science is increasingly being advocated to develop the science-society interface and benefit research endeavours, particularly in long-term care settings (Clark & Cornes, 2023). Consequently, research methodologies that include or privilege engagement with the communities or populations studied are commonplace and are often now adopted as an ethical approach to research (Lignou et al., 2019; Willis et al., 2018).

In social sciences and health sciences, PPIE is expected by funders (Cornwall, 2004) and is considered a 'prerequisite for high-quality research' (Johnson, Davies, et al., 2021, p. 1638). If done well, involving people with lived experience of using services can help improve the relevance, quality and direction of research. Trust, power-sharing, bidirectional communication and financial compensation are all recognized as critical elements to successful PPIE (Harrison et al., 2019).

Recent studies have highlighted the complexity and challenges of involving PPIE members in research. Inadequate pragmatic and emotional support, tokenism and unconscious bias are

documented problems (Richards et al., 2023). The provision of support is seen as critical in mitigating the difficulties for PPIE members (Johnson, Ogden, et al., 2021; Perkins et al., 2007). Yet, providing this assistance can be a source of administrative and emotional labour for academics and may be the responsibility of junior researchers on fixed-term contracts (Boylan et al., 2019; Green & Johns, 2019; Pearce, 2021). The distribution of power and decision-making can also be a site for tension (Boaz et al., 2016), and thus recognising reciprocity, mutuality and different areas of expertise is important (Burke et al., 2023).

The integration of PPIE requires both infrastructure (methods, approaches) as well as specific guidelines to facilitate better reporting (such as GRIPP2, a 5 point-reporting checklist for PPIE) (Staniszewska et al., 2017), alongside the negotiation of relational dynamics (Wilsdon et al., 2005). The latter is often described as encompassing multiple tensions, including reconciling the interest of the PPIE members with the research focus of the academic (Heckert et al., 2020). Where PPIE members vie for space alongside academics (Béland et al., 2022), epistemological dissonance can emerge as each party queries the legitimacy of the other's contributions (Ward et al., 2010).

Relationship building is therefore central to functional user involvement (Crawford et al., 2002), including respect, shared power and trust (Harrison et al., 2019). Yet, developing equitable relationships between academics and PPIE members is complicated by the tight timeframes that research projects operate within (Gilchrist et al., 2022). Pragmatics can impinge on PPIE members fully understanding the purpose, methodology and terminology of the research or how their input would be used. There is a clear onus on academics to support PPIE, while they simultaneously meet the demands of the research institutions and funders (Heckert et al., 2020).

Cornwall (2004) conceptualises PPIE as a 'spatial practice'. Both research project meetings and forms of a-synchronous participation are contested and curated spaces, holding multiple contradictions that both academics and PPIE members work to negotiate where a heterogeneous set of actors have their own expectations and experiences which influence their participation. Power permeates interactions and can initiate multiple points of resistance, while also reproducing institutional practices (Cornwall, 2004).

Maguire and Britten (2018) also use the metaphor of space, with PPIE conceived as a liminal knowledge arena inbetween user and academic/professional spheres. While for some there is a clear distinction between these identities, blurred boundaries were highlighted, and adopting professional behavioural norms was sometimes perceived as a form of self-colonisation. Others understood their role as being a disrupter of hierarchies that favour clinical and academic knowledge over experiential, embodied knowledge (Maguire & Britten, 2018).

Foucault's work on knowledge and power is a valuable lens to examine PPIE. For Foucault (1977), power operates at multiple levels and involves a range of people in its production. Disciplinary power is enacted through hierarchical observation, normalising judgement and examination (Foucault, 1977) and produces self-regulation in line with normative roles and expectations, including the roles and expectations of people with lay or academic experience. Governmentality, a 'regulated freedom' (Rose & Miller, 2010) involves subtle practices that mould behaviour and is inherently intertwined with the framing of issues in such a way as to instil beliefs, norms, identities and values (Glenn, 2019). Compliance is not commanded; more mundane and routinised techniques are employed that foster self-regulation (Solvang & Juritzen, 2020). Consequently, individuals are not merely subjects, but instead play an active role in the exercise of power (Rose & Miller, 2010).

Two territories, of lay or academic, have developed and become entrenched as separate specialties or 'facts of discourse' which dominate the health and illness research landscape (Foucault, 2002). These positions, and related disciplinary practices, profoundly shape the possibilities in research interactions, whereby lay members enact knowledge about personal experience and academics enact knowledge about methodology as divorced from lived experience.

This article aims to contribute to the small, but growing, body of literature, seeking to critically engage in the tensions in PPIE work. It heeds Boaz et al.'s (2014) call to acknowledge the effort, skill, time and resources required for PPIE members to participate fully in research processes. Before introducing the evaluation methods, a description of the study in which the evaluation is located is presented alongside details of the PPIE members and their roles in the work. The subsequent section therefore provides context, given the variability in how PPIE is enacted.

PPIE IN THE STUDY

The study had three co-investigators who were PPIE members. They were recruited using a UK website that advertises PPIE opportunities, with an invitation to join the study as people who could speak about their lived experience in relation to care homes and/or palliative care. The advert noted the study's focus on adapting an Australian model for use in the UK, of providing palliative care and end of life care to people living in care homes for older people.

One PPIE member had an uncle living in a care home (not one of the study sites), who died towards the end of the implementation phase. A second PPIE member had undertaken lay inspections in care homes. The third PPIE member did not have direct experience of care homes or palliative care and spoke from the position of a community member and a potential future user of care homes. Terms of reference were drawn up at the start of the funded project, with statements regarding inter alia, communication, engagement and reimbursement, recognising the need for such clarity from the outset (Aas et al., 2023).

