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TITLE: Involving Experts by Experience in Adult Social Care Research Capacity Building: Impact and Reflections

AUTHORSHIP

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ABSTRACT

To ensure that adult social care delivery is informed by evidence, it is crucial to establish links between the social care workforce, researchers, and people with lived experience of accessing services, as well as their families/carers. The Kent Research Partnership is one such research capacity building initiative in adult social care, supported by a public-led Expert by Experience (EbyE) working group. This paper discusses the nature of group activities and their model of involvement, as well as evidencing the group's impact on the partnership overall. We present three evaluation approaches used to date: (1) an impact log, (2) bi-annual surveys and (3) an NIHR-sponsored 'CUBE' evaluation on the quality of public involvement and partnership working and show that each have enabled us to capture different aspects of EbyE impact. Based on this, we argue that a single evaluation tool is unlikely to be sufficient, or adequately uncover both EbyE experiences and impact. EbyE impact is typically captured as part of research projects. Novelty, this paper showcases the impact of and reflections on EbyE involvement in a research capacity building initiative, which has a broader and more emergent remit.

KEYWORDS

adult social care; research capacity; experts by experience; evaluation; impact; reflections

KEY MESSAGES

- Involving Experts by Experience in advisory and participatory roles within a research capacity building initiative in adult social care is achievable and shows positive impact

- However, to benefit both the initiative and the Experts by Experience themselves, the involvement process requires careful, iterative, multi-method evaluation
- Such evaluation then open opportunities to spot challenges in a timely manner and address them

Research ethics statement

The authors declare that ethical approval for the evaluation elements of the Kent Research Partnership was obtained from the University of Kent Staff Ethics Review Committee (Reference: 0708).

Consent for publication statement

This article uses data from the Expert by Experience group for evaluation and critical reflection. The authors declare that consent to publication of findings – including quotations and any personal or identifiable information – was secured prior to publication.

Conflicts of interest statement

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

Research Capacity in Adult Social Care

Adult social care (ASC) covers a wide range of services in people's own homes, day centres or care/nursing homes (Kings Fund, 2023). Its aim is to help adults living with disability, frailty, physical and/or mental illness, and other challenges to stay as well, safe, and independent as possible (ibid). ASC is fragmented, with services delivered by statutory, private and charity sectors (Bayliss and Gideon, 2020; Chaney, 2022; Hudson, 2021), along with complex funding arrangements that people supported by services have to navigate (Thorlby et al, 2018). How social care is delivered and who is eligible for support also depends on complex influences, including legislation, market forces, and changing demographics (Glasby et al, 2021). Compared to healthcare, social care practice in England is also considerably less research-informed; most new ASC programmes are not evidence-based (Mullen and Bacon, 2004; Steventon et al, 2012). There is both a notable gap between research and practice in how ASC is delivered (MacIntyre and Paul, 2013; Marshall et al., 2016), and an increasing deficit in research capacity across the ASC workforce (MacIntyre and Paul, 2013; Morago, 2010).

To support evidence-informed ASC practice, there has been a growing demand to build research capacity in ASC through “real partnerships between the research community and local authorities (and other stakeholders)” (Cyhlarova and Clart, 2019, p.1). We followed the Cooke (2025) framework for research capacity building, which defines it as developing research skills and confidence, ensuring research is ‘close to practice’, supports linkages and partnerships, develops appropriate dissemination, builds sustainability and continuity, and invests in infrastructure (for further detail, see Abrahamsson et al, 2026; Zhang et al, 2025). To achieve any of the above, building links between the social care workforce with their practice knowledge and skills, and researchers who generate robust and relevant research findings is insufficient; involving people with lived experience of accessing services, as well as their families/carers, is equally important (Holmes et al, 2021).

Historically, people with lived experience were only invited to act as research participants rather than playing an active role in the design, development, and management of research (Higgins and Lenette, 2024). Recent decades, however, have welcomed the recognition of the importance and necessity of service user voices in all aspects of research from design to delivery. This fundamental shift in thinking and practice was driven by various rights-based movements such as the disability movement and recovery movement (see Morrow et al 2012) who challenged the pervasive rhetoric around the passivity of research ‘subjects’, positioning the researcher as all-powerful and all-knowledgeable. It is not rocket science to recognise and understand that we all have a right to be involved in issues that affect us - whether directly or indirectly - and research is no different. The disability rights slogan “nothing about us without us” captures this perfectly (Charlton, 2011).

The UK-based National Institute for Health and Care Research (NIHR) is committed to capturing and embedding lived experience to improve research (also known as Patient and Public Involvement (PPI); NIHR, 2024). Not only is PPI a prerequisite for NIHR funding but it can also enhance research quality, relevance, accessibility, and impact (Angell et al., 2003). The term ‘Experts by Experience’ in research highlights the move away from previous paternalistic approaches and instead recognises the expertise and knowledge of people with

lived experience (Fox, 2016). However, including those with lived experience does not automatically mean equal power-sharing within a project, as discussed later in the paper.

This paper describes how a public-led Expert by Experience (EbyE) working group has supported an ASC research capacity building initiative called the Kent Research Partnership (KRP). The paper discusses the nature of group activities and their model of involvement, as well as evidencing the group's impact on the partnership overall. We present three evaluation approaches used to date, and comment on the merits of multi-method iterative evaluation.

