# Developing and evaluating PPI research guidelines

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**Structured Abstract:**

**Purpose:** A growing literature reports the benefits and challenges of patient and public involvement (PPI) in research; nevertheless, understanding PPI in research design remains under-developed. We report learning experiences from involving service users as research partners in two projects that developed and evaluated guidelines for good practice in this regard. Our main objective was to evaluate these guidelines.

**Design/Methodology/Approach:** Guidelines for PPI in research were developed through five workshops involving service users/patients, carers, health and social care professionals/managers and academics. Using a participatory qualitative approach, these guidelines were evaluated through mapping them against the experience of two service user research partners within another project.

**Findings:** The guidelines were found to be fit for purpose, as they allowed easy identification of problems, as well as reassurance that required standards were being met. Both academic and service user research partners gained key learning and relevant skills from their experience. Two service user research partners also found their skills for daily living being unexpectedly enhanced by their participation in the project.

**Practical implication:** PPI in research can introduce challenges requiring consideration. Our experience has shown that comprehensive planning in the early stages of a project is essential, and has demonstrated that using the guidelines during a project allows easy and timely identification and subsequent addressing of unforeseen challenges.

**Originality/value:** The PPI guidelines developed for this project were produced by consensus involving a range of stakeholders. Service users involved as research partners in our project experienced unanticipated personal benefits owing to their participation.

**Keywords:** Public and patient involvement in research, PPI, guidelines for good practice, evaluation.

## Introduction

In the United Kingdom (UK) the Department of Health (DH) value genuine service user engagement in all areas of healthcare delivery, including research and knowledge exchange (KE), that has the potential to inform service delivery improvement (DH 2007). This is essential in order to ensure that services are responsive to what the people using them want and need and are accountable to service users and local communities (DH 2006). To this end, patient and public involvement (PPI) in health and social care delivery and related research in the UK has increased following governmental policies for improving the quality of health and social care (Cabinet Office, 2011; DH,2007; House of Commons Health Committee, 2007). Policy adoption

has been further aided by strategy changes to requirements of funders such as the National Institute for Health Research (NIHR) (2012); publisher requirements, where publication can be dependent on evidencing active PPI in research, as well as good practice guidance (Social Care Institute for Excellence (SCIE), 2008; INVOLVE, 2007).

The increase in PPI has arisen due to the widespread assumption that its effects are generally beneficial, although some issues are not straightforward, e.g. debate continues as to whether patients, carers or other members of the public can claim to be truly representative of a population and if so, whether they should be (Ward *et al.*, 2009).Despite the expansion in PPI in wider service delivery, there is a degree of uncertainty about its added value in research (Owens *et al.*, 2011; McKevitt *et al.*, 2010; Hounsell *et al.*, 2005). Common concerns include financing service user time, issues with service user benefits and payment, and need for training and support (Beresford, 2013; INVOLVE, 2013a; Pollard and Evans, 2013; Brett *et al.*, 2012). Nevertheless, reported advantages include improved alignment of research topics with service user priorities, service user empowerment and the development of service user research skills (Brett *et al.*, 2012; McKevitt *et al.*, 2010; Staley, 2009; Boote *et al.*, 2002).  On the strength of this, PPI involving service users as team members with an active role in the research process continues to expand. However, understanding and acceptance of service user engagement in many aspects of research design, particularly data collection, remain under-developed (Shippee *et al.*, 2013; Brett *et al.*,2012; Ward *et al.*, 2009).

Terminology regarding PPI is still problematic, with little consensus as to whether relevant groups of individuals should be referred to as 'patients', 'clients', 'service users', 'the public', or by some other name. In particular, self-determination is a key issue for people in receipt of mental health services, and this extends to the terminology applied (Donskoy and Pollard, 2014). We use the term 'service users' to denote individuals who are not health or social care professionals; they may or may not currently be users of health or social care services. We refer to individuals caring for friends and/or family members on an informal basis, i.e. not employed to do so, as 'carers'.

This paper is in two halves. The first presents the development of guidelines for PPI in research and the second presents and discusses the evaluation of the guidelines through a local study.

## Part 1: Development of guidelines for PPI in research

Guidelines for good practice regarding PPI in research (University of the West of England (UWE), 2010) were developed as a component in a joint project which aimed to transfer expertise and skills between the academic, practice and service user communities through partnership working and continuing professional development (CPD) (Pollard *et al.*, 2010).