PPIE representatives were involved from study conception as co-applicants to ensure the research questions and aims were informed by people with non-academic and non-clinical experiences of care homes. Once funding was secured, opportunities were offered to all three PPIE co-investigators throughout the study, starting from proposal development, based on their interests and time. PPIE members attended monthly investigator meetings and provided advice on all aspects of the study. After each monthly meeting, they were invited to a debrief where further thoughts, reflections and questions could be raised with a member of the academic team. At least two PPIE members attended all monthly investigator meetings and two attended quarterly Steering Group meetings.

PPIE members informed the choice of family outcome measures (focusing on a measure which would be least burdensome and most meaningful to relatives). PPIE members were on interview panels for the appointment of a research fellow and in co-constructing interview topic guides for data collection, reading a sample of transcripts and discussing data analysis. All PPIE members contributed to the development of ethical approval paperwork, with one attending the ethics committee meeting. PPIE members contributed to study outputs and were co-authors on draft funder reports, journal articles (including this one) and conference abstracts. PPIE members all acted as advocates and champions of the research, for example, through promoting the study via their networks (e.g. Twitter, LinkedIn). Early in the study's timeline, PPIE

members made a video talking about themselves and their role in the study, which was distributed to all research sites, to underline the importance of their role in the study.

One PPIE member expressed an interest in conducting research interviews. They were provided support to learn about research interviews, by shadowing an academic research team member. However, the short timeframe in which interviews were arranged and conducted, and PPIE availability, meant that they were unable to lead any interview data collection during the study.

PPIE members had opportunities to strengthen existing and develop new relationships, which led to invitations to join other research teams and grant applications about care homes.

Informal bespoke training was provided on a range of topics and processes. For example, at the start of the study, sessions were held on implementation science and study design. As the study progressed, support and training changed to focus on topics relevant to the stage of the research.

The aims of the evaluation were as follows: (i) to understand the impact and experience of PPIE from the perspective of all team members and (ii) to contribute to the literature on patient and public involvement regarding what works well and less well.

The evaluation involved inductive qualitative interviews, embedded within a critical realist implementation science study of palliative care provision in care homes (Macgregor et al., 2022). All research team members (including academics, clinicians and PPIE members) were invited to participate in a one-off interview focused on their experiences of PPIE throughout the study. One-to-one phone or video-conference interviews were conducted to examine the successes and opportunities of patient/public involvement in this study, to enhance future PPIE work.

EVALUATION METHODS

Data were collected by an independent researcher in October and November 2022. The questions had been developed by the PPIE members and academics in the team. This component of the study was conducted by a female qualitative researcher completing her doctorate in the social sciences. The decision to work with a researcher external to the team was to ensure that all participants had the opportunity to speak without self-censoring negative feedback on the study. This choice also reflected the anticipated skillset of an academic, rather than a PPIE researcher. We considered recruiting a highly recommended PPIE researcher external to the team. The external PPIE researcher advised that they did not feel they had the appropriate skill set to manage the evaluation. Thus, we recruited an academic evaluator instead. Prior to the study, the independent researcher had no relationship to any of the PPIE members and only a limited relationship with three of the academics, who she knew on an informal basis through university networks. Interviews ranged from 23 to 72 min, with an average of 49 min. Interviews were recorded and transcribed. Transcripts were then anonymised and are referred to in this report via their role in the study (e.g. academic 1 or PPIE 1).

Transcripts of audio data and documentary evidence were stored and organised using Nvivo 20. Analysis was conducted by the independent researcher to maintain the confidentiality of respondents. Thematic analysis underpinned the analytic approach to all qualitative data, following the five-step process outlined by Braun and Clarke (2006). Stage 1 involved familiarisation with the dataset through repeated re-readings. Stage 2 involved identifying an initial thematic framework, which was used in Stage 3 where data were indexed with reference to the thematic framework. In Stage 4, data were synthesised from across respondents into

consolidated themes. Stage 5 focused on data interpretation and finalisation of key themes generated from the data.

The NHS Frenchay Research Ethics Committee approved this study, ref: 287447. The GRIPP2 checklist has been used to guide the reporting of this study (Staniszewska et al., 2017). Identifying details have been removed, though members of the research team are likely to be able to identify speakers from the quotations used.

The PPIE approach was informed by the UK's National Standards (NIHR, 2018).

FINDINGS

Eleven interviews were conducted; three with PPIE members and eight with academics (some of whom also held clinical roles).

Four themes were generated from the data, focusing on (i) the positioning of team members, (ii) how meetings were required to hold space for academics to share the technicalities of their process, whilst also being accessible to all members of the research team, (iii) management of both the focus and pace of the meeting, whilst also allowing for tangents and (iv) tangible impacts of the involvement and engagement.

The positioning of team members and experience

A designated PPIE budget was available to the three co-investigators to reimburse their time as they wished; they advised that this was a novel, empowering experience which demonstrated trust. The consequence was that PPIE members controlled how much input they had and chose activities which fitted their interests and skill sets best. All PPIE time spent on the project was remunerated.

All interviewees were eager to indicate that PPIE members were on an '*equal footing*' with the academic members of the research team. PPIE members were seen as '*peers*', '*equal partners*' and all members of the team were seen to be '*mucking in together*'. Interviewees saw a '*lack of distinction*' between academics and PPIE members, which contributed to the involvement and engagement's overall success.