The Kent Research Partnership (KRP)

KRP is one of six ASC partnerships in England funded by the NIHR. Over the 4-year programme of work, the partnership aims to build ASC research capacity (NIHR, 2021). The partnership started in June 2021 and is led by the University of Kent and Kent County Council, with collaborators from the University of Brighton, Kent Integrated Care Alliance, The Home Care Association, and the National Care Forum. The partnership is additionally supported by the NIHR Applied Research Collaboration Kent, Surrey, and Sussex and the NIHR Clinical Research Network Kent, Surrey, and Sussex (ibid). The partnership has four interlinked streams of work: (1) hosting communities of practice, that bring a range of stakeholders together in ASC and aims to generate and share knowledge on evidence-based practice, (2) employing researchers-in-residence to support the development and sustainability of a research culture in the ASC sector, research and training fellowships, (3) funding members of Kent's ASC workforce to undertake pilot research projects in regional ASC priority areas, and (4) sharing knowledge and creating impact by providing audience-tailored access to research. All KRP activities are supported by a working group of members of the public with lived experience of ASC (for further detail see Abrahamsson et al, 2025; Hashem et al, 2023; Smith et al, 2025; Zhang et al, 2025).

Expert by Experience Working Group

A public involvement and engagement working group (henceforth EbyE working group) first met in July 2021 and its purpose was to ensure that EbyE informed every aspect of the partnership. The group was established and is co-led by a public member project co-applicant (JP) and a Digital and Innovation Lead (GW) for Adult Social Care and Health at the Kent County Council (KCC). The group consists of 12 Experts by Experience, who meet bi-monthly to review existing partnership activities and seek areas of change and improvement.

Group members were recruited through JP and GW's existing contacts, the People's Panel (a joint initiative between KCC and Healthwatch Kent to bring a range of ideas in discussions about social care service delivery; Healthwatch Kent, 2019) and at online networking events organised by KRP. The group originally had 9 members, with 2 people subsequently leaving (both citing time/work pressures as the reason) and 5 new members joining later. All members, past and current, have experience of receiving social care support or caring for a family member/friend who does (Figure 1 shows the experience and expertise areas of the current working group members). [Insert Figure 1 about here]

Figure 1. Working group member profiles, areas of interest and wider links (each box represents a different Expert by Experience; names have been redacted)

When I retired from being a primary school headteacher, I wanted to get involved with voluntary work in my community so joined the Local Involvement Network – now Healthwatch (since 2014). I have several long-term conditions and I can offer my lived experience of these to different health and social care arenas.

Key areas of interest: building relationships with providers and commissioners and bringing the patient voice and importance of integrated health and care to their attention.

Other roles/networks: Healthwatch, Swale Community Empowerment Network and Swale Patient Liaison Group alongside networks for the acute Trusts, community Trusts, IC24 and SECamb and related health/social care networks.

My lived experience is as a carer, and I also have experience with the care workforce at home and in Housing 21 Extra Care Residence.

Key areas of interest: Brain Injury and Stroke, social care workforce and housing.

Other roles/networks: I am a local volunteer for Stroke Survivors and attend bi-weekly meetings. I am also a member of the Stroke Association and Kent Headway (Brain Injury Support) as a carer. I am also a shop volunteer at Pilgrims Hospice and a volunteer IT buddy at Kent Libraries.

I am a carer for my son who has schizophrenia (for 12 years) and currently lives in supported housing. He is on section 117 and has a care package including regular social care visits organised by his care-coordinator.

Key areas of interest: younger people using social care services, mental health, housing.

I've worked as an organisational development consultant for a local authority for 33 years. I have a 24yo son with a rare complex disability who, after attending a residential special needs college, now lives at home with us. We employ a team of carers through direct payments and also purchase day care services. Our son has been through children's, adults and the 16-25 transition social care teams.

Key areas of interest: younger people using social care services, transitions between services.

I am a long-term mental, physical and social care service user with over 10 years of PPI experience.

Key areas of interest: advocacy for people with Autism and/or in criminal justice system.

Other roles/networks: I review services for the RCPsych and have many other experiences of PPI work.

My introduction to Care followed my involvement with our local Patient Participation Group, and subsequent membership of the Kent County Council People's Panel, which led to the opportunity to join this Project.

My role in the project as a joint applicant is all about ensuring public engagement and undertaking the role of lay representative. As a member of the main team, I have a voice in all areas and will always ensure the public are a key part of our working with co-production being addressed at all levels.

Key areas of interest: Integration of health and social care, including technology as I have a background in IT. Social prescribing and other developments helping to change culture to meet the needs of users of people in communities.

Other roles/networks: I have various roles in health and social care groups in my local area and the Kent and Medway ICS.

My lived experience is through caring for my mother who had Vascular Dementia. Also, I am supporting friends with parents/partners with Alzheimer's, so have an active interest in how their social care could improve. Additionally, I have research experience involving people with dementia, as whilst caring for my mother, I involved my mother and friends' parents with dementia in my designs to improve their quality of their lives, whilst studying my BSc in Computing and Design at the Open University.

Key areas of interest: Dementia, data and digital innovation

Other roles/networks: Currently I am a public advisor for ARC Kent, Sussex and Surrey for the Digital Innovation Theme, as well as being a volunteer for the Alzheimer's Society Dementia Voice Team. I am also the public advisor for the SHCAB IG & Data Access Group based in Kent

I am interested in so many aspects of social care and the wellbeing of all people. My husband is in a wheelchair, so we live in a sheltered housing community, and this has really made me realise about older people who are struggling with isolation and other mental health

Key areas of interest: wellbeing and mental health and supporting all people with addiction

My social care experience is both personal and professional. I oversee the care of my younger brother who is on the Autism spectrum and I help to care for my goddaughter who needs 24hr support. I have also worked in social care since 2005 and was registered manager of services for young adults with learning disabilities, mental health issues and complex behavioural needs. I am now the business development manager for the same company and oversee all referrals to our service.

Key areas of interest: Autism, learning disability, mental health, DoLs

Other roles/networks: I was a mentor for Canterbury Christchurch mental health students for their learning disability placements for 10 years.