While many PPI guidelines for research (e.g. INVOLVE, 2013b; Kotecha *et al.*, 2007) already exist, the rationale for developing new guidelines resulted from a perception among concerned academics and service users that many individuals engaged in research or evaluation within local services had difficulty engaging with PPI as a concept and as a process. While there was a general awareness of the need for PPI, there was also a clear disconnect with implementation, partly due to misunderstanding of what PPI actually entails, as well as inappropriate organisational systems. Therefore it was felt that a local framework for PPI, developed with the support of and aiming at local stakeholders, including practitioners, service

managers, academic researchers, service users and carers, might address this specific issue. It was anticipated that engagement with the development of local guidelines would help create ownership of the process among stakeholders, and thereby support appropriate PPI in research and evaluation projects. It was also felt that local guidelines would strengthen the existing links between academia, National Health Service (NHS) and DH funders as well as the service user and carer communities locally.

Initial planning for the project involved two academics from UWE. Three service users (CD, A-LD, CR) were recruited to the team through the UWE mailing list circulated regularly to service users and carers interested in involvement in research. They came from different backgrounds, which promoted appreciation of diversity within the team. Service user CD is a retired teacher who is involved in a range of PPI activities with her local health services. Service user CR is a younger stroke survivor with a background in journalism. Only A-L D, a mental health survivor researcher and activist, had any substantial experience in research; the other two had very little or none. Their role in the team was as 'service user research partners' (hereafter 'research partners'), a UWE term for service users active in research.

### Methods

Guideline development in health and social care typically involves the formation of guideline development groups composed of professionals and members of the public, service users and/or carers, whose task is to review available evidence on a topic and then translate it into recommendations for practice (Harding *et al.*, 2010; Shekelle *et al.*, 1999). A major focus of the project reported here was that local concerns about PPI should be addressed in a practical way; it was therefore determined that evidence should come from local stakeholders themselves. This approach prioritized the value of individuals' 'situated' knowledge derived from their own experience, above that of 'objective' knowledge; this approach was consistent with the wider promotion of PPI (Pollard and Evans, 2013; Harding *et al.*, 2010).

The project design was loosely inspired by a constructivist approach to grounded theory, acknowledging the influence of symbolic interactionism, that is, that human beings shape their world through interacting with one another (Oktay 2012). The underlying heuristic concept was also influenced by the experience and expertise of the team members. The methodology involved developing the project organically through an accumulative process based on five linked CPD workshops aimed at different local stakeholders: health and social care professionals in a range of roles (managers, practitioners, academics and researchers), as well as service users and carers. Recruitment to the workshops was through a self-selection process following widespread publicity. Three of the five workshops were for all these groups and specific attention was paid to ensure a good mix of participants during small group work. Additionally, there was one dedicated workshop for service users and one for academics and practitioners. All five events were hosted at UWE between February and June 2010. Attendees to the workshops were clearly made aware that the purpose of the workshops was to develop local PPI in research guidelines. Despite and because of this 'local' flavour, they attracted a few attendees from other English regions with a similar interest in local guidelines.

The first two mixed workshops involved gathering attendees' opinions and thoughts about PPI in research. Issues identified were then presented in the two dedicated workshops for discussion; this strategy encouraged consideration of salient topics by attendees without

fear of offending perceived 'others'. The final mixed workshop was used to prioritise issues raised in the previous workshops. All the workshops involved small group work facilitated by one service user research partner and one academic. Overall the workshops echoed many of the dynamics that have been reported when users and 'professionals' work together (Pollard and Evans, 2013; 2009; Brett *et al.*, 2012; Ward *et al.*). For instance, some professionals were extremely cautious about user participation, a stance which in some cases appeared to be the outcome of poor experience. Conversely, others with more positive experience were inclined from the start to assume that service users and professionals could work together well.

The workshops were attended by 45 individuals in total: 13 service users, 19 UWE academics and 13 academics or practitioners from other universities and practice organisations. More than half of those attending came to more than one workshop. Fifty-four evaluation forms were completed, on 43 of which participants expressed positive/strongly positive views about their experiences in the workshop series; specifically, the project team members were commended for offering what were regarded as groundbreaking and worthwhile events. There was only one negative evaluation.

Consistent with a grounded theory approach, the two researchers and three research partners together analysed the data collected at the workshops with the aim of understanding participants' conception of 'good' PPI, that is, of generating 'theory' regarding PPI in research (Oktay, 2012). This process resulted in recommendations for good practice, which were subsequently formulated by the project team as a set of nine guidelines for practitioner and academic researchers (Figure 1) (UWE, 2010). Logistics and time constraints precluded involving other workshop participants in this process.