However, this *lack of distinction* did not hold up under closer scrutiny, as interviewees discussed roles and contributions to the project. While we would not expect team members to become indistinguishable in their expertise or experience, the rhetoric of wishing to position the team members as being on an equal footing was very strong. Power differences remained, despite all team members' stated best intentions to tackle hierarchies. The co-production approach was framed as '*positive othering*' (academic 6) in recognising different inputs as valuable. PPIE members were provided with technical and emotional support, as well as simplified explanations of complex epistemologies and research processes. In so doing, this signified both their status and difference to academic team members:

> I recognise that's not straightforward, that some of the reasons you might distinguish people and say, 'these are PPIE members', it might be because you want to give them more support or you're trying to accommodate that. But I think that can also be divisive, or then make you feel your input's different in some way.
>
> (Academic, interviewee 2)

The status and experiences of team members was not static, with some experiencing substantial change over the 34-month study timeframe. A PPIE member spoke of how her input changed when someone close to her who lived in a care home died during the study:

> I was giving [the PI] quite a lot of detail in that because it was the exact sort of resident who should be taken to [the study intervention].
>
> (PPIE, interviewee 8)

Importantly, the positioning of team members as *either* PPIE *or* academic did not stand up to a simplistic divide. Most academics in the team had current or recent relevant personal experience, including having a close relative residing in a care home:

> There's kind of weird insider-outsider sort of business, and that's what I've mentioned before about these kind of blurred boundaries within this project. Like, you know, [academic colleague]'s parents who are in the care home just now and she supports them and that's lived experience. So having these kinds of boxes of 'you have lived experience'; 'you have academic experience'. [...] It's blurred.
>
> (Academic, interviewee 1)

One PPIE member highlighted how she felt ambivalent about crossing boundaries from talking about her personal experience to research skills she had developed:

> **Interviewee**: I like doing interview topic guides, so that was something else that I had the opportunity to do. I perhaps interfered with the research a little bit too much, if I'm honest about it. Because a PPI member is there to give lived experience PPIE perspective but because I've been doing it for so long, I can kind of spot things on the research side of it. Now, I don't know how they felt about that. Perhaps I should ask [the PI] at some point. Does she think that I overstepped the mark at times?
>
> **Interviewer**: Was there anything that gave you that impression?
>
> **Interviewee**: Just I remember [the Research Fellow] saying that she said to [PI], "Oh, [Name] knows so much about research." And I thought that was a good thing, but then it could be a bad thing. Really, you know. It just depends how the lead applicant views that. (PPIE, interviewee 8)

In this quotation, and throughout her interview and project meetings, this PPIE member identified herself as having accrued academic expertise. Despite integrating this academic identity into her sense of self, she did not know how this was received by others in the team. The positions of 'academic' and 'lived experience' were porous, where each member of the team occupied multiple identities and knowledge. Yet team members still occupied primarily different roles, and held a sense of what identity and input they should bring to the team. This awareness of their role and identity thus acted as a form of governmentality, maintaining boundaries and moulding conduct.

Technicalities versus accessibility

Several interviewees discussed the tension of maintaining a collaborative atmosphere in which academics and PPIE members were on an equal footing, while creating a space in which technicalities could also be discussed in detail. For example, academics described straddling both supporting PPIE members and engaging in detailed epistemological and methodological discussions:

> I think sometimes [PPIE] comment on things which are more within I think the academic methodological clinical sphere, and they'll ask questions which demonstrate that they're kind of maybe moving beyond where their role sits. So they'll say "Oh, I don't understand this term," and it would be a methodology paper. And they'll have been included for information and then they'll say, "Oh this doesn't make sense," and it's actually for an academic journal, and PPIE people aren't the audience for this output. So, actually, I don't really mind if they don't understand it.
>
> (Academic, interviewee 6)

The quotation points to a tension of whether team members should occupy set-roles and hence demarcate where someone moves 'beyond' their anticipated singular role. Thus, while there was a desire to frame the relationships as equal, data such as the quote above reposition individuals as having set frames for their contributions. Transgressions of expertise were not necessarily welcomed by academic members, and highlighted the delicate footwork engaged in to be inclusive without jettisoning technical specificity. Yet, as PPIE members participated in discussions about methodology they further demonstrate the multiplicity of power—being able to resist expectations of technicalities being solely the domain of the academic members of the team.

Academics described having to discern *when* to explain the research to the PPIE members and when it is acceptable to maintain the complex technical language and detail required for academic reporting:

> Every single aspect of the project has been done with [PPIE] partners [...] Things have been broken down in a way that makes it understandable for everyone. Without being patronising, but also really drawing on and respecting their expertise. [...] my recollection of some of those team meetings was that there was always the consciousness that people thought where the PPIE background were in the room and that we had to stop and pause and make sure that they were got up to speed, if we were in full technical language flow. And ... just checking [their understanding] and sometimes they would say 'not really, but it doesn't matter because it's not something important'. And that was fine, too. But that was good that they were able to say that. They weren't feeling as if, somehow, they were being left out.
>
> (Academic, interviewee 11)

The tension of knowing when to support and include PPIE members and when to prioritise technical discussions hinges on the degree to which there is mutual understanding of each person's role in the team. Consequently, it also then relates to how bounded or flexible the roles of both PPIE and academic are, and negotiating an acceptable balance for all parties.