I have both personal and professional experience. I am a qualified counsellor and used to do Street Pastor work. I am very interested in enabling people to be involved in their communities as much as they want to. I used to work as an expert patient trainer to help people take charge of their own disabilities and learn how to cope with challenges.

Key areas of interest: direct payments, personalisation and trying to help disabled people recognise and achieve their full potential.

Other roles/networks: I am a member of the direct payments group at KCC and involved with ARC KSS Social Care Theme. Also involved with Wheelchair Group and People's Panel in Maidstone. Equipment Services.

After moving to Kent in 2007 I decided to do some voluntary work and was invited to join a new patient voice group called LINK. After joining I became aware that it was a new statutory organization to listen to the patient voice (which later became Healthwatch). This organisation opened many doors into health and social care services. As I and other members became more and more trusted by parts of the NHS and social care organisations, the list of invitations to join other groups grew like topsy which is how I joined this partnership.

Key areas of interest: Making sure health and social care work for everyone. Part of my work with Healthwatch includes scrutinising consultation materials to ensure that they meet the requirements for the process which very importantly includes equality of access for all, and also the scrutiny of service specifications.

Other roles/networks: I am currently involved in both Healthwatch Kent and Healthwatch Medway alongside KCHFT, KCC – especially the Esther coaching project, IC24 and SECamb. I chair my practice PPG. Occasionally I help individual patients to navigate the system.

My personal experience is as a carer of both the young and elderly – of a young person with semantic pragmatic language disorder whose social care support differs to that of my elderly mother who has mobility difficulties and is severely sighted (registered blind).

Key areas of interest: young people over the age of 18 who have communication difficulties or are neurodiverse. Interested in changing the view of social care as just personal care as it is very much about social support to allow people to live a fulfilled and happy life.

Other roles/networks: parents who care for young people over the age of 18 who have similar concerns to the type/ amount of social care and support their children will get after education or after they die.

Working Group Activities

Upon formation, the EbyE working group identified the need for specific co-production training. Using an external agency with previous experience of working with KCC, working group co-leads, along with significant input from the group members, developed course objectives. This training, split across four sessions with a mix of virtual and face-to-face delivery modes, was well-received by the group and identified as a source of motivation. This training was distinct from broader research capacity-building initiatives aimed at the adult social care workforce. It was a tailored, EbyE-specific component that then enabled EbyEs to play an active role in workforce capacity-building, for example by contributing to the training design and presenting at Community of Practice meetings.

Group members have engaged in all streams of the Kent Research Partnership work. Box 1 outlines some examples.

Box 1. Summary of EbyE working group activities

The working group members have:

- provided advice on event content and structure
- helped refine researcher-in-residence roles and their remit
- took part in setting regional priorities for ASC research in Kent
- helped to translate regional research priorities into communities of practice
- guided research training focus and process of training delivery
- provided advice on making digital platforms (for meetings and information sharing) inclusive and accessible
- contributed to KRP newsletters by:
 - authoring content
 - advising on what content the newsletter should contain
 - reviewing newsletter pieces
- supporting Training and Research fellowship applicants' by
 - commenting on Plain English Summaries pre-submission
 - in some cases meeting fellowship applicants pre-submission for more in-depth discussions and advice
- taking part in the fellowship funding panel
- continuing to advise successful Training and Research fellows, including some group members being part of project steering groups and/or commenting on recruitment and data collection strategies
- informing how the impact of working group meetings is recorded and evaluated
- joining and remaining active in research-focussed KRP Communities of Practice, both as participants and, in some meetings, as speakers.
- attending training sessions aimed at ASC workforce and delivered by the partnership
- six EbyE working group members acting as contributors on a response to the call for evidence for the House of Lords select committee inquiry titled 'Lifting the veil: Removing the invisibility of adult social care' (Towers et al., 2022).

Part of the group activities involved both informing and participating in the evaluation of EbyE impact.

EbyE Working Group Impact

Impact on the partnership and its overarching objective to build research capacity in ASC was measured iteratively in a variety of ways, including; an impact log, bi-annual surveys, and an NIHR-sponsored 'CUBE' evaluation on the quality of public involvement and partnership working. These approaches are described in detail below. Separate analyses were conducted for each evaluation method, informed by an explicit commitment to methodological triangulation and the recognition that no individual approach offered a way to capture impact in a comprehensive way (Vivek et al, 2023). Integration focused primarily on complementarity across methods, aiming to enrich our understanding of the working group impact by applying different lenses, rather than simply 'cross-checking' whether different methods provide the same results (Moran-Ellis et al, 2006).

Ethical permission for the evaluation of the Kent Research Partnership, including its EbyE working group was granted by the University of Kent Staff Review Committee (Application: 0708). During the reported period, the impact log was compiled by Researchers in Residence and did not carry individual EbyE details; we periodically checked with the working group if the impact log entries were correct and comprehensive. Both the bi-annual survey and the CUBE evaluation were completed anonymously and were optional activities, to enable honest and potentially critical contributions. Close relationships as well as trust built over time between Working Group members and Researchers in Residence also served as a way to bolster openness and honesty. Emotional wellbeing was also ensured through consistent and timely communication, incorporating both professional and personalised interactions (e.g., follow-up on prior conversations or individual circumstances). This approach was intended to signal respect for participants as individuals and to reinforce their sense of value and engagement with the project. Boundaries were also adhered to by safeguarding personal contact information, and obtaining explicit consent before sharing any participant-related information within the research team.

EbyE Working Group Impact Log

How was the information collected? Six months into the partnership, a Public Involvement Impact log was introduced, documenting how the working group influenced different strands of the KRP project. This approach has been used by many health and social care research teams (e.g. Mann et al. 2018; UCL, 2024) to capture EbyE involvement activities across projects. The log, which can be viewed in Supplementary Material 1, records EbyE working group members' comments and contributions during the meeting, alongside researcher reflections and EbyE influence on the partnership. The last section of the log also maps working group activities (and meetings as whole) to the UK Standards for Public Involvement (NIHR, 2019): inclusive opportunities, working together, support and learning, governance, communications, and impact.