**Figure 1 here**

The guidelines were produced in leaflet form and also as A3 posters and can be downloaded from the internet (UWE, 2010). Leaflets were distributed to local organisations and at various conferences in the UK and in Europe, where the posters were also displayed. The collaborative processes involved in planning, running the events and developing the guidelines resulted in a cohesive project team that worked well together. Although this might have been the result of chance or that the human chemistry worked serendipitously well, the researchers made a conscious and concerted effort to ensure cohesion and co-operation. Strategies included being as aware as possible of interpersonal issues, holding meetings in an informal way and, most importantly, ensuring that everyone had space to air their views and that decisions were taken based on consensus as far as was possible.

Following the success of this project, the guidelines were applied in another study, the evaluation of a leadership programme delivered by colleagues from UWE to personnel from a large urban hospital (Moule *et al.,* 2011a). The remainder of this paper reports findings from evaluating the use of the guidelines in that study. In order to make the context clear, we first outline the evaluation of the leadership programme itself, and then report the methods and findings from the guideline evaluation.

**Part 2: Evaluating the guidelines**

**The leadership programme**

The leadership programme was delivered to a range of frontline, supervisory and senior NHS managers (clinical and non-clinical) from a large hospital during 2009 and 2011. The programme was organised into four study days and a number of courses ran over a period of two years. Cohorts were drawn from a range of services including clinical, administrative, support services and general management, with leaders learning together (Moule *et al.*, 2011a). The design of the evaluation involved academics and one service user (CR). Once funding was secured, other team members were recruited. The complete project team included two academics and one service user (CR) from the study in which the guidelines were developed, four other academics and another service user research partner (ML). Research partner ML had attended two workshops in the guidelines development project as a participant. The two research partners, both younger stroke survivors, were included in the team to bring a perspective uncoloured by a professional background in health care.

A participatory study was developed to evaluate the leadership programme, wherein data were collected at three Knowledge Café events adapted to suit the project circumstances, and also through individual interviews. A Knowledge Café (Brown and Isaacs, 2012) is a data collection approach that has gained some popularity within participatory research designs. The café offers a relatively informal and convivial way of engaging participants in conversations, often making it easier for those whose voices are not normally heard to be engaged (Thunberg, 2011). Such conversations can reveal tacit organisational knowledge that can inform organisational learning. The format thus allows attendees to explore questions that matter to them, in a process that values everyone's contributions. Before data collection began, a pilot Knowledge Café event was held to familiarize all the team members with this approach; this was followed by two meetings in which specific facilitation points were considered. During the main Knowledge Café events, research team members, including CR and ML, (co-)facilitated small groups of four to six participants. Thirty-six individuals participated in the evaluation of the leadership programme, and 15 participants took part in individual telephone interviews. In keeping with the Knowledge Café approach (Brown and Isaacs, 2012; Thunberg, 2011), data from the Knowledge Café events were recorded manually by participants and facilitators as the event unfolded; the interview data were audio-recorded and transcribed. All data were analysed thematically. All team members were involved in data analysis and writing up of the findings (Moule *et al.*, 2011a).

**Evaluating the use of the guidelines**

*Methods*

A participatory qualitative approach was adopted to evaluate the implementation of the guidelines within the study addressing the leadership programme. Approval for that study was gained from a University Research Ethics Sub-Committee; the evaluation of the guidelines was outlined as an explicit component within the application for ethical approval. One academic (KP) had a role within the team that focused solely on evaluating CR and ML's experiences on the project. This evaluation started during the planning stages for the first Knowledge Café event and ran for the duration of the project (10 months). Academic KP met both research partners on three occasions throughout the project to record their reflections and experiences

as project team members. This component of the overall evaluation had two key objectives: (i) to evaluate CR and ML's experiences in the project *per se;* and (ii) to map CR and ML's experiences against the detail of the individual guidelines formulated during the guideline development workshop series (Figure 1).

The inclusion of CR and ML in the team was consistent with an intention to evaluate the guidelines in circumstances that could be challenging at times. At the time, CR suffered from significant levels of fatigue and some difficulty with writing, while ML had a severe degree of aphasia, which affected her speech, reading, writing and self-confidence.

At each meeting, KP asked CR and ML to discuss their experiences in general and then in relation to particular guidelines, relevant for the stage of the project. Their observations and comments were recorded in note form. After each meeting, KP wrote up this material in a structured format. The resulting document was then sent to CR and ML for confirmation and agreement before being shared with the rest of the project team. Academic KP also made notes detailing CR's and ML's activities in one of the Knowledge Café events to observe their participation in the data collection phase of the leadership programme evaluation. The research partners' final reflections on their experiences in the project also contributed to the data set.