Thus, all team members were actively and continually engaged in conveying their own boundaries and contributions, to offer insights without foreclosing discussions or seemingly overstepping into each other's expertise. The Principal Investigator (PI) was ultimately seen as holding power in determining the depth of technical discussions and how a plurality of identities were recognised:

> When there was technical jargon, she [the PI] always had a bit where she explained it, when she communicated with the group. And she regularly made the offer to the members to say, 'if this bit doesn't make sense to you, and you want to have a chat with me before the meeting, then do that'.
>
> (Academic, interviewee 2)

One PPIE felt that meetings provided adequate time to unpick the methodological complexities:

> Sometimes the documents can be very complex. And I mean the challenges I found were the, you know, the theories behind things, and I think I was a confused critical realist at one point, you know. I'm just absolutely, totally gobsmacked at how [complex] things are.
>
> (PPIE, interviewee 4)

In the above quotation, the speaker reflects on their experience of receiving research meeting papers and workshop planning documents. Given the methodological framework of realism, which was drawn on in study documentation to orientate discussions and decision-making, the PPIE member became alert to the complexity lying behind seemingly straightforward tasks, such as facilitating a workshop discussion. These technical details were required in study documentation to ensure methodological robustness of the research; the inclusion of PPIE in all facets and stages of the project meant that they too were privy to the (otherwise hidden) epistemological and methodological underpinnings of research activities.

Pace, focus and tangents

The project required active and ongoing negotiations to stay focused, manage tangential points and maintain the pace of discussions:

> No matter how much or little, how contributory or not, sometimes I didn't say very much, I just like to listen, and sometimes I spoke but either way, always felt welcome. And always felt comments were appreciated. So, never anything negative about that experience at all, quite the opposite. I think [the PI] was very accommodating of us. Sometimes we'd ask the same questions over and over.
>
> (PPIE, interviewee 10)

Academic interviewees raised experience of team meetings where 'tangents' were introduced by PPIE members that could be at odds with the meeting agenda and limited meeting timeframe.

The meeting Chair (study PI) managed the flow of discussion and decided whether (and how) to open up or close down topics:

> ...structure the meetings that people were clear and knowing... that there wasn't any sort of faff and, it was an hour meeting it meant that we got... the agenda was always got through by the end of the meeting.
>
> (Academic, interviewee 9)

Exploring tangents could divert from more relevant discussions, yet not giving space to PPIE ideas could invalidate their contributions and silence reflections. Academics ultimately decide what is relevant or not, illuminating the inherently unequal positioning between PPIE and academics. Four academics suggested that some of the contributions made by PPIE members could occasionally be tangential, yet broadening discussions was a cornerstone of having non-academic members:

> Some things were kind of tangents. I mean, that's difficult because part of the reason is to have people ask questions that you don't think of. So, things that might seem like tangents might actually be good. So, it has to be a little bit careful. [...] It can be difficult to say, well, 'that is important, but it's not actually part of what this part of the project is doing'.
>
> (Academic, interviewee 3)

PPIE members did not feel as though their contributions were truncated. One participant (interviewee 4) saw her role as providing ideas that academics 'didn't think of', which they could put 'on the back burner' and revisit later.

The study lead was frequently mentioned as responding positively to PPIE contributions. Both academics and PPIE members mentioned how the PI would continually thank the PPIE members for their input in meetings:

> I've got to commend [the PI] for her openness about that, you know, whenever we've come up with a suggestion, she's considered it seriously and where she's been able to accommodate us that opportunity. She has, you know. So, yeah, it's been a special working relationship, you know.
>
> (PPIE, interviewee 8)

The wide-ranging ideas brought up created a more open dynamic which was experienced by one academic as permission to talk more broadly too:

> [The PI] was always affirming and saying "Thank you," but she didn't let them go on too long, if I felt they were going on a bit long, she would bring them [...] just gently say, "Oh, thank you so much, that was really helpful." She was incredibly affirming which actually gave...even made me feel relaxed, you know, to say something that I might want to say, you felt you could contribute to the meeting because sometimes it's difficult, you know, because you don't want to waste people's time with a useless thought. [...] I suppose it's... I found myself saying, "Okay, [name of PPIE] you know, let us speak," type of thing, you know. There was a little bit of that. But that was

great that she felt she could speak because I sometimes don't feel I can speak, but there was this freedom to speak.

(Academic, interviewee 7)

The curation of this open space, was nevertheless an unspoken negotiation of the focus of the meeting, to manage potential relational dilemmas arising. The PI was cited as being the main person who engaged in this work. Other academics talked about facilitation rather than curtailing discussion, and in all cases it was the PI who was positioned as navigating this.

Tangible impacts from PPIE

As noted above, some of the tangible impacts included guiding decision-making on specific outcome measures used within the study and being part of the appointing panel for the main study research fellow. These activities occurred prior to funding being secured and prior to commencement of the study, respectively. This shared decision-making approach was therefore embedded very early in the project's life and likely acted as a template for PPIE and academics as to the relative importance and role that PPIE would have, and hence to the power dynamics for the project lifespan.

Notably, including a PPIE member in the appointment of the research fellow underlined the critical role of involvement also to the new member of staff:

When I'd done my interview [a PPIE member] was on the panel. So, from my very first interaction with the project team, there's PPIE included within that, and each member of the panel had their own set of questions and [the PPIE's questions] were all asking about PPIE views and experience of that, so that was kind of my first introduction as part of this project.

(Academic, interviewee 1)

PPIE members and academics were able to take stock of the impact of PPIE, for example, suggesting new data collection variables:

[One PPIE member] asked a question about the cost of private ambulances [prompting a new economic data collection variable], it was a really good... it was a good spot.