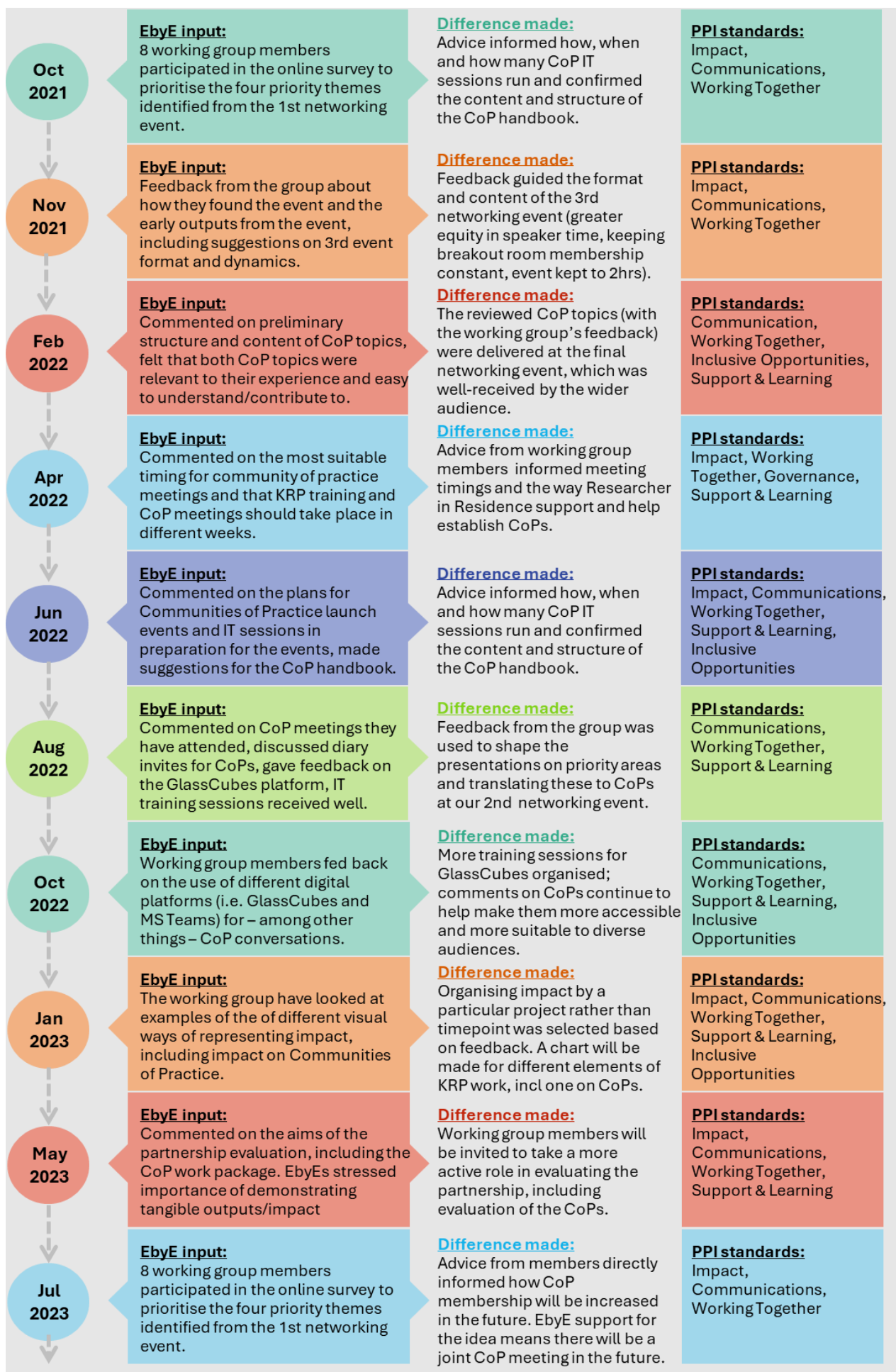
Alongside the impact log, and with the input of the EbyE working group members, a way of visually tracking continued impact on specific elements of KRP's work has also been

developed. The visualisation focuses on separate elements of the partnership, and summarises EbyE working group member impact over all the meetings where that element is discussed. Figure 2 provides an example of one such element - Communities of Practice (COPs) (Hashem et al, 2023, p3).

What did we find? As Figure 2 demonstrates, EbyE input has been instrumental in determining the content and format of priority-setting events, including piloting prioritisation/ranking processes. This was to both ‘sense-check’ the approach, and also to ensure that Experts by Experience, both within and external to the working group, found the event accessible and felt able to share their views and opinions. Working group members were also crucial in ‘translating’ priority areas into communities of practice, commenting on early versions of CoP conceptual frameworks and focus. In subsequent meetings, members informed timings for the newly established CoPs and associated digital platforms, and helped to define Researcher-in-Residence roles for supporting the CoPs. Further input involved advising on drop-in IT sessions for CoP members, as well as comments on the content and structure of the CoP handbook.

[insert figure 2 here]

Figure 2. Expert by Experience Impact on Communities of Practice



The CoP example demonstrates the potential for the impact log and its associated timeline visualisation to capture the substantial and tangible changes that EbyE input makes to the partnership. Updating and circulating the log in a timely manner ahead of each group meeting has ensured that nothing has been missed and has been a useful tool to promote ongoing discussion about EbyE impact.

A limitation of the impact log, however, is that it does not record members' experiences or the impact their ongoing involvement has on them. To evaluate these elements, additional methods were used, including a survey.