### Findings

The findings from the guideline assessment are presented through extracts from the mapping of the research partners' experience against the guidelines, additional issues requiring consideration and dissemination from the programme evaluation.

### The research partners' experience mapped against the guidelines

It was agreed that guidelines 1 and 2 (Figure 1) were not appropriate for evaluation in this project as the academic researchers were already working closely with the research partners and the evaluation of the guidelines had stemmed from a previous project, which already involved one of the research partners. As the guideline mapping was completed before dissemination of the findings began, there was no mapping for guideline 9 (Figure 1). Mapping the meeting notes against the guidelines showed that the team processes usually adhered to the latter's recommendations. Where they did not, it was sometimes the case that it was thought unnecessary by all involved, in view of mutual familiarity between them. The format developed for e-mail communications had afforded inclusion and allowed ML to prioritize the time and effort given to the information sent out. Scheduling activities within a time-limited period and in the mornings had enabled CR to maintain a commitment to the project. Research partners CR and ML often described their membership of the team in positive terms (Figure 2):

**Figure 2 here**

Research partners CR and ML were both involved in the project from the beginning. While resources to support their involvement in the project were generally appropriate, there were occasions when their physical needs were not met; e.g., they both require a large flat surface on which to write at meetings, and this was not always made available (Figure 3):

**Figure 3 here**

Research partners ML and CR were generally happy with the amount of clarity there was about what was required from them for the project. However, when mapping the project processes against guideline 5, it appeared that there was a lack of systematic provision of information at times (Figure 4):

**Figure 4 here**

Although CR and ML reported feeling that they received sufficient support in the project, it was clear that there was occasional shortfall in this regard; e.g. on one occasion a member of staff who usually arranged transport was on leave and CR found herself having to liaise with a taxi firm on ML's behalf. Mapping the two service users' experiences against the guidelines was useful in highlighting some of these problems (see Figure 5). Interestingly, ML and CR said that having KP in the role of evaluating their experiences made them feel that they had an academic on the team who was 'on their side'; KP's data collection role therefore also provided opportunities for service user support. Both CR and ML were actively involved in the Knowledge Café events and also in data analysis. Ad-hoc training was provided for both, so that they could adequately contribute to these activities. Regular feedback to all involved was an integral component of the research process (Figure 5):

**Figure 5 here**

Communication appeared to be handled well in the project. All involved were clear how communication was to be effected, particularly in terms of ML's needs and regular meetings were planned and held (Figure 6):

**Figure 6 here**

It was felt that there was appropriate use of materials throughout the project. However, apart from the need to devise a format for e-mail to suit ML's needs, both research partners' requirements in this regard were minimal (Figure 7):

**Figure 7 here**

*Additional issues requiring consideration*

Engagement in the Knowledge Café events was enjoyable for both service users. Research partner CR reported she gained confidence in her ability to facilitate groups. During the events, ML had been able to undertake some of the physical tasks needed during the table discussions and had participated in the group verbally, though this input was limited. These positive outcomes notwithstanding, some situations were challenging for both research partners and academic researchers. Research partner ML found contributions in the Knowledge Café event were an effort; observations undertaken by KP suggested other group members could become engrossed in discussion and were not always aware that ML was trying to speak. Research

partner ML also expressed difficulties in one large project meeting that had a busy agenda. It was felt that academic members had not allowed her enough time to express her opinions.

Both research partners would have liked to have been involved in interviewing the participants. However, the logistics involved were prohibitive for CR, in that she would have only been able to arrange and conduct interviews at particular times, dependent on her levels of fatigue; in addition, necessary training for her to use relevant equipment would have entailed extra time and travel, and much energy, which at the time would have been out of proportion to potential benefits for her and/or the project. Research partner ML would have found conducting a telephone interview challenging. Nevertheless, they both contributed to data analysis of material from the Knowledge Café events and were satisfied with their experience in this regard, despite their lack of academic expertise in this area. The learning they reported from their engagement in this process was perceived to have long term benefits should they engage in future research projects. Research partners ML and CR reported that their involvement in the project also had an important impact on their lives generally. A few months into the project, KP and CR said they had both noticed significant improvements in ML's speech. At the end of the project, ML said:

> Today my speaking is a whole lot better than when I started the project. Half of that improvement I would attribute to being involved in the project. I'm saying twice as much, both longer sentences and more overall speaking.