(Academic, interviewee 10)

Interviewees were consistently clear that the PPIE members changed how accessible team meetings and workshops were:

We got really helpful feedback from [PPIE members] about the need to make it more accessible, so kind of adapted the approach, and from that came up with this idea of guardian angels.

(Academic, Interviewee 1)

The previous quotation refers to an adaptation of how study workshop discussions were run, and the agreement that PPIE members act as 'guardian angels' to call out academics if they veered into technical or complex descriptions that others might experience as exclusionary.

DISCUSSION

This implementation science study actively sought the engagement and inclusion of non-academic stakeholders throughout (Burgher et al., 2023). The evaluation allowed for several tensions to be documented and interrogated, and in doing so highlighted some of the micro-power negotiations and impact of team meetings as spatial practices. Two overarching core practices were evident in the data (focus and identities) and will be discussed in this section, drawing together the four themes from the findings.

With regard to focus, while the format of meetings and allowable digressions provided 'space to talk' (Knowles et al., 2021), our data highlighted some of the labour involved to integrate PPIE members in the research team. Several tensions required continual engagement and negotiation, with the study PI setting the tone for how contributions from all parties are heard and treated, determining prospectively what was an appropriate or inappropriate focus. Use of an agenda, tight time frame for meetings and focused chairing, are disciplinary practices and acts of governmentality by 'configuring habits' (Li, 2007). These approaches were not experienced as disempowering by PPIE members or academics. Yet, the use of these strategies could be understood as more subjugation than co-production. Constructing some of the contributions of PPIE members as tangential is an act of power, determining what is within and beyond the scope of the project. Yet, PPIE members nevertheless felt comfortable raising issues and ideas, which itself is a mode of resisting conventional or presupposed topics that were within remit. Consequently, the consistency of PPIE members freely raising a wide range of ideas demonstrates the ongoing negotiations and work within the team to promote agency and a flattening of hierarchies. 'Tangents' were deemed accepted and acceptable, by the team, and while managed by the chair, were also subject to each individual shaping their own conduct and contributions in line with the normative expectations of the content of project meetings, as well as privileged knowledges and ideas.

The meeting space creates boundaries around autonomy, reminiscent of Foucault's concept of heterotopia, where the context is proposed to impose an ideology of practices (Foucault, 1966). Hence, while tangents could act as acts of power and sites of resistance, they were actively monitored and governed by participants to restore the focus on the core academic business. The spatial practices engaged in by all members reduce the possibilities of involvement being 'sites of radical possibility' (Cornwall, 2004).

The data identify the PI as a core purveyor of control, but that this was not sovereign; power was dispersed and taken-up by all team members, and in so doing created a self-governing team aware of their enactments. This mirrors Foucault's framing of how power operates not through a single person but through many individuals, disciplinary practices and governance (Foucault, 2007). The strategies to monitor and moderate the content and scope of discussions are core acts of governmentality (Madsen, 2014). This goes beyond the challenge academics faced in responding to the contributions of PPIE members, which they felt were 'outside of the scope of the research aims [...] and did not appear directly relevant to the health topic' (Heckert et al., 2020) to consider how power is distributed and enacted within the team. Foucault's concept of governmentality, 'techniques and procedures for directing human behaviour'

(Foucault, 1997) resonates since it is the mechanisms drawn upon by team members which produce the dynamics in which topics are considered within or beyond scope. Each team member acted in ways that constructed and exercised power. This echoes Foucault's conceptualisation of a form of governance that captures the multiplicity and nuance of power, with some regulated freedom, which operates within governmentality. The dynamics of research with active PPIE members needs to identify mechanisms that fit the context, and where power is neither wholly macro nor micro, but where PPIE members have agency within the structures in which they are embedded.

Regarding identities, typically, PPIE in research assumes that people occupy a demarcated locale or identity. In so doing, team members are regulated and occupy a position as lay or academic, but not easily both. The positioning of team members calls forth ideas of 'spatialisation' (Foucault, 1977), with PPIE as a spatial practice (Cornwall, 2004). In this study, shared spaces included, for example, the monthly team meetings and publications and were also metaphorical spaces such as the coexistence of both personal and professional experience. A person's spatial location indicates who they are and the powers that are available to them. Moments of subversion are visible as team members identify themselves or others to transgress these normative roles and spaces. Spaces of co-ownership and influence were an explicit element of this study, with PPIE being named as research team members (not external or auxiliary) and given budgetary control and influence. These shared spaces perhaps were sufficient to germinate the blurring of identities and positions. Research teams with integrated PPIE therefore may buck the specialisation, spatialisation and narrowly defined roles which are typical in medical spheres (Foucault, 2000).

The construction of lived experience as being intrinsically different from academic experience requires further interrogation. Academics' lived experiences have typically entered the literature in routinised reflexivity and auto-ethnographies (for example in palliative care settings, Carroll, 2020; Condon et al., 2021). Considering how knowledge and separations are created and sustained echoes Foucault's ruminations: 'we must also question those divisions or groupings with which we have become so familiar' (Foucault, 2002). Holding firm to the two distinctions must 'require a theory' (ibid., p. 29) of what separates them. Porous boundaries of team members' identities and experiences were visible in meetings, described in the interview data; to enrich both the interactions within teams and enhance the research itself, it is imperative that we find discourse and practices that allow this richness to thrive. To date, the plethora of meanings attached to labels such as lived experience of PPIE have yet to be fully ascribed and understood (McIntosh & Wright, 2019). The tensions in positioning of 'PPIE' versus 'academic' illuminate these roles as discursive objects rather than naturally occurring divisions (Foucault, 2002).