Bi-Annual Survey

How was the information collected? To uncover barriers and facilitators to involvement, a survey was devised by the working group, with input from the PPI advisor (AB). The survey asked group members to feedback (anonymously) on their experiences of being involved in the partnership. The survey is circulated, completed, and discussed at six monthly intervals to assess overall satisfaction with participation and explore how group member perceptions and experiences evolve over time. The first two waves of the survey (September/October 2022 and April/May 2023) are reported here.

At both baseline and 6 months later, the survey was completed by 6 working group members; as the survey is anonymous, it is impossible to say with confidence how many group members completed both surveys. Open-ended questions covered the following topics: (1) importance of respondent / EbyE working group involvement in the KRP; (2) the most important contribution made by the EbyE working group; (3) the most important contribution made by the survey respondents; (4) other significant contributions; (5) greatest source of satisfaction in working with the wider KRP team; (6) barriers and facilitators of working with the wider KRP team; (7) lessons that could be learnt (for the respondent and/or the wider team; and (8) any other comments. Responses were thematically analysed for common trends and analysis resulted in three main themes: the *purpose* of the EbyE working group, the way being part of the group benefitted the members themselves, and taking the group forward.

What did we find? In terms of the *purpose of the EbyE group*, member responses focussed on sharing their own experiences and learning from the diverse experiences of others and raising the profile of ASC. However, the initial survey also revealed some uncertainty about the group's role, with two of the six respondents considering it to be a steering or a project oversight group.

"[Group's purpose is] to ensure that social care gets the higher profile it deserves, and the working group is there to promote it and have oversight" (EE_T1_R6)

Six months later, completing identical survey questions, the respondents were more unanimous in how they defined the importance of being involved in the EbyE working group and its purpose – that of ensuring EbyE perspectives were represented in and informed the KRP.

“Knowing there’s a common purpose/goal and that all contributors are like minded in the desire for change and to make it happen” (EE_T2_R2)

When asked about the most important contributions made by the working group, respondents at both survey timepoints spoke of *“being able to support the [KRP] team working on this”* (EE_T1_R6), *“ability to question, particularly the researchers in residence”* (EE_T1_R4), *“establishing Communities of Practice”* (EE_T1_R5), *“highlighting the reality of people’s experiences and needs”* (EE_T2_R4), as well as *“raising awareness of how difficult it can be to access support”* (EE_T1_R2).

As well as seeing an overall group purpose, members reported personal benefits of EbyE working group membership. For many, group activities (including training) have improved research knowledge:

“My knowledge of research has greatly improved and the ability to also see others viewpoints” (EE_T1_R5)

Some respondents stressed the importance of feeling useful and intellectually stimulated, which was characteristic of survey responses at both timepoints:

“Having given up work to care this project allows me to carry on using my brain again. Part of a team. Caring can be isolating and at some points quite monotonous so it is nice to have something to work towards” (EE_T1_R5)

“Being included in the Group has revived my interest in research” (EE_T2_R6)

The group also commented on ways to take the group forward in the future and identified existing barriers. At both survey timepoints, group members referred to challenges in finding time to attend meetings and contribute:

“Time is the greatest barrier, but it is something we feel needs to be very high on our priority list” (EE_T2_R6)

In terms of personal benefits that in turn benefit the entire group, members expressed a growing appreciation for the magnitude of challenges facing both the ASC sector and specifically ASC research:

“Social care is a huge area to research; lack of progress to solve its difficulties is arguably due to being 'overwhelmed'” (EE_T1_R3)

In fact, many respondents stressed the importance of bi-directional learning – researchers learning from the EbyE working group members, and group members benefitting from researchers.

“Researchers learn the value of working with volunteers and we have learned that we can be involved in research without knowing the technicalities, and that it is a very rewarding path to follow” (EE_T1_R5)

“We find the research team we work with are extremely well motivated, well prepared [...] and some of their enthusiasm rubs off on the other contributors to the group” (EE_T1_R4)

In terms of taking the group forward, members shared desired changes, particularly in the first survey. This was partly about identifying barriers, which tended to be practical in nature:

“Only tech issues, it would be lovely to have some face to face [meetings]” (EE_T1_R5)

The KRP team have attempted to address this feedback by providing in-person opportunities (including a celebratory get-together and holding some co-production training sessions in-person), in addition to delivering six bespoke technological support drop-in sessions for group members and wider stakeholders and providing equipment such as web cameras. Nonetheless, and despite a £5 additional allowance for home-working which is meant to subsidise costs for internet access, digital accessibility, and Wi-Fi connectivity in particular, remained the most frequently mentioned barriers in the second survey.

“The need to provide free Wi-Fi” (EE_T2_R2)

Practical challenges were only one aspect of desired changes and ideas on how to move the group forward. Greater representation of younger people in the group was wished for (which the working group leads and the wider KRP team have worked on since, with limited success):

“It would be nice to see a wider range of ages of carers and cared for represented in the group. Young people should have a voice in their future care and this is the place for them to be included” (EE_T1_R2)

Opportunities to make an impact and progress the partnership were also important to respondents to the first survey:

“To date progress has felt slow, but as more bits of the process come together, progress seems to be accelerating” (EE_T1_R4)

Six months later, pace no longer came up as a concern. Providing a clearer account of the group’s impact and whether progress is on track was also desired.

“More precise and regular updates on progress would be helpful and give us a sense that things are moving forward. This would give us more confidence that we are on track to deliver” (EE_T2_R4)

Visualisation of the impact log (Figure 2), the continued surveys, and particularly the ‘CUBE’ evaluation (below), as well as this paper have all been attempts to provide a clearer account of both progress and impact.