Research partner CR said that her engagement in the project had given her more confidence in her facilitating skills and had contributed to a steady improvement in the strength of her handwriting. For both service users, these were completely unanticipated benefits of involvement.

*Dissemination findings*

In common with all research projects, the dissemination process occurred over a relatively lengthy period following the completion of the project. The final guideline (9) states that everyone should have the opportunity of being actively involved in dissemination of project results or findings and that individuals' involvement in presentations and publications from the project should be acknowledged (Figure 1). All service users involved in the development and evaluation of the UWE guidelines (UWE, 2010) contributed to their dissemination, including the final project reports (Moule *et al.*, 2011a; Pollard *et al.*, 2010) and this article. Additionally, A-LD, CD, CR, PM and KP were involved in facilitating a workshop about the development of the guidelines, which was presented at the Royal College of Nursing (RCN) Annual Research Conference (Moule *et al.,* 2011b). Research partner ML co-presented findings from the evaluation project at another international nursing research conference (Moule *et al.*, 2012a). Both ML and CR were named as authors on a presentation delivered at a nursing education conference in Baltimore, USA (Moule *et al.*, 2012b).

**Discussion**

The project to evaluate the leadership programme, involving substantial and active PPI, met its overall aim of identifying key learning to inform those delivering education to

healthcare managers. The team was therefore effective in conducting the project and providing useful findings and recommendations to relevant stakeholders (Moule *et al.,* 2011a), as well as evaluating the UWE guidelines for PPI in research (UWE, 2010).

The aim of developing these guidelines was to provide academic researchers and research partners with a clear and systematic framework that identifies relevant issues and crucial areas of attention. The assumption was that such clarity will aid all parties in conducting research and evaluation in a way that minimises tokenism, avoids exploitation and unrealistic expectations and provides benefit (in variable forms) to all concerned. Whilst general guidelines are available to support researchers in implementing PPI (e.g. INVOLVE, 2013b), the UWE guidelines were uniquely developed through an organic and systematic process involving academic researchers, health and social care practitioners and managers, and service users, carers and members of the public (Pollard *et al.,* 2010). The UWE guidelines are consistent with recently identified components of patient and service user engagement (Shippee *et al.,* 2013), namely, *Patient and service user initiation, Building reciprocal relationships, Co-learning process* and *Re-assessment and feedback*.

Our data showed that the UWE guidelines were fit for purpose and facilitated consideration of essential issues; e.g. how support was provided to research partners with a relatively high degree of physical impairment. Working through the guidelines allowed systematic and easy identification of any problems, and reassurance that required standards were being met.

However, using the guidelines in the project threw into relief that they can only ever be an aid to appropriate planning and conduct of research; using guidelines does not ensure that all appropriate systems will be implemented or action taken.  It is clear that effective engagement for CR and ML in this project required pre-planning that needed to account for the wider research team, including administrative support. In particular, the challenges of working with service users with fatigue, mobility and communication concerns needed to be addressed. Developing strategies for organising research meetings and data collection and communication formats, especially with e-mail, seems to have been effective. Additional needs were also identified as the project progressed, including the requirement for certain facilities within meetings, such as the provision of adequate writing surfaces.

The members of the research team were obviously familiar with the UWE guidelines (UWE, 2010), as they had all been involved in their development. Nevertheless, it became clear that despite this familiarity and the awareness of CR's and ML's needs, not all relevant issues were sufficiently thought through either before the project began, or in its early stages. Knowledge Cafés can be challenging, particularly for persons with difficulties in written and verbal communication. The use of a pilot session and setting additional meetings to agree approaches to co-facilitation enabled ML to participate in the events; nevertheless, involvement could have been improved, as at times ML found it difficult to capture her group's attention.  On reflection, there could have been more specific focus on her communication needs during preparation including negotiation with her beforehand about how best to get attention should she feel the need to do so. Research partner CR was unable to contribute to the telephone data collection phase of the project. Organisational and fatigue issues were prohibitive on this occasion but have provided learning that can be used to inform future research where research partners are engaged in data collection; e.g. considerable thought and

practical planning for this activity at a very early stage of the project. Additional administrative support would also have been required to organise training and set up interviews well in advance.

More focussed discussion, ideally at the funding application stage, could have enhanced both research partners' experiences, as putting all the necessary strategies in place to provide CR and ML with an optimum experience would undoubtedly have had further resource implications for the project. It has been frequently reiterated that comprehensive PPI in research requires substantial financial support (Beresford, 2013; McLaughlin, 2013; Pollard and Evans, 2013), and the demand for evidence of PPI in research funding applications is therefore to be welcomed (NIHR, 2012).