CONCLUSION

Power is a core concern for PPIE and academic members of the research team. Although this research enterprise was described by participants as embodying a '*lack of distinction*' and '*equal footing*' between academics and lay members, the data nevertheless pose some key questions and insights into the disciplinary powers at play. While the hierarchical form of the team was framed as flattened, there was nevertheless leadership and (formal and informal) agendas which operated to boundary and constrain discussion, as disciplinary practices. Power/ knowledge were intricately intertwined and displayed and managed through relational

practices. Power was not simply held by academics nor by PPIE members. All parties were actively aware of and engaged throughout in the ethical and moral implications of what was said and unsaid, managed by and through the relationships between team members.

Research teams are restricted by the linguistic capacities for holding the complex interrelationships between academics who have acquired lived experiences and knowledge and people with lived experience who develop academic knowledge and experience. Identities in PPIE and academic research are proposed as static, yet the evaluation data presented in this article highlights the multilayered shifting positions drawn on and adopted in different domains. Strategies of resistance to polarised identities in the accounts of academics and lay members are visible alongside disciplinary practices that seek to maintain binaries. We argue that there should, perhaps, be synthesis, integration or fluidity allowing for more complex identities to be enacted and valued. Future work should seek to excavate the multiplicity of positions enacted by all members of research teams, seeking to add nuance rather than categories to the identities displayed and drawn upon.

We note that this theory paper presents complex ideas which, while familiar to many academics, will not be to PPIE. The decision to write the paper reflects one of the quotations embedded in the findings, which seeks permission to adopt technical and complex approaches without an expectation that this will be wholly accessible to all PPIE members. The academic style and content of the paper therefore poses further questions regarding the power to author a paper which excludes lay readers and which is at odds with the less technical communication used in running the study. PPIE members reflected that power is intimately bound to decision-making and that generating consensus is not always possible. Although this paper is not 'easy going', the ideas contained within it are important, as one co-author PPIE member noted:

> The first part (of this paper) is very 'heavy'—I just hope PPIE members don't give up—if they proceed to the 2nd part I think they'll enjoy it.
>
> (PPIE Interviewee 4)

As a response to the paper being experienced as heavy and potentially therefore exclusionary, the team has proposed writing an accessible Foucault-focused paper for a lay audience summarising the ideas contained within this article and distributed via non-academic channels.

AUTHOR CONTRIBUTIONS

Liz Forbat conducted formal analysis, acquired the funding (lead), conducted the investigation, designed the methodology (lead), project administration (lead), provided resources and supervision, wrote the paper's original draft (lead) and reviewed and edited the paper. Aisha Macgregor conducted the investigation, designed the methodology, supported project administration, wrote the paper's original draft and reviewed and edited the paper. Talitha Brown conducted formal analysis (lead), conducted the investigation and reviewed and edited the paper. Brendan McCormack conducted the investigation, designed the methodology, reviewed and edited the paper. Karen Spilsbury conducted the investigation, designed the methodology, reviewed and edited the paper. Alasdair Rutherford conducted the investigation, designed the methodology, reviewed and edited the paper. Barbara Hanratty conducted the investigation, designed the methodology, reviewed and edited the paper. Jo Hockley conducted the investigation, designed the methodology, reviewed and edited the paper. Maisie McKenzie conducted the investigation, reviewed and edited the paper. Irene Soulsby conducted the investigation,

designed the methodology, reviewed and edited the paper. Margaret Ogden conducted the investigation, designed the methodology, reviewed and edited the paper.

CONFLICT OF INTEREST STATEMENT
The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT
The anonymised data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Requests must be accompanied by a research protocol and letter confirming ethical approval from a recognised ethics board. Data are available on request from the corresponding author and on receipt of an ethics-committee approved protocol.

ETHICS STATEMENT
This study gained ethical approval from the NHS via Frenchay REC (reference 287447).
Patient consent statement: no patients were involved in this study.
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REFERENCES
Aas, S. N., Distefano, M. B., Pettersen, I., Gravrok, B., Nordvoll, L. Y., Bjaastad, J. F., & Grimsgaard, S. (2023). Patient and public involvement in health research in Norway: A survey among researchers and patient organisations. *Research Involvement and Engagement*, 9(1), 48. https://doi.org/10.1186/s40900-023-00458-x

Barnes, C. (2019). Understanding the social model of disability: Past, present and future. In N. Watson, A. Roulstone, & C. Thomas, *Routledge handbook of disability studies* (pp. 14–31). Routledge.

Béland, S., Lambert, M., Delahunty-Pike, A., Howse, D., Schwarz, C., Chouinard, M. C., Aubrey-Bassler, K., Burge, F., Doucet, S., Danish, A., Dumont-Samson, O., Bisson, M., Luke, A., Macdonald, M., Gaudreau, A., Porter, J., Rubenstein, D., Sabourin, V., Scott, C., ... Hudon, C. (2022). Patient and researcher experiences of patient engagement in primary care health care research: A participatory qualitative study. *Health Expectations*, 25(5), 2365–2376. https://doi.org/10.1111/hex.13542

Bennett, H., & Brunner, R. (2022). Political and ethical dilemmas in multi-agency participatory research: The role of the buffer zone. *Methodological Innovations*, 15(3), 387–399. https://doi.org/10.1177/20597991221129775

Beresford, P. (2020). PPI or user involvement: Taking stock from a service user perspective in the twenty first century. *Research Involvement and Engagement*, 6(1), 1–5. https://doi.org/10.1186/s40900-020-00211-8

Beresford, P., & Rose, D. (2009). Background. In A. Sweeney, P. Beresford, M. Faulkner, M. Nettle, & D. Rose (Eds.), *This is survivor research* (pp. 11–21). PCSS Books.