Overall, the two waves of the EbyE working group member survey have allowed us to track group member experiences and anonymously capture challenges, and desired changes, for the working group co-leads and the KRP team to address. In terms of impact, the survey showed that group members have gained a clearer understanding of their roles and the purpose of the working group, as well as a deeper knowledge of research and practice in ASC.

The Cube evaluation is the third evaluative approach with EbyE working group members and allowed for a quantifiable ‘snapshot’ metric of felt active involvement, and influence or power over the working group.

The ‘CUBE’ Evaluation

How was the information collected? The work of the EbyE working group coincided with the piloting of a new public involvement, NIHR-sponsored, four-dimensional tool called the ‘Cube Evaluation.’

This digital web-based framework derived from Rauch and Jordan’s (2021) work aims to gather anonymous and self-reported levels of involvement within a research project or an EbyE group. The Cube presents four questions which are answered on a sliding scale leading to immediate visual feedback of how far EbyE feel they are involved in the KRP. It taps into people’s perceptions of power i.e. who holds the power in the Partnership, is it researchers / EbyE group Leads or is it EbyE themselves (Hinton et al, 2023).

The four questions were adapted from the original CUBE evaluation tool for specific use with the KRP by AB. They covered 1) different ways to participate, 2) having a voice in discussions and decisions, 3) the ability to set and influence the agenda, and 4) ability to create change based on own input (see Table 1 for details). Following a presentation of the Cube including reasons for its use and how results might benefit the group, nine working group members individually generated a response to the set questions during a meeting in March 2023. The Cube display shown in Figure 3 combined responses from EbyE group members.

Table 1. CUBE questions

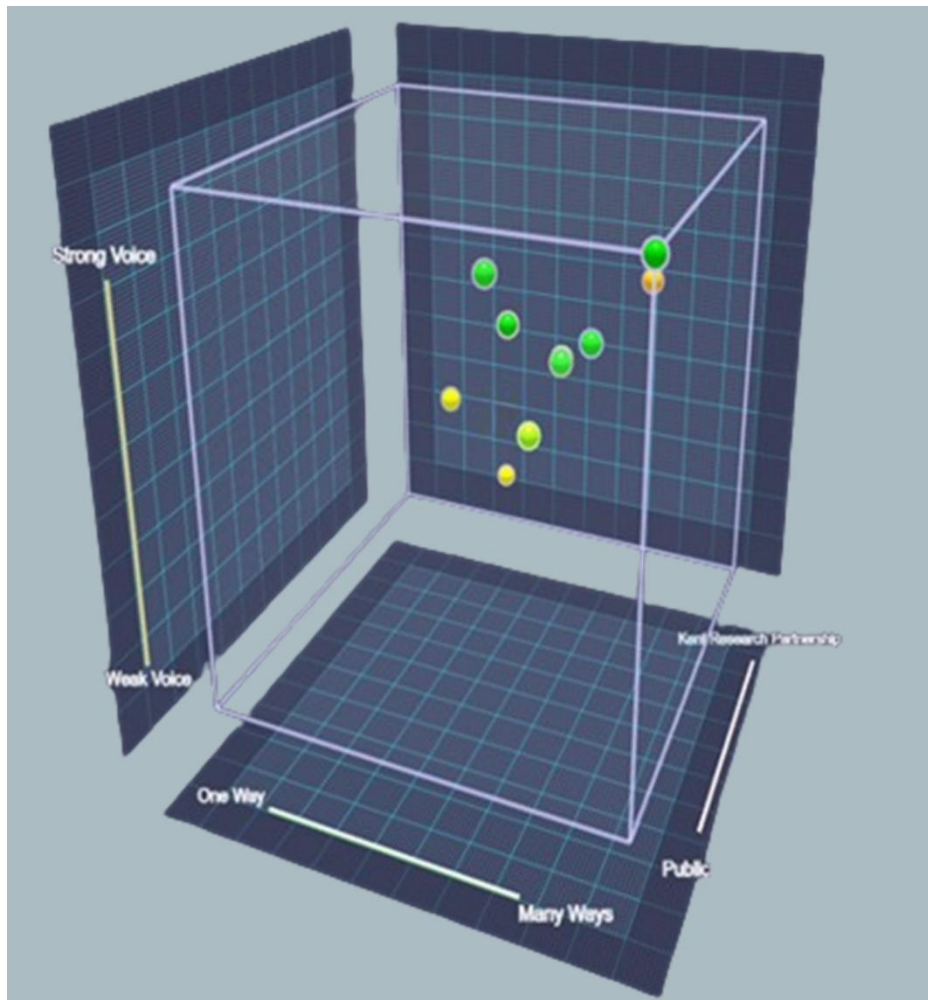
CUBE dimension	Question*
Contribute	Do you think there are different ways for people to participate in the Kent Research Partnership Working Group activities and contribute to its future directions?
Voice	Do you feel you have a strong or weak voice in decisions about Kent Research Partnership working group activities and its future directions? A strong voice participates in discussions, makes suggestions, and

	influences decisions. A weak voice participates in discussions but has little chance of making suggestions or influencing decisions.
Agenda	Who sets the agenda? Do you think that you can influence the Working Group's agenda and its forward direction? If so, why? If not, what are the barriers?
Change	How much of the Kent Research Partnership Working Group agenda and its future directions do you think will change or have changed based on your suggestions and input?
<i>*Each of the four questions ended with 'If so, why? If not, what are the barriers; there were also free text boxes for people to make additional comments if they wished.</i>	

What did we find? While no results were in 'red,' meaning there was no resistance to change by KRP staff, the sliding scale and free text comments showed mixed feelings about involvement in the Partnership. Responses were, however, mostly positive. Those who did not feel they contributed in a multitude of ways might have felt this way because they were relatively new to the group; people commented that more opportunities became apparent as people bedded into the role. Over half of respondents felt they had a 'strong voice,' although they recognised this might be because they were naturally 'expressive' and / or 'respected' by others.