From our data, it is also evident that consequences of decisions were not always predicted; e.g., it was interesting to find that the decision to have one academic researcher on the project whose dedicated role was to evaluate the research partners' experience within it, led to their feeling supported. The participatory nature of the evaluation complemented this situation, as there was no methodological imperative for KP, as the researcher, to preserve a traditionally 'neutral' stance (McLaughlin, 2013; Boote *et al.,* 2002). While it is obvious with hindsight that this was likely to be the case, it was not something explicitly anticipated by the researchers.

Our study has highlighted the importance of research teams' exploring how service user support can be an integral part of a project. One issue that requires consideration is whether the principal investigator should take on the role of supporting and monitoring the quality of PPI or whether this role should go to a dedicated member of staff. Whatever the mechanism, it is essential that support is provided in a consistent and systematic fashion; professional researchers have a moral duty towards service users whom they involve as research partners (Pollard and Evans, 2013). Additionally, from a practical point of view, it is obviously desirable that research partners use their sometimes limited energy to contribute substantively to a project, rather than having to use it to address their own support needs.

As is consistent with findings from other authors (Brett *et al.,* 2012; McKevitt *et al.,* 2010; Staley, 2009; Boote *et al.,* 2002), their engagement in the project does appear to have been beneficial for both CR and ML. In particular, acquiring research skills that may be applied in further projects supports previous assertions suggesting possible benefits of engagement for service users (Pollard and Evans, 2013). We can argue that involvement in research allows other forms of development, such as CR's confidence in facilitating groups, which are transferable to other areas of life. However, it seems that the effects of involvement can go considerably deeper. The experience of gaining unexpected benefits, e.g. improved function for both CR (writing) and ML (speech), which they attribute to their engagement in the project, has major implications for how and why research and service user communities negotiate and enter into PPI. The engagement of all the research partners in contributing to, and participating in, project dissemination is particularly satisfying. The range of outputs (Moule *et al.,* 2012a; Moule *et al.,* 2012b; Moule *et al.,* 2011a; Moule *et al.,* 2011b; Pollard *et al.,* 2010) provides evidence that service users can be actively involved in a variety of events in spite of difficulties associated with their individual circumstances.

Academic team members also benefited in terms of learning from the project. In particular, they learned the importance of comprehensive early planning, and the advantage of

using the guidelines consistently throughout a project to identify and judge relevant strategies for enhancing PPI. In the evolving policy climate (NIHR, 2012; Cabinet Office, 2011; House of Commons Health Committee, 2007; INVOLVE, 2007; DH, 2007), it is not overstating the case to say that PPI in research, service evaluation and evaluation of educational initiatives for health and social care staff is fast becoming the norm. It is therefore imperative that both professional researchers and research partners receive appropriate support to acquire or enhance requisite skills (McLaughlin, 2013; Pollard and Evans, 2013; Staley *et al.,* 2013). Moreover, processes for PPI must be developed and streamlined to provide optimum outcomes for both groups; in particular, these processes should not simply be developed by academic or clinical researchers and imposed on service users who wish to be actively involved in health and social care research. In this project, the UWE guidelines (UWE, 2010) proved a useful tool.

This was a small-scale evaluation of PPI guidelines developed to respond to the needs of a local context and only involving two research partners, so caution must be exercised when drawing conclusions. While the guidelines had an initial research focus, their application in a context using similar processes (evaluation) highlighted their versatility and flexibility. They were applied and mapped against the needs of service users with challenging needs; they showed that they were fit for purpose, allowed confirmation of appropriate processes and identified areas for improvement. Closely considering the guidelines at regular intervals therefore proved effective in helping to monitor the quality of the service users' experience as research partners.

**Conclusion**

Whilst general guidelines are available to support researchers in implementing PPI, there may be a conceptual and practical disconnect at local practice level. The development of local PPI guidelines in partnership with local stakeholders, including service users and carers, aimed to address this issue.

The inclusion of PPI in the evaluation of a leadership programme enhanced its conduct and findings in that it allowed broader grounding for consideration and interpretation of emergent issues and results by including and validating service user perspectives and opinions. This grounding was reinforced by the research partners' active involvement from an early stage in the PPI guidelines development and the evaluation project design, as well as in the production and dissemination of outcomes from both projects.

While the academic members were already conscious of the potential financial restraints where PPI is concerned, they emerged from the two projects with greater awareness of the challenges posed by other aspects of PPI in research, such as timing of meetings and events, accessibility and the development of effective communication mechanisms.