Beresford, P., & Russo, J. (2016). Supporting the sustainability of mad studies and preventing its co-option. *Disability & Society*, *32*(2), 270–274.

Boaz, A., Biri, D., & McKevitt, C. (2016). Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom? *Health Expectations*, *19*(3), 592–601. https://doi.org/10.1111/hex.12295

Boaz, A., Chambers, M., & Stuttaford, M. (2014). Public participation: More than a method? Comment on "Harnessing the potential to quantify public preferences for healthcare priorities through citizens' juries". *International Journal of Health Policy and Management*, *3*(5), 291–293. https://doi.org/10.15171/ijhpm.2014.102

Boylan, A. M., Locock, L., Thomson, R., & Staniszewska, S. (2019). "About sixty per cent I want to do it": Health researchers' attitudes to, and experiences of, patient and public involvement (PPI) – A qualitative interview study. *Health Expectations*, *22*(4), 721–730. https://doi.org/10.1111/hex.12883

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Burgher, T., Shepherd, V., & Nollett, C. (2023). Effective approaches to public involvement in care home research: A systematic review and narrative synthesis. *Research Involvement and Engagement*, *9*(1), 38. https://doi.org/10.1186/s40900-023-00453-2

Burke, N. N., Stewart, D., Tierney, T., Worrall, A., Smith, M., Elliott, J., Beecher, C., Devane, D., & Biesty, L. (2023). Sharing space at the research table: Exploring public and patient involvement in a methodology priority setting partnership. *Research Involvement and Engagement*, *9*(1), 29. https://doi.org/10.1186/s40900-023-00438-1

Carroll, A. (2020). An autoethnography of death and dying in Northern Ireland. *Journal of Integrated Care*, *28*(4), 327–336. https://doi.org/10.1108/jica-02-2020-0007

Clark, M., & Cornes, M. (2023). Citizen science as a framework for improving the science-society interface in long-term care research. *Journal of Long-Term Care*, 92–99. https://doi.org/10.31389/jltc.142

Condon, A., Johns, L., & Chester, P. (2021). Utilizing an autoethnographic case study approach to explore patient-centered care and its principles in an oncology and palliative care setting. *Illness, Crisis, and Loss*, *29*(3), 241–256. https://doi.org/10.1177/1054137318800862

Cornwall, A. (2004). Spaces for transformation? Reflections on issues of power and difference in participation development. In S. Hickey & G. Mohan (Eds.), *Participation: From tyranny to transformation: Exploring new approaches to* (pp. 75–91). Zed Books.

Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, *325*(7375), 1263. https://doi.org/10.1136/bmj.325.7375.1263

Daly Lynn, J., Washbrook, M., Ryan, A., McCormack, B., & Martin, S. (2021). Partnering with older people as peer researchers. *Health Expectations*, *24*(5), 1879–1889. https://doi.org/10.1111/hex.13331

Faulkner, A., & Thompson, R. (2023). Uncovering the emotional labour of involvement and co-production in mental health research. *Disability & Society*, *38*(4), 537–560. https://doi.org/10.1080/09687599.2021.1930519

Foucault, M. (1966). *The order of things: An archaeology of the human sciences*. Routledge.

Foucault, M. (1977). *Discipline and punish: The birth of the prison*. Vintage books.

Foucault, M. (1997). *Ethics: Subjectivity and truth. Essential works of Michel Foucault, 1954–1984*. New Press.

Foucault, M. (2000). *The birth of the clinic*. Routledge.

Foucault, M. (2002). *Archaeology of knowledge*. Taylor & Francis Group.

Foucault, M. (2007). *Security, territory, population. Lectures at the colleage De France, 1977–78*. Palgrave Macmillan.

Gilchrist, K., Iqbal, S., & Vindrola-Padros, C. (2022). The role of patient and public involvement in rapid qualitative studies: Can we carry out meaningful PPIE with time pressures? *Research Involvement and Engagement*, *8*(1), 67. https://doi.org/10.1186/s40900-022-00402-5

Glenn, J. G. (2019). *Foucault and post-financial crises: Governmentality, discipline and resistance* (1st ed.). Palgrave Macmillan.

Green, G., & Johns, T. (2019). Exploring the relationship (and power dynamic) between researchers and public partners working together in applied health research teams. *Frontiers in Sociology*, *4*, 20. https://doi.org/10.3389/fsoc.2019.00020

Haarmans, M., Nazroo, J., Kapadia, D., Maxwell, C., Osahan, S., Edant, J., Grant-Rowles, J., Motala, Z., & Rhodes, J. (2022). The practice of participatory action research: Complicity, power and prestige in dialogue with the 'racialised mad'. *Sociology of Health & Illness*, *44*(Suppl 1), 106–123. https://doi.org/10.1111/1467-9566.13517

Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C., Banta, J., Symczak, G., Robinson, E., Schnipper, J., Wong, C., & Weiss, R. (2019). Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. *Health Expectations*, *22*(3), 307–316. https://doi.org/10.1111/hex.12873

Heckert, A., Forsythe, L. P., Carman, K. L., Frank, L., Hemphill, R., Elstad, E. A., Esmail, L., & Lesch, J. K. (2020). Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for engagement. *Research Involvement and Engagement*, *6*(1), 60. https://doi.org/10.1186/s40900-020-00227-0