[insert Figure 3 here]

Figure 3. Screenshot of the CUBE. Each dimension is on a different axis: Contribute on the x-axis, Voice on the y-axis, agenda on the z-axis and change as colour of the data point (yellow is neutral; red is resists change, green is willing to change)



When asked about the influence people felt they had over the EbyE working group and its forward direction, including the agenda, the sliding scale suggested that the KRP (staff) team mostly set the agenda and direction. However, free text responses indicated some felt they could “100%” (be influential; EbyE2) and there was “always opportunity for influencing what happens in the group” (EbyE5), in addition to feeling “listened to” (EbyE3). Others were not so positive and said that understanding the terminology and information was a barrier (Beresford, 2013; Dawson et al, 2017). Their free text indicated some felt they needed to justify requests to influence agendas: “I think that if I ask for an item to put on the agenda and give a good reason for it, it will be added” (EbyE1). Further, “we are asked for AOB etc and we are able to contribute once the agenda is sent”(EbyE6) again suggesting that people’s feedback is invited post-meeting and post-agenda setting rather than at the planning stage. As a result of the CUBE evaluation, the co-leads have worked further on addressing power imbalances in the way contributions and ownership of the group are encouraged, and in transparent communication of progress, focussing on involving rather merely informing group members.

Finally, when asked if the KRP’s agenda and direction has changed or will change, as a result of group member’s input, responses included “100%” (EbyE2). People felt they could influence research fellowship application outcomes and noted there was no “resistance to change” (EbyE6). In line with the survey results, respondents wished to increase group diversity (e.g. involving young people and a wider range of carers), suggesting a wider recognition that their impact could be greater: “As a group I think that we are trying to change this” (EbyE8).

The core partnership team reflected on the ‘power imbalances’ identified in the CUBE evaluation, particularly that Working Group members did not feel able to set the agenda. Efforts to address this were gradual, and many occurred beyond the period reported in this paper. Changes included revisions to Working Group meeting practices, with the EbyE co-lead more proactively inviting agenda items from group members, and two Working Group members taking over responsibility for impact logging. Alterations to the format of the impact log and to who collected the data limited comparability across all timepoints; however, this was considered a worthwhile trade-off to enable power-sharing and greater group ownership by EbyEs. Power-sharing also extended beyond Working Group meetings, with some members becoming co-chairs of Communities of Practice and facilitating partnership events.

Reflections on process and impact

In addition to evaluating impact as covered above, the Kent Research Partnership team members with responsibility for supporting the EbyE group have also routinely met to reflect and consider both the process and the impact of the EbyE activities. Presented below are reflections from JP, the working group co-lead, and AB, the Patient and Public Involvement (PPI) adviser for the Kent Research Partnership.

Reflections from the EbyE working group co-lead

As a co-applicant to the partnership, I was delighted to take on the role of co-lead of the EbyE working group together with a senior local authority manager. Our individual skills and

experience complemented each other in developing the group. Through our personal networks with both KCC and other Health and Social Care providers, as well as EbyE attendees of the initial Partnership Networking events, we engaged a good representation of members. There is always room for improvement, and we continue to seek younger members and to always broaden the demographics of the group.

Working with the group we recognised that some co-production training to bring members to a common standard would be of benefit to the group members. Having agreed the need with the group we used an external training organisation to run a 4-session event (2 virtual and 2 face-to-face). This approach had a significant impact on the team dynamics as up to this point there had been no face-to-face meetings. The lessons learnt in respect of co-production were recognised by all and a further follow-up event was held in January this year. We have established bi-monthly meetings to ensure the group are kept updated on the overall Partnership and can all share the achievements and future tasks of the group. The introduction of our Impact Log, which is now managed by group members, continues to demonstrate the work of the group.

On reflection, we could have delayed the formation of the group by up to 6 months to ensure that we had initial work and tasks for the group to keep them better-motivated. It has been encouraging to see the willingness of our members to get involved and they have proved to be a valuable asset to the partnership, especially for their work with the Communities of Practice and involvement with the selection and support of the Research and Training Fellowships. A further output from the group has been the publication of Co-production and Team internal working papers.

Along with the other group members, I look forward to continuing to develop the role of our group and its contribution to the continuing success of the Partnership. Through the development of the group, we have enabled members to self-develop, which has built considerable new Research capability. Overall, this has been a very interesting and rewarding role, seeing the development of the individuals and the impact on the Partnership together with seeing the principles of co-production across the Partnership.

Reflections on payments from the PPI Adviser

As PPI Lead for a health and social care research centre, and PPI Adviser on the KRP, the issue of PPI/EbyE payments is often difficult to navigate. The current project was no exception. Originally, payment to EbyE working group members was to be made by the partner institution who held the PPI budget, but this proved too complicated in terms of processes and systems. Institutional barriers to EbyE payments are frustratingly common and often pertain to institutions not being setup for EbyE payments (Selman et al., 2021).

Another project partner institution was already setup to pay EbyE in a non-onerous way (EbyEs complete a short claim form declaring they are not an employee and are responsible for paying tax and National Insurance) so this institution facilitated EbyE payments instead. BACS payment (Bankers' Automated Clearing System; a secure electronic payment method) is made within 4-6 weeks although ideally the timeframe would be shorter. The claim form

also makes clear that accepting payment could affect people's entitlement to certain benefits. This is a complex and sensitive area and as such risks to benefit entitlement was highlighted before people joined the group and it was raised again at the introductory meeting. Whilst important as research/ PPI advisers to not set ourselves up as benefits specialists, it is appropriate to flag this potential issue and to signpost people to appropriate support (e.g. the NIHR Benefits Advice Service co-ordinated by the Bedford Citizens Advice Bureau for EbyE involved in NIHR funded projects).