This experience showed that pre-planning is crucial to supporting engagement and it should be acknowledged that despite all efforts, ML and CR could only be involved to a limited extent in some of the evaluation activities. The leadership programme evaluation project also extended the academic researchers' understanding of how to engage service users with challenging communication difficulties in the Knowledge Café events, an approach that relies on effective communication. This knowledge can be transferred to similar situations such as focus groups.

Despite these difficulties, both research partners and academic researchers gained valuable learning from the experience. Additionally, the research partners identified unexpected personal benefits arising from their involvement in the evaluation project. Evaluation of the systematic application of the UWE guidelines throughout the project revealed that they were fit for purpose in the context in which they were applied.

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**Figure 1:** Guidelines for PPI in research (UWE, 2010)

*1.Educate researchers about public\* involvement in research*

Introduce researchers to the 'involvement continuum' (from consultation to user-led research).

Highlight the different roles that people\* can play in a project.

Raise awareness of relevant issues (including appropriate payment).

Highlight potential ethical issues.

Provide examples of successful public involvement in research.

Run a joint workshop so that researchers and people involved can increase their mutual understanding of relevant issues.

*2. Consult the community before setting the research agenda*

Create real opportunities for people to influence what is being researched.

Go into the community/use existing networks to find the 'right' people\* to consult.

Use community contact, networks, etc., to reach 'hard to reach' groups (need to be aware of cultural and other sensibilities).

Create a database of people with details of interest and availability.

*3. Build enough time into the project for meaningful public involvement*

Take time to understand people's motivation for involvement, as this will encourage commitment.

Adjust the pace and way of conducting the project where necessary/ possible to suit the people involved.

*4. Involve people in the project as early as possible*

Involve people right at the beginning of the project, or as soon as you possibly can.

Ensure appropriate resources, e.g. access to e-mail, websites, etc.

Offer real opportunities for so-called "hard to reach" groups to get involved at an early stage (you need to be aware of cultural and other sensibilities).

*5. Be clear about what is required from people involved in the project*

Draw up clear person specifications for people involved in the project.

Define/negotiate people's roles, allowing for flexibility when appropriate/possible.

Ensure that people know relevant details about the start, process and completion of their involvement in the project.

Make sure that researchers and people involved jointly decide the terms of reference and membership of any Advisory Panel.

Ensure and share clear processes for planning and design.

Avoid the use of jargon and acronyms when explaining plans and processes.

Explain that people may have to make an effort to learn some of the language of research.

*6. Provide on-going support for people involved in the project*

Have a named person at the centre of the project who will be accessible to people and sensitive to potential issues.

Negotiate appropriate payment and expenses for people involved.

Run a joint workshop so that researchers and people involved can increase their mutual understanding of relevant issues.

Set up an Advisory Panel to have a 'watching brief' on the conduct of the project.

Be aware of the need to make accommodation for different kinds of diversity.

Identify the training needs of people involved in the project. Provide appropriate funded training opportunities/mentorship.

Give feedback on a regular basis to let people know that their contribution is valued.

Ensure that all those involved are aware of what has been achieved in the project, and of any possible next steps.

*7. Make sure that there is clear communication between everyone involved in the project*

Make sure that researchers and people involved work together to decide appropriate lines of communication for the project.

Adjust communication methods to suit people's available resources, e.g. e-mail, phone, etc.

Schedule regular meetings of all involved so that all can be updated on progress.

*8. Make sure that all materials, namely, research documents, communications and outputs, are accessible.*

Avoid the use of jargon and acronyms but also educate those concerned to avoid any "dumbing down" effect.

Ensure that the design of research materials suits people's needs, e.g. pictures, language, font, colours.

Work with people involved in the project to ensure that the design of any outputs suits the needs of the community concerned.

*9. Involve everyone in dissemination of the project results or findings*

Invite and support people involved to contribute to disseminating the project results/findings: presentations, writing of academic and other publications as co-author, design of project outputs, etc.

Acknowledge people's involvement in any presentations/publications from the project.

* Public/people: service users, carers or other members of the public.