Henwood, F., Wyatt, S., Hart, A., & Smith, J. (2003). 'Ignorance is bliss sometimes': Constraints on the emergence of the 'informed patient' in the changing landscapes of health information. *Sociology of Health & Illness*, *25*(6), 589–607. https://doi.org/10.1111/1467-9566.00360

Hodge, S. (2005). Participation, discourse and power: A case study in service user involvement. *Critical Social Policy*, *25*(2), 164–179. https://doi.org/10.1177/0261018305051324

Johnson, H., Davies, J. M., Leniz, J., Chukwusa, E., Markham, S., & Sleeman, K. E. (2021). Opportunities for public involvement in big data research in palliative and end-of-life care. *Palliative Medicine*, *35*(9), 1724–1726. https://doi.org/10.1177/02692163211002101

Johnson, H., Ogden, M., Brighton, L., Etkind, S., Oluyase, A., Chukwusa, E., Yu, P., de Wolf-Linder, S., Smith, P., Bailey, S., Koffman, J., & Evans, C. (2021). Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation. *Palliative Medicine*, *35*(1), 151–160. https://doi.org/10.1177/0269216320956819

Knowles, S. E., Allen, D., Donnelly, A., Flynn, J., Gallacher, K., Lewis, A., McCorkle, G., Mistry, M., Walkington, P., & Drinkwater, J. (2021). More than a method: Trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production. *Research Involvement and Engagement*, *7*(1), 34. https://doi.org/10.1186/s40900-021-00262-5

Li, T. M. (2007). Governmentality. *Anthropologica*, *49*(2), 275–281.

Lignou, S., Capitao, L., Hamer-Hunt, J. M., & Singh, I. (2019). Co-Production: An ethical model for mental health research? *The American Journal of Bioethics*, *19*(8), 49–51. https://doi.org/10.1080/15265161.2019.1619877

Macgregor, A., McCormack, B., Spilsbury, K., Hockley, J., Rutherford, A., Ogden, M., Soulsby, I. M. M., Hanratty, B., & Forbat, L. (2022). Supporting care home residents in the last year of life through 'Needs Rounds': Development of a pre-implementation programme theory through a rapid collaborative online approach. *Frontiers in Health Services*, *2*. https://doi.org/10.3389/frhs.2022.1019602

Madsen, O. J. (2014). Governmentality. In T. Teo (Ed.), *Encyclopedia of critical psychology* (pp. 814–816). Springer New York.

Maguire, K., & Britten, N. (2018). 'You're there because you are unprofessional': Patient and public involvement as liminal knowledge spaces. *Sociology of Health & Illness*, *40*(3), 463–477. https://doi.org/10.1111/1467-9566.12655

McIntosh, I. A. N., & Wright, S. (2019). Exploring what the notion of 'lived experience' offers for social policy analysis. *Journal of Social Policy*, *48*(3), 449–467. https://doi.org/10.1017/s0047279418000570

McLaughlin, J., Scambler, S., & Thomas, G. (2023). Introduction to special issue: New dialogues between medical sociology and disability studies. *Sociology of Health & Illness*, *45*(6), 1133–1145. https://doi.org/10.1111/1467-9566.13652

NIHR. (2018). National standards for public involvement in research. Retrieved May 3, 2024, from https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf

Pearce, C. (2021). The complexities of developing equal relationships in patient and public involvement in health research. *Social Theory & Health*, *19*(4), 362–379. https://doi.org/10.1057/s41285-020-00142-0

Perkins, P., Barclay, S., & Booth, S. (2007). What are patients' priorities for palliative care research? Focus group study. *Palliative Medicine*, *21*(3), 219–225. https://doi.org/10.1177/0269216307077353

Richards, D. P., Poirier, S., Mohabir, V., Proulx, L., Robins, S., & Smith, J. (2023). Reflections on patient engagement by patient partners: How it can go wrong. Research involvement and engagement. *Research Involvement and Engagement*, *9*(1), 41. https://doi.org/10.1186/s40900-023-00454-1

Rose, D., & Kalathil, J. (2019). Power, privilege and knowledge: The untenable promise of co-production in mental "health". *Frontiers in Sociology*, *4*. https://doi.org/10.3389/fsoc.2019.00057

Rose, N., & Miller, P. (2010). Political power beyond the state: Problematics of government. *British Journal of Sociology*, *61*(s1), 271–303. https://doi.org/10.1111/j.1468-4446.2009.01247.x

Solvang, I. M., & Juritzen, T. I. (2020). Between empowerment and discipline: Practicing contractualism in social work. *Journal of Social Work*, *20*(3), 321–339. https://doi.org/10.1177/1468017318815326

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., & Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *Research Involvement and Engagement*, *3*(1), 13. https://doi.org/10.1186/s40900-017-0062-2

Ward, P. R., Thompson, J., Barber, R., Armitage, C. J., Boote, J. D., Cooper, C. L., & Jones, G. L. (2010). Critical perspectives on 'consumer involvement' in health research: Epistemological dissonance and the know-do gap. *Journal of Sociology*, *46*(1), 63–82. https://doi.org/10.1177/1440783309351771

Willis, P., Almack, K., Hafford-Letchfield, T., Simpson, P., Billings, B., & Mall, N. (2018). Turning the co-production corner: Methodological reflections from an action research project to promote LGBT inclusion in care homes for older people. *International Journal of Environmental Research and Public Health*, *15*(4), 695. https://doi.org/10.3390/ijerph15040695

Wilsdon, J., Wynne, B., & Stilgoe, J. (2005). *The public value of science: Or how to ensure that science really matters.* Demos.