The project started during the COVID pandemic which resulted in a further EbyE finance issue. It was originally planned that EbyE group meetings would be in-person and as such, travel expenses and refreshments would be covered. However, online meetings were the only available option in the initial phases of the project and meeting online has continued in line with group member's preferences. We were therefore aware that group members were not offered refreshments due to home-working and were also paying for electricity and the Internet. Therefore, NIHR guidance around covering costs for remote/homeworking led to an additional £5 payment to group members as well as their meeting attendance payment. It was also apparent that not all group members chose to claim or were able to claim. Therefore, we wished to thank people for their time in other ways and as such, we sought agreement from NIHR to offer a thank you voucher to those who were not claiming payment (with the caveat that accepting vouchers can still impact benefits). It was also agreed to send "letterbox hampers" to group members six times a year as a thank you but also to acknowledge that catering was not being automatically arranged due to online meetings.

Conclusions

Undertaking social care research without EbyE perspectives runs the risk of missing important elements pertaining to the feasibility, scope, and execution of the project (Stanley, 2013). When researchers and EbyE come together and have honest and robust discussions about aspects of the project whilst truly acknowledging and valuing each other's positions it is unsurprising that real and tangible changes to the project and its activities happen (McVey et al, 2023). Opportunities to work together and good intentions from researchers who, by definition of research projects or initiatives, hold the power, is not in itself sufficient (ibid). Checking-in with EbyEs throughout the process is paramount. As discussed, the use of iterative evaluation enabled us to identify and respond to issues related to power-sharing with EbyEs over time. This process can also challenge commonly-held perspectives on what 'good' EbyE involvement looks like. For example, researcher perspectives suggest that EbyE involvement should begin as early as possible (e.g. Jackson et al, 2020). While this remains broadly appropriate, our findings indicate that further consideration may be needed regarding the timing and scale of EbyE involvement. Although the Working Group was established early in line with best practice, members reported that the initial six months lacked momentum and risked frustration. In this context, a delayed or more phased establishment of the Working Group may have been preferable. It is therefore crucial for Expert-by-Experience groups to continually share their involvement experiences so necessary changes can be made. Care must also be taken to provide feedback to EbyE on the value of their input (Wilson et al, 2015).

Our paper goes further, to emphasise that a single evaluation tool is unlikely to be sufficient or adequately uncover both EbyE experiences and impact. The impact log has clearly demonstrated how the KRP has and continues to benefit from EbyE input on its various work packages and elements. On its own, however, it would not have captured how working group members felt or how their experiences (and the working group overall) could be improved. The bi-annual anonymous survey has enabled challenges and issues to be shared as well as positive feedback and allows the group to comment on whether subsequent changes have resulted in improvements. However, further challenges of power imbalances were uncovered via the CUBE Evaluation which in particular showed space for improvement. Our approach to evaluation is consistent with participatory and co-production evaluation approaches and frameworks. These approaches emphasise shared control in generating evaluative knowledge (Leask et al., 2019), position iterative and participatory evaluation as an integral part of the co-creation cycle rather than an external add-on (Agnello et al., 2024; McLean et al., 2023), and advocate for the use of both formative and summative multi-method approaches that are responsive to stakeholder priorities and changing contexts (Lee et al., 2022).

Nonetheless, EbyE involvement is usually evaluated in relation to research projects (Greenhalgh et al, 2019). This paper instead showcases the impact of and reflections on EbyE involvement in a research capacity building initiative, co-led by an academic team and a local authority. A different kind of research involvement has therefore been covered with some notable differences from existing literature. For example, the broad remit of research capacity building makes it more difficult to have a shared understanding of goals compared to more concrete EbyE input in a traditional research project. Even when there is a shared understanding of purpose, as had developed by the second survey timepoint, the slow pace of change in research capacity building can be frustrating to EbyEs, especially for those with research steering or advisory group experience. Impact is also less self-evident to EbyEs, underscoring the importance of routinely feeding back on impact made. Lastly, engaging EbyEs in research as early as possible is recommended (e.g. Dawson et al, 2020) to democratise research, but this might not fit research capacity initiatives as well, where the initial pace may result in frustrations and/or disengagement of EbyEs.

EbyE involvement in health and social care research in the UK has predominantly focussed on health topics (Brett et al, 2014). ASC research initiatives have not been extensively covered in PPI literature, with the exception of lived-experience input in social work research (Cossar and Neil, 2015). As the literature is dominated by healthcare perspectives, social care researchers care typically draw from healthcare research/guidance when setting-up and facilitating EbyE involvement and engagement. In addition to offering a detailed and reflective account of the EbyE working group as part of an ASC research capacity building partnership, this paper goes some way to suggest PPI approaches in health research may not be suitable to 'lift and shift' across to social care research. Our EbyE working group evaluation to-date has not explicitly focussed on how and why EbyE involvement may be different in ASC research; this is now a focus of future evaluative work within KRP. Nonetheless, as discussed above, working group members have repeatedly remarked on both the breadth of aspects that social care covers, and the magnitude of challenges the sector currently faces, suggesting that it is, indeed, 'different in social care.'

To conclude, evaluating EbyE involvement in research capacity building initiatives in adult social care is feasible, but requires careful, iterative, multi-method evaluation. Both EbyE activities and the evaluation itself benefits from being informed by EbyEs themselves. This ensures that lived experience is represented in leadership structures (e.g. EbyE group leadership and partnership co-applicant roles), which then goes towards ‘flattening’ unequal power structures between researchers and people with lived experience. Such approach to evaluation then allows to promptly spot and address arising challenges, further benefiting EbyE involvement and the partnership overall.

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