**Figure 2:** Extract from mapping for guideline 3: Build in enough time to the project for meaningful public involvement (Moule *et al.,* 2011a).

| Guideline criterion | Research partners' experience |
|---|---|
| Take time to understand people's motivation for involvement, as this will encourage commitment. | As CR and ML were known to the project team members before the project started, this guideline did not really apply to this project. |
| Adjust the pace and way of conducting the project where necessary/possible to suit the people involved. | This happened to a large extent. Timing and duration of meetings in view of CR's requirements, and building in space for communication with ML.<br><br>ML's comment:<br>I'm happy with my experience as a member of the project and feel that I'm able to communicate and express myself satisfactorily, because I'm given the opportunity to do so and the other members are patient. |

**Figure 3:** Extract from mapping for guideline 4: Involve people in the project as early as possible (Moule *et al.*, 2011a).

| Guideline criterion | Research partners' experience |
|---|---|
| Involve people right at the beginning of the project, or as soon as you possibly can. | CR was recruited to the project at the design stage, and was a co-applicant on the funding bid. She contributed to discussions about appropriate model of public involvement for the project.<br>ML was recruited as soon as the funding was in place – there was some discussion with her at the funding stage. |
| Ensure appropriate resources, e.g. access to e-mail, websites, etc. | Communication mechanisms, e.g. e-mail worked well. Format was devised to make e-mail communication as straightforward as possible for ML. Some work still needed around other resources, e.g. making sure that a big table is available for all project meetings, to make it easier for CR and ML to write. Planned to develop a checklist for all team members, to consult when booking facilities, etc. |

**Figure 4.** Extract from mapping for guideline 5: Be clear about what is required from people involved in the project (Moule *et al.*, 2011a).

| Guideline criterion | Research partners' experience |
|---|---|
| Draw up clear person specifications for people involved in the project. | This has not been done for this project. In discussion, we identified that CL and ML had been recruited mainly for personal qualities, e.g. flexibility, that they had brought to the project. As their role in the project is exploratory by nature, it was considered important that they both appeared to demonstrate a positive attitude and a willingness to try things out in a somewhat *ad hoc* and organic manner. Not sure that a clearer person spec would have been possible/desirable. |
| Define/negotiate people's roles clearly but allow for flexibility when appropriate/ possible. | Both CL and ML feel that this is an on-going feature of the project. There is always the opportunity to try new things, e.g. facilitating a Café group, but no pressure to do so. Michele's comment: I'm happy with my responsibilities but I'm open to exploring and trying other things if people find that it would improve or help the project. |
| Ensure and share clear processes for planning and design. | This has been done to an extent, but could be more streamlined. As the academic researchers are all working on other projects, they are used to 'jumping' between them. Something more substantial might improve processes for CL and ML, but it is not clear what form this could take. |

**Figure 5:** Extract from mapping for guideline 6: Provide on-going support for people involved in the project (Moule *et al.*, 2011a).

| Guideline criterion | Research partners' experience |
|---|---|
| Have a named person at the centre of the project who will be accessible to people and sensitive to potential issues. | Both CR and ML both feel that they receive sufficient support in the project. However, there is no named person as such, probably because of the small size of the team, and the history of individuals working together to varying degrees. Earlier in the project, this resulted in CR having to take on the task of sorting out a problem with ML's taxis when the administrator was on leave, which was not appropriate. CR and ML would now both take problems either to KP or PM. |
| Identify the training needs of people involved in the project. | Ad hoc training has been provided, e.g. preparation for participation in the Knowledge Cafés and involvement in data analysis. |
| Give feedback on a regular basis to let people know that their contribution is valued. | This has worked well in the project. |

**Figure 6:** Extract from mapping for guideline 7: Make sure that there is clear communication between everyone involved in the project (Moule *et al.*, 2011a).

| Guideline criterion | Research partners' experience |
|---|---|
| Make sure that researchers and people involved work together to decide appropriate lines of communication for the project. | This was done effectively in the project, with regards to a range of lines of communication. |
| Adjust communication methods to suit people's available resources, e.g. e-mail, phone, etc. | This was not an issue, as all team members had access to e-mail and phone. The e-mail format was developed to aid ML's participation in e-mail communication. |
| Schedule regular meetings of all involved so that all can be updated on progress. | CR and ML felt that there were sufficient meetings and communication to ensure that they knew what was happening with the project. |

**Figure 7:** Extract from mapping for guideline 8: Make sure that all materials, namely, research documents, communications and outputs, are accessible (Moule *et al.*, 2011a).

| Guideline criterion | Research partners' experience |
|---|---|
| Avoid the use of jargon and acronyms but also educate those concerned to avoid any "dumbing down" effect. | General awareness among project team members, with occasional lapses. CR and ML feel that this is adequate. |
| Ensure that the design of research materials suits people's needs, e.g. pictures, language, font, colours. | This has not been applicable in the project to date, as neither CR nor ML have particular needs in this respect